

Issues in Clinical Child Psychology

Derek D. Reed
Florence D. DiGennaro Reed
James K. Luiselli
Editors

Handbook of

Crisis Intervention and Developmental Disabilities

Issues in Clinical Child Psychology

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Handbook of Crisis Intervention and Developmental Disabilities

 Springer

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ISSN 1574-0471

ISBN 978-1-4614-6530-0

ISBN 978-1-4614-6531-7 (eBook)

DOI 10.1007/978-1-4614-6531-7

Springer New York Heidelberg Dordrecht London

Library of Congress Control Number: 2013934351

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Printed on acid-free paper

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Preface

According to the Centers for Disease Control and Prevention (2011), approximately 14 % of 18-year-old children or younger in the United States are diagnosed with a developmental disability. Developmental disabilities include a number of different disorders or impairments including vision or hearing disabilities, intellectual disability, autism spectrum disorders, and others. Estimates suggest that between 5 % and 16 % of individuals with developmental disabilities engage in some form of self-injurious behavior (e.g., slapping or biting, head hitting, eye poking, and others; Schroeder, Rojahn, & Oldenquist, 1991), with some studies reporting this number to be as high as 50 % (Baghdadli, Pascal, Grisi, & Aussilloux, 2003). Numbers for aggressive behaviors (e.g., hitting, kicking, biting, scratching directed toward others) are equally staggering, with prevalence estimates ranging upwards of 20 % for children (Hartley, Sikora, & McCoy, 2008) and 50 % for adults (Matson & Rivet, 2008). Given the severity of these challenging behaviors, many individuals with developmental disabilities require intensive behavioral and psychological services. In about 7 % of this population, problem behaviors are so severe that out-of-home residential services are necessary (Larson, Lakin, Salmik, Scott, & Webster, 2010). Thus, it is not surprising that the estimated per capita annual costs associated with treating developmental disabilities exceed \$3.2 million in the United States alone (Ganz, 2007).

Recent research into the etiology of severe problem behavior of individuals with disabilities suggests a combination of biological and environmental precipitants (Iwata, Roscoe, Zarcone, & Richman, 2002). Given the difficulties associated with isolating such precipitants, as well as the dynamic nature of the environment, some individuals' behaviors quickly, and seemingly mysteriously, evolve into clinical crises that spiral outside of the scope of their current educational or clinical programming. Such crisis situations are often frightening, dangerous, and require immediate intervention. Unfortunately, the only resources available for professionals to consult in such times are (a) peer-reviewed scientific articles (often exclusively focusing on one treatment type or crisis scenario), (b) various web-based recommendations (many of which may come from unqualified contributors or based upon anecdotes or opinions), or (c) advice from colleagues. In our personal clinical experiences providing services to children with developmental disabilities and comorbid behavior disorders experiencing a behavioral crisis, the task of providing clinical recommendations (e.g., how to train staff or educators to implement

the treatment, whether to utilize protective equipment such as a helmet for self-injury, whether a transition to more restrictive and intensive placement is necessary) can be daunting.

The purpose of this handbook is to provide a compilation and analysis of the most recent research in crisis intervention for individuals with developmental disabilities, from the foremost experts in severe problem behavior and crisis management. Much research has been done on individual treatment components for addressing behavioral crises in individuals with developmental disabilities. This handbook synthesizes the relevant literature and integrates its findings into a comprehensive review of the continuum of services. In addition, the handbook serves as an accessible resource for researchers, scientist-practitioners, and graduate students interested in crisis intervention for individuals with developmental disabilities.

As scientist-practitioners, we have experienced a myriad of complications and decisions associated with behavioral crisis management. We have worked with families as they made difficult and emotional decisions regarding clinical services for their loved ones. We have served as the clinicians providing therapeutic services to individuals exhibiting behavioral crises and have consulted with staff and caregivers regarding how best to proceed with service delivery. Finally, we have each served as trainers to both parents and staff to best prepare them to address the complex needs of their clients and loved ones when behavioral crises emerge. This book is dedicated to the many clients, families, staff, and colleagues with whom we have worked who sparked our interest in compiling this volume.

Dr. Reed acknowledges Dr. Karla Doepke for introducing him to behavior analytic interventions for children with autism and inspiring him to embark on this career. I thank Dr. Brian Martens and Dr. Laura Lee McIntyre for shaping me to think like a scientist while providing clinical services and consultation to families. While working with Dr. Gary Pace, I learned the importance of creating a collegial atmosphere and finding the joys in even the most incremental of improvements in the data. I was privileged to work with wonderful clinicians like Richard Azulay, Dr. Hannah Rue, and Dr. James Chok; many of the conversations we had influenced the content of this handbook. Finally, I owe my biggest thanks to Dr. Florence DiGennaro Reed and Dr. James Luiselli for being tireless supporters and incredible collaborators, not only on this project, but for everything I do. Flo and Jim continue to amaze me with their clinical scholarship. It is an absolute honor to consider them my colleagues.

Dr. DiGennaro Reed would like to express warm appreciation to her many mentors over the years: Dr. Raymond G. Romanczyk who—without knowing—single-handedly shaped my desire to enter this profession; Dr. Mary E. McDonald for giving me many unique and wonderful professional development opportunities as a young and inexperienced clinician; Dr. Brian K. Martens for introducing me to the joys of *The Far Side*® when I needed it most; and Dr. James K. Luiselli for raising the bar and challenging me to reach it. I would also like to acknowledge the support of my family who have been my greatest cheerleaders and devoted fans for decades. A special thank you to our Jack Russell terriers, Bella and Watson, is warranted; they patiently tolerated long hours in our home office, abbreviated walks, and our diverted attention without holding any grudges. I would like to extend warm appreciation for the numerous

families with whom I have worked and have learned a great deal about life, love, and advocacy. Finally, and perhaps most importantly, I would like to express my deepest appreciation to and admiration of my life partner and best friend. This has been, and will continue to be, an amazing journey!

Dr. Luiselli thanks the many people who served as his teachers, mentors, and professional role models. With a fresh undergraduate degree in hand, I was blessed to have the tutelage of Drs. Donald Anderson, Jerry Martin, Paul Touchette, and Andy Wheeler. Dr. Van Westervelt was another influence, an ally, tennis partner, and coauthor on my first peer-reviewed publication. In graduate school and beyond, I was privileged to learn from Drs. David Marholin II, Henry Marcucella, David Mostofsky, Warren Steinman, and Ron Taylor. Dr. Michel Hersen and Dr. Nirbhay Singh set the occasion for many career goals and accomplishments—I am forever indebted to them. And what a joy it is to collaborate with Dr. Flo DiGennaro Reed and Dr. Derek Reed, two rising stars I am able to call colleagues and friends. Finally, my wife, Dr. Tracy Evans Luiselli, and our children, Gabrielle and Thomas, have taught me the life lessons you do not find in textbooks and inspired in ways that only a family understands.

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Introduction

This handbook describes the various challenges associated with behavioral crises for individuals with developmental disabilities and details the continuum of service options available for treatment. But what constitutes a behavioral crisis? The word *crisis* is defined by the Oxford English Dictionary as “a time of intense difficulty, trouble, or danger” (<http://www.oxforddictionaries.com>). Indeed, behavioral crises are intense, difficult, troublesome, and in many situations, dangerous. When individuals with existing special needs begin to exhibit signs of behavioral crises, it becomes imperative to quickly act with informed decisions. Given the complex needs of individuals diagnosed with developmental disabilities (e.g., behavioral excesses, communication deficits, health/medical needs, intellectual disabilities), behavioral crises may be especially disconcerting, warranting complex solutions and procedures.

The concept for this handbook evolved from numerous conversations amongst the editors about (a) what constituted a *behavioral crisis*, (b) what

resources were available to guide clinicians when a client began to exhibit a behavioral crisis, and (c) how one should describe service delivery options and approaches to caregivers. Over many conversations, it became clear that there was relatively little consensus about each of these points. Nuanced literatures were available on highly specific concerns (e.g., functional analysis, self-injurious behavior (SIB), residential programming), but we could find no compendium that presented the continuum of topics necessary for staff or caregivers to use as a resource when difficult decisions must be made. Unfortunately, behavioral crises are not the time for teams of individuals to go digging for research or recommendations on what to do next. Behavioral crises demand quick, informed decisions and recommendations so precious time is not wasted. Turning to our colleagues for recommendations on such resources, we were typically told something along the lines of “Hmm. Good question. I don’t know of anything, but if you find a resource, let me know! Someone should definitely write a book on this,” thus spawned the premise for this handbook.

What constitutes a behavioral crisis is likely to vary between individuals, service delivery settings, and clinical teams. We believe that behavioral crises are best regarded as relative instances wherein a client’s behavior escalates beyond baseline levels to a point that stretches the competency and abilities of the staff and resources serving that client. That is, a behavioral crisis emerges when staff can no longer rely on their

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day-to-day operations to appropriately serve the client. A behavioral crisis may be considered *emerged* when staff begins questioning whether the current clinical service delivery approaches are sufficient or caregivers begin to question whether placement should be moved to another service delivery locale.

This handbook is organized into three units: (Unit I) *Organizational Preparedness*, (Unit II) *Crisis Identification and Acknowledgement*, and (Unit III) *Navigating the Continuum of Care*. Unit I is concerned with organizational preparedness; that is, the issues and topics that agencies or institutions should evaluate when designing programs to handle behavioral crises. In Chap. 2, Dixon and Loukus provide an overview on how human service agencies should integrate concepts and ideas from behavior analysis and organizational behavior management to create an organizational model conducive for handling challenging behaviors and crisis management. By proactively designing organizational infrastructure for handling behavioral crises, many issues related to crisis management may be prevented. As a specific example of preventative organizational practices, Luiselli describes a model of peer review in Chap. 3 that should be integrated into the organizational infrastructure of human service agencies to enhance accountability for data management concerning behavioral crises. The approach described within the chapter not only improves data management, it simultaneously fosters a culture of proactive discussions and problem solving so that crises that emerge can be dealt with using the full capacity of clinical staff and experts. As decisions regarding treatment options begin to be made following peer review processes, clinical teams must rely on evidence-based practices to best address the needs of the client. In Chap. 4, Maffei-Almodovar and Sturmey provide a thorough review of the literature on effective treatments for severe challenging behaviors commonly associated with behavioral crises. The authors supplement their review with both qualitative and quantitative data on the empirical support for the treatments identified in their review. Upon identification of treatment options and formulation of intervention

protocols, care providers must train therapists and staff to implement the plan to effectively service the client. Chapter 5 describes how agencies interested in providing services directed at behavioral crises for individuals with developmental disabilities can effectively prepare staff using empirically supported procedures. The authors provide a cogent argument for front-end training as an investment in agency, rather than as a reactive approach to crisis management. Unit I concludes with a discussion of restrictive procedures in Chaps. 6 and 7 that are sometimes necessary in treatment protocol for behavioral crises for individuals with developmental disabilities. The topic of protective equipment in service delivery for behavioral crises is discussed in Chap. 6, with Chap. 7 reviewing the literature on best practices associated with therapeutic restraint and protective holding.

Unit II focuses on crisis identification and acknowledgement and details unique constellations of behaviors associated with behavioral crises, along with approaches to assessment, ways to involve families during treatment decision making, and ethical and legal considerations that must be made when a student is deemed to be in a behavioral crisis. The unit begins with a review of problem behavior assessment procedures in Chap. 8, with discussions ranging from standardized assessment tools (e.g., scales) to descriptive assessments using observational technical (e.g., time sampling). Chapter 9 continues the discussion of measurement of behavioral crises by focusing exclusively on functional analysis procedures that are becoming the gold standard in problem behavior assessment. In Chap. 10, Patel describes unique challenges associated with the assessment of feeding problems often associated with behavioral crises in individuals with developmental disabilities. Chapter 11 provides a similar discussion of assessment and treatment concerns associated with Prader-Willi syndrome (PWS), such as hyperphagia and self-injury. SIB—a very serious and challenging component of behavioral crises for individuals with developmental disabilities—is discussed in Chap. 12. Specifically, McComas and Symons review classic discussions of the kinds of events or

consequences that maintain self-injury in individuals with developmental disabilities. Beyond the unique needs of PWS or SIB, Chap. 13 describes various comorbid disorders commonly observed in individuals with intellectual disability and developmental disabilities. Ricciardi provides a comprehensive detail of the various methods to assess comorbid conditions and provides advice for ways to integrate these considerations into individualized treatment plans when intervening on behavioral crises. In Chap. 14, McIntyre and Brown describe a three-tier model of prevention that integrates family involvement and consultation. This model is aimed at improving home supports that ultimately improve outcomes for the client with developmental disabilities or intellectual disability. Unit II concludes with Chap. 15 by Sheldon and Sheldon-Sheldon that describes the legal and ethical rights afforded to clients with developmental disabilities. The authors provide the reader with information on proactive approaches to ensuring that service delivery providers operate in a legally and ethically appropriate manner.

Unit III rounds out the handbook by offering a description of the continuum of services available to individuals with developmental disabilities that are facing behavioral crises. The unit begins with Chap. 16 by Yell and Drasgow. This chapter describes the process of determining whether a client's current placement setting can appropriately serve his/her unique needs associated with behavioral crises, as well as the legal requirements associated with such decisions. In addition to planning placement and programming, the clinical team must make complicated and tough decisions regarding the use of pharmacological treatment in severe cases of behavior problems. Chapter 17 walks the reader through the decision-making process associated with the evaluation of pharmacological treatments paired with behavioral interventions—a common scenario in service delivery for behavioral crises when less restrictive interventions fail to produce positive outcomes. Following Chaps. 16 and 17, Unit II progresses to detailed descriptions and reviews of various care models associated with behavioral crisis management, ranging from how

placement decisions are made and intake evaluations are completed to thorough reviews and discussions of various components within the care models. Chapter 18 begins this dialogue by describing consultation models in public school settings. Because many individuals with developmental disabilities may first exhibit signs of behavioral crises in such settings, DiGennaro Reed and Jenkins outline the consultative process wherein educational and/or behavioral staff may first attempt to manage emerging problem behaviors. This chapter concludes with a discussion of how the consultation process may inform decisions regarding transitioning the client out of the public school to more restrictive placements. In Chap. 19, Tarbox, Persicke, and Kenzer review various models of home-based services for individuals with developmental disabilities, including considerations for early intensive behavioral intervention (EIBI), parent training, and problem behavior management. When consultative supports fail to address behavioral crises in a student's public school setting and need to surpass what may be handled using home-based services, personnel may recommend placement in a private school setting. Fienup, Baranek, Derderian, Knox, and Pace author Chap. 20, which outlines various system supports integrated into comprehensive private school programs serving children and adolescents exhibiting behavioral crises. Chapter 21 describes a variation on private school programs wherein clients are placed in an intensive day-treatment setting that focuses specifically on reduction of severe problem behaviors that have evolved to crisis levels. This model differs from private school placement in that it does not address academic skill acquisition. As the authors describe, intensive day-treatment programs may best be conceptualized as partial hospitalization that permits the client to continue residing at home. In Chap. 22, Milnes and Piazza outline the best practice components associated with intensive pediatric feeding disorder treatments, often delivered in private school, intensive day-treatment, outpatient, residential, and/or hospital settings. In concert with Chap. 10 of this volume, Chap. 22 describes interdisciplinary programs that are designed to assess and

treatment issues of feeding that commonly occur during behavioral crises. Wacker, Berg, Schieltz, Romani, and Dalmau discuss another approach of service delivery to assess and treat behavioral crises within an outpatient approach to treatment in Chap. 23. Chapter 24 describes more intensive outpatient units wherein behavior disorders are closely monitored and intensely treated for very short periods of time. This model is considered more intensive than the standard model of outpatient services described in Chap. 23. When outpatient models fail to address clients' needs during behavioral crises, the final option is to transition the client to a residential program where services are provided 24 h a day, 7 days a week. As the anchor at the most intensive and restrictive end of the continuum of care, residential programs provide around the clock services, including nutritional, educational, health, behavioral, and psychological/psychiatric programs. Residential placement involves moving out of one's home into a new home or facility directed and managed by care providers. The handbook

ends with an example of one agency's approach to residential services in Chap. 25. Because of the intensity of services and restrictive nature of residential placement, it is imperative that staff are provided high-quality supervision and oversight and that empirically supported approaches to staff training and clinical services be adopted at the organizational level. Strouse, Sherman, and Sheldon describe how decisions regarding behavioral crises can be made within residential programs and offer examples of such decisions that have led to development of successful models and systems.

In sum, our goal for this handbook is to provide the reader with a comprehensive review of considerations and options regarding the management of behavioral crises with individuals with developmental disabilities. We hope that this handbook will serve as a reference and training tool for both caregivers and clinical staff, as well as a review for readers hoping to learn more about severe problem behavior and developmental disabilities.

Part I

Organizational Preparedness

Mark R. Dixon and Amy K. Loukus

In human services, all resources are valuable, and hence should be utilized with care. Budgets can be tight, funding often cut, and workers transient. When crises arise, consultants are typically called upon to provide a solution, yet their outcomes can be questionable. Taking an outsider perspective can result in seeing disconnects in optimal infrastructure; however, the lack of understanding of the subtleties of the organization can mitigate success. Given the complexity of human services and the need for individualized intervention plans, consultant promises may be deemed unrealistic and essentially turned down by the administrators. In contrast, others may naively trust the consultant, as crisis often breeds dependence and vulnerability on the part of the agency. Administrators and service providers in general should come to understand that within human service settings, there is little that can be fully controlled, and there are few interventions that can solve every problem in one swift application. Instead, they should assume some level of control could be found in the immediate environment, and with the help of a solid systems infrastructure, the vision of “control” may be actualized despite relative mishaps or, worse, crises. To do so requires a mutual understanding at the administrative and consumer level,

and is of primary interest in the relationship shared between all parties. In many ways, behavior of these individuals becomes the input in the human service organization, and likewise affects the behavior of clients and consumer families.

Organizational Infrastructure

Organizational infrastructure is a term most appropriately utilized to describe a systematic framework comprised of specific features and expectations. Infrastructure provides a basis of support by means of strategic planning of service execution by administrators and employees within an organizational hierarchy (Townsend, 2006). Organizational growth is directly influenced by the presence or non-presence of a solid, thoroughly planned infrastructure, responsible for incorporating the missions, goals, and expectations for any entity, which stems from the initial phases of development. Every successful organization, no matter the current size or consumer impact factor, began with a single idea. Ideas may have been constructed in remote environments of the day-to-day life of their originator. They are developed with careful consideration as they became shaped to represent realistic outcomes, and some ideas flourish to provide some insurmountable influence on consumers. Some of the most successful contemporary organizations in the realms of consumer products (Apple computers) and human services

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(e.g., The United Way; Goodwill Industries International, Inc. [Goodwill]) began as a result of one person or a small group of people. Ideas that helped establish these successful organizations were likely sparked by a passion for better circumstances in products or services. For Steve Jobs, a goal of easier access to information and increased socialization abilities comprised the solid foundations for his enterprise (Isaacson, 2011). United Way and Goodwill shared the goal of prosperity for those not currently able to provide for themselves and their families (United Way, 2011; Goodwill, 2011). This led to the establishment and attainment of various goals and eventual realities of affordable, effective, quality services for underserved populations provided by these and other human service giants.

The imminent necessity of thorough planning, and the influence early action plays as the organization matures, suggest that early stages of development should be conducted with careful consideration and future outcomes in mind. Definite activities, people, and goals should be linked with accuracy through thoroughly planned systems and processes. To better ensure such outcomes, careful planning must be committed to designing an insurmountable infrastructure upon which foundations for consumer services may reside (Townsend, 2006).

Infrastructure in Human Services

Like other organizations, human services were founded as a means to improve the lives of those affected in various ways, but in this arena of consumer interest, the concept of infrastructure becomes of utmost importance—not for the sake of profit alone, but for the sake of health and life quality. Over two decades ago, the assertion was made that human services would touch the lives of all Americans at some point (Riley & Frederikson, 1984). Today one may confirm such a notion, as the influence increases and impacts all, from the normal functioning adult to the adult or child with mental or physical disabilities. Infrastructure plays a major role in adaptation

and building a foundation upon which effectiveness, cost, and productivity lie, with ongoing interventions devised to help “pound out the kinks” in the day-to-day processes. This may be especially true of those who specialize in caring for individuals with developmental disabilities, whose lives depend on the stable, effective provision of services by skilled professionals working with this population.

Consumers of disability services often begin their relationship with an agency due to an unfortunate life event or bodily condition requiring their fight in a constant battle against exacerbated challenges in daily living. Challenges and resulting behavior likely influence every decision the individual forms. Features of such decisions are commonly both sensitive and life-altering in terms of resulting functional deficiencies present in various aspects of the consumer’s everyday experience (Falvo, 2009). Proper management of detrimental behavior warrants the need for human service professionals to step in and influence the change for the better, though requires intensive treatment and an ongoing, effective approach (Phillips, 1998; Sturmey, 1998; Sulzer-Azaroff & Mayer, 1992).

In today’s world, advancing technologies and high demand for additional services resulting from an increase in diagnoses lead to increased expectations for quality (Falvo, 2009; Wilk, 2009). Consequently, costs accrued by organizations to better meet consumer needs and provide a competitive edge against other agencies who offer similar services necessary to maintain operations are at an all-time high (Wilk). Service delivery, affordability, facility appearance, and even amenities offered during a routine visit have all become relevant factors upon which consumers determine permanent health care providers, thus instilling a sense of urgency by small business or low-income providers to increase profits, increase services, and increase the quality of experience to even compete with high-income providers.

Leaders of organizations deemed most successful given the market today, likely spend a considerable amount of time and preparation in devising a solid infrastructure, and will have

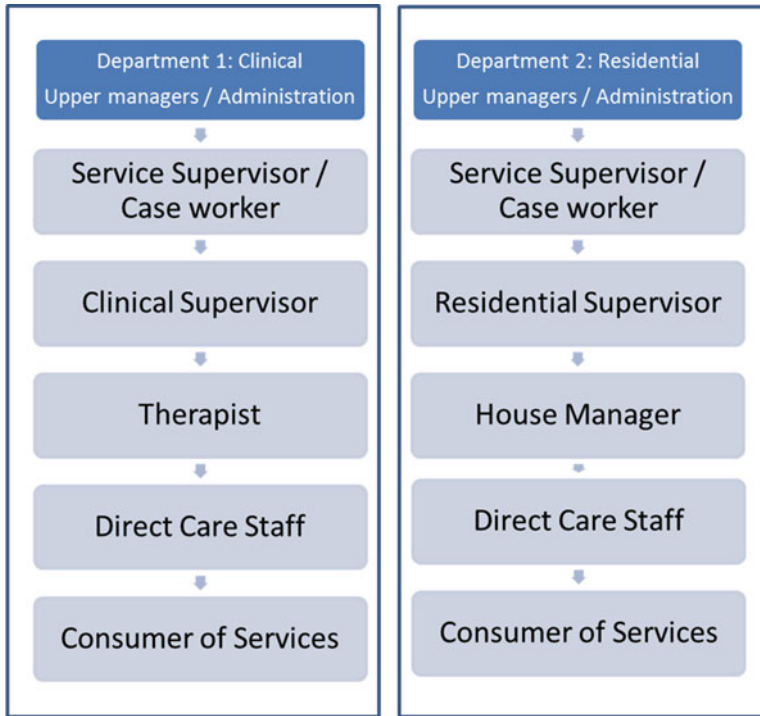


Fig. 2.1 Visual depiction of a vertical hierarchy that may exist in human service organizations

already factored such performance and service advancements in their overall guarantee to consumers they serve. These factors lie amongst the additional, essential process factors required to adequately habilitate those in need, often designed with the consideration of limited resources (Sturmey, 1998). In such analyses of infrastructure components, organizational goals are identified and directly related to the processes and people expected to help attain them (Townsend, 2006).

The Vertical Organizational Hierarchy

Like other organizations, human service organizations have a definite hierarchy, or assumed “chain of command” followed with regards to people of authority and process of services. As many hierarchies are founded, organizations have an almost cliché, vertical hierarchy that is known and followed (sometimes referred to in the organizational literature as a “silo” effect on hierarchical

planning; Rummler & Brache, 1995). In vertical hierarchies, upper management lies at the very top of command, with middle managers and clinicians lying somewhere in the middle, who then supervise the direct employees that provide care to the consumer. In the case of residential facilities, these refer to the direct care staff, or in the case of school settings, the paraprofessionals and volunteers who assist clients and are responsible for implementing treatment in any given day. Figure 2.1 illustrates the vertical hierarchy as seen in most human service agencies.

In organizations that use a vertical infrastructure, middle managers may serve as liaisons to manage the gap and translate expectations from upper management or administration to front-line employees, and as a result, interaction between top management and direct care staff is essentially nonexistent. Rummler and Brache (1995) describe this as a silo effect for many reasons, but mainly because it seems there is a clear linear command chain that is followed by all in the agency, which promotes altercation

when low-level employees attempt to address leaders above their immediate supervisors. Further, the linear model is constructed within organizations which may have various departments (e.g., residential, clinical), so communication rarely occurs between middle managers across such departments, and issues that involve more than one department involve only top managers who really have other things they should be working on, that perhaps, middle managers below them could devote time to solving. Oftentimes, organizational “silos” breed competition between departments, and blame is passed from one to the next with upper management frustrated and jumping through hoops to solve the issues. Incidentally, these issues may simply be miniscule process issues that should not pose much effort in resolving, and require little technical knowledge of the process whatsoever (e.g., mishandled/misfiled paperwork). Information is said to be lost between the cracks, or, as their book title suggests, “within the whitespace” of the organization, often not formally managed by anyone. Rummler and Brache state, “an organization behaves as a system regardless of whether it is being managed as a system...if you put a good performer against a bad system, the system will win every time” (p. 13, 1995).

An Alternative Approach: A Horizontal Matrix or Adapting Across Performance Levels

The vertical approach to infrastructure was successful in industrialized America. However, as the country moved from a “stuff” producing market to a “service” delivery market, the top-down approach tended to not work as well. The beauty of the vertical approach was that each worker was boxed into a small set of responsibilities and skills. It resulted in highly skilled, yet narrowly defined workers. When “stuff” is being produced, high precision is needed. Yet, the dynamic nature of service delivery tended not to fit such a mold. Instead, services that involved interaction with people appeared to need more variability in deliv-

ery. Today’s human service organizations grew out of the antiquated model of state-operated facilities for persons with mental retardation or mental illness. In addition to the variety of human rights issues that resulted in a cascading of closures to state facilities, the entire vertical management model was brought into question. Furthermore, stakeholders across the country wondered, could more be done with less? The answer to this question is an encouraging “yes,” and great strides have been made utilizing the principles of behavior analysis in human service settings.

Organizational behavior management (OBM), as a subfield of applied behavior analysis (ABA), directs its focus on large-scale behavior change, in organizations just described. OBM professionals serve as consultants, both internal and external to organizations, and provide insight to processes and performance likely to allow an organization to develop and meet outlined goals and missions to the degree necessary to provide a competitive edge in the consumer market (Bucklin, Alvero, Dickinson, Austin, & Jackson, 2000; Geller, 2003). Recent advancements in organizational research, and a stated need for improved quality of organizational management, have led the way for behavior analysts and organizational managers to influence the human services sector (see Phillips, 1998; Sturmey, 1998, for literature reviews of OBM’s influence in human services). Just as applied behavior analysts effectively improve the behavioral repertoires of individuals, OBM professionals strive to identify causal variables likely to produce and maintain desirable performance at three distinct levels within any organizational system: level of the performer, the department, and organization (Austin, Carr, & Agnew, 1999; Malott, 2003; Rummler & Brache, 1995).

Performer Level

At the level of the performer, common issues include productivity, quality, and consistency in work produced or outcomes achieved. Clearly specified expectations, individualized feedback on performance, and necessary reinforcement/correction for desired behavior

increase the abilities of the performer and provide a means by which employees can advance within the organizational hierarchy (Malott, 2003; Rummler & Brache, 1995).

In human service agencies, oftentimes direct care providers represent the performer described here. Following an initial training, ongoing performance monitoring allows for individuals to succeed in accomplishing the assigned work tasks and consumer goals. With continuous monitoring, ongoing, in situ training will allow performers to constantly evaluate and improve upon individual performance. In OBM, behavioral skills training or the application of a four-component package intervention consisting of instructions, modeling, guided practice, and performance feedback, plus reinforcement for correct performance (Komaki, Barwick, & Scott, 1978; Sulzer-Azaroff & Mayer, 1991), offers a concise, consistent, and empirically validated method for implementing such training, with repeatedly demonstrated outcomes of success associated with the use of training with human service direct care providers. All four components comprise the training model, but in some cases, single components or combinations of single components are often utilized with other methods as alternative package interventions to address issues when more immediate adaptation is necessary. Most often, feedback is commonly targeted as a stand-alone intervention for improving individual and group performance (Austin, Kessler, Riccobono, & Bailey, 1996; Balcazar, Hopkins, & Suarez, 1986). Beyond training, however, other factors must be considered and addressed to ensure success within any human service agency.

Maintaining Motivation

Performance of employees in human service agencies greatly benefit from behavioral skills training procedures, with quality of service and expected outcomes for consumers especially impacted. Over time, without constant supervision of a supervisor, it is likely that employees will drift away from procedures on which they were initially trained and cut corners to make tasks more efficient and less aversive or cumbersome. To maintain desired performance in the

everyday environment, care must be taken to ensure motivation or the demonstrated desire (Malott, 1993; Reid & Parsons, 2006) of direct care providers to work toward client goals and objectives (Reid & Parsons). Plainly stated, the nature of human service employees (e.g., socioeconomic status, education, motivation) and, further, the nature of human service tasks (e.g., laborious duties, long work hours) determine the level of motivation an employee is likely to possess independent of supervisory intervention (Reid & Parsons). In the OBM literature, employees demonstrate what is termed “Discretionary Effort” (Daniels & Daniels, 2006), when one exhibits performance above and beyond expectations of the employers or the status quo. Employers often attribute the traits identified by employees as originating within the skin of the performer and often utilize theories of unobservable phenomenon to account for the often described, “motherly nurturing” demonstrated by employees toward the consumers.

What employers fail to recognize, however, are the various aspects of the job that allow the employee to contact intrinsic reinforcement, whether by means of small personal successes in the clients with whom they work or feelings of accomplishment associated with the completion of tasks identified as crucial to the success of the organization or position. In human services, residential and unit supervisors assume the task of enhancing Discretionary Effort® of direct care providers by motivating employees to *want* to perform, with difficulties often exceeding simple delivery of praise and tangible rewards to employees who exhibit this trait (Daniels & Daniels, 2006; Reid & Parsons, 2006). Specialized OBM-based analyses and implementation of contingencies of reinforcement provide a reference point for supervisors that are relatively easy to implement, but all must begin with an infrastructure designed to allow for adaptation to new situations, not always part of the employee’s expectations.

Department Level

At the job or departmental level, contingencies must be developed and implemented that expose

members of a group to opportunities that may result in success of all members, with feedback and reinforcement used as small-scale methods of contingency arrangement responsible for shaping and maintaining desirable outcomes which meet the mission of the department and contribute somewhat to the overall mission of the organization (Brethower & Smalley, 1998; Rummmler & Brache, 1995). In human services, interdisciplinary teams comprised of direct care providers (e.g., family, guardian, and support personnel), residential supervisors, and clinicians may advance specific skills of a consumer. Each of these groups of people should be provided with specified group goals to strive to accomplish that further the outcomes and enhance the likelihood of consumer success over time. Ideally, these goals and outcomes should be stated at the start of the team member's role in caregiving position. Again, OBM interventions have been developed and utilized which allow for such influence, with performance-based lotteries (Cook & Dixon, 2006), and preference assessments for reinforcing employee behavior (Wilder, Rost, & McMahon, 2007; Wilder, Harris, Casella, Wine, & Postma, 2011) easily implemented and utilized within departments and across groups of individuals.

Organizational Level

Goals and mission statements are constructed in an attempt to define the purpose of an organizational system (Malott, 1993; Daniels & Daniels, 2006). Frequent analyses of whether such goals are being met, or are met to the degree in which they support the organization's mission, signify necessary components of any evaluation of the infrastructure's effectiveness during implementation. Missions are brief statements of accomplishments that can be expected from an agency, with clearly defined outcomes and measures of outcomes indicated (Daniels & Daniels). Organization administrators create a mission statement as a means to convey a sense of purpose and desired outcomes for the consumers they serve, as a broad depiction of company initiatives (Malott, 2003). Performance of the organization is affected by the discrete actions shaped

and maintained by individuals on the department and performer levels discussed previously. When problems arise and behavior fails to exceed expectations at the performer or departmental analysis, total systems analyses (Brethower & Smalley, 1998; Rummmler & Brache, 1995) can be conducted to allow administration to determine where exactly in the process disconnects occur. Once identified, further analysis of the issue may better inform management on variables maintaining the issue, and intervention can allow for resolve.

Process Mapping

The concept of "process mapping" has gained popularity in recent years as a procedure that allows an outsider to observe how materials and resources invested as inputs into an agency can lead to effective outputs (e.g., products and services that benefit organizational consumers). First utilized in the area of business administration (Brethower & Smalley, 1998; Rummmler & Brache, 1995), and later introduced as one of a few crucial first steps of the consultation procedures (Rummmler & Brache), process mapping ensures that individual contribution is accounted for and all inputs are used to their potential. Further, process mapping ensures that inputs and processes result as expected, in a definite product that either moves on to a separate system or department, or rather, results in a terminal link or final product of consumption. Throughout the procedure, individual relations may come to be identified that were previously overlooked and included as variables that surround individual performance and influence terminal success.

Process mapping, or this means of adopting a horizontal organizational hierarchical viewpoint, can be a complex endeavor, however may be especially useful in human service agencies. Here, various employees serve to produce a variety of services deemed necessary requisites to other employees or as final products in the lives of consumers who utilize them. To illustrate, consider the following example of a residential facility that serves individuals with severe developmental disabilities. Administration and case managers produce means by which the fund-

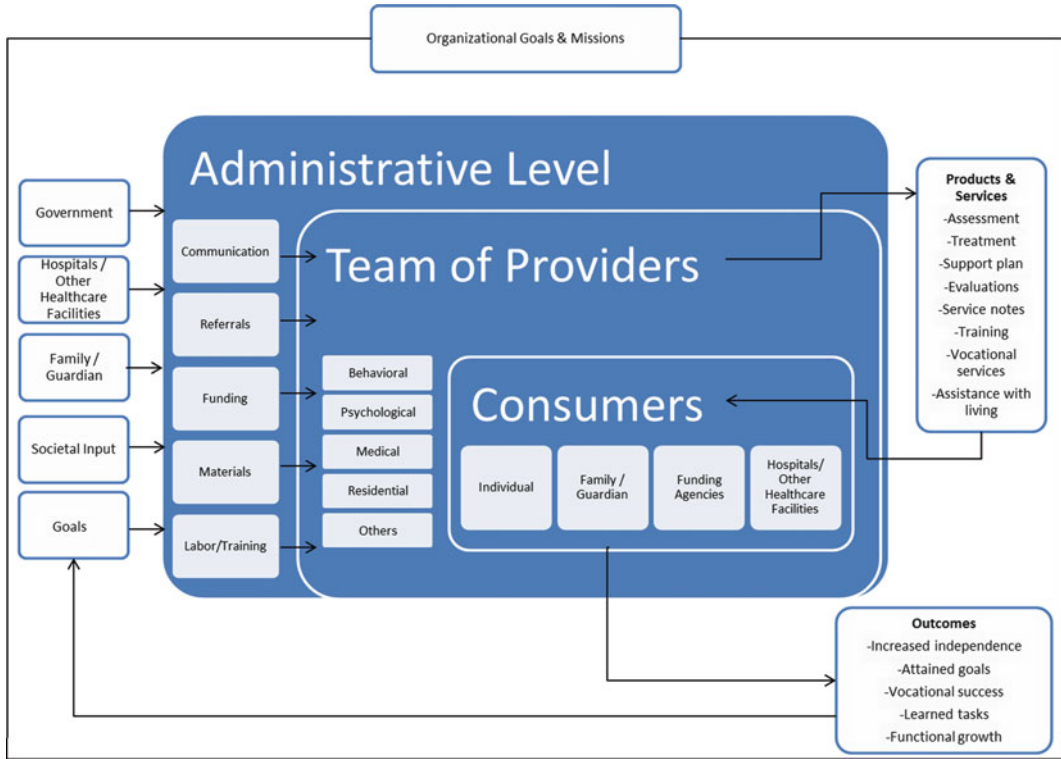


Fig. 2.2 Visual representation of the interworking components of a human service agency from a systems standpoint

ing and services may be afforded to the clients by completing essential paperwork and contacting various representatives responsible for releasing funds to consumers. Funds produced by administration and case managers serve as input resources to clinicians who specialize in providing evaluation and treatment to the various individuals. These services may also be observed in the form of various therapies provided depending on the clinician's role within the interdisciplinary team described previously (medical, behavioral, psychological, physical, occupational, speech, etc.). Evaluation and therapies delivered can be seen as a product by which consumers immediately benefit and also may produce some form of internally based, informational resources (service reports, behavior support plans, etc.) by which procedures for emergency responding may be outlined and explained at a level that is understandable to direct care providers within the residence or on residential units. Reports, then, serve as internally supplied input to the direct care pro-

viders, who utilize the information as guidance for providing definite outcomes (e.g., attained goals, increased independence) to consumers in the form of effective service delivery (terminal output). Refer to Fig. 2.2 for a visual depiction of this process, and notice the cyclical or bidirectional nature of processes as they impact all levels of the organization.

The illustration just provided outlines a very basic overview of input/output exchange amongst employees at varying levels of expertise. More often, however, thorough analysis of this same procedure will surmount to a tangled web of exchange with difficulties likely in the initial establishment. The final product of comprehensive service delivery, however, is then possible to be carefully outlined and explained using process mapping that is easy for administrators and consumers to comprehend. Once constructed, any disconnect in services rendered by consumers or members within the organizational hierarchy are easily identified, and interventions may

be implemented to remedy the variables causing the stopped progression of services. Performance and process management are likely to benefit those in areas where disconnects occur and may lead to an increase in future consumer progress.

Total Systems Analysis

Like process mapping, total systems analysis relies on the identification of resources that serve as necessary inputs to maintain successful operation of any agency but also provide a more thorough analysis of interworkings between agencies or departments of a single agency. Total systems analysis implies that every single input and, likewise, every single output is accounted for, with clearly specified links identified between each component. This means that the roles of each employee are thoroughly analyzed, with direct links between process and outputs blatantly identified and evaluated for effectiveness. In the illustration depicting process mapping, a total systems analysis would include all information of the process map, but with specific detail addressing the bidirectional influences of various employees, departments, and organizations, all serving the individual consumer of developmental training and services.

Brethower developed and termed "Total Performance System (TPS)" (Brethower & Smalley, 1998) as a behaviorally framed total systems analysis. As the name suggests, Brethower's model allowed for a total analysis of performance as a function of the varied levels and types of resources (termed inputs) that eventually amount to products or services through organizational processes (termed outputs; see Hyten (2009) for a comprehensive discussion). A major benefit of Brethower's system was that incongruence in performance as it relates to the organizational goals could be easily identified as they occur given a thorough analysis of relevant variables and processes of turning inputs to outputs. This could be conducted at all levels of performance including the organization as a whole (regardless of its size), an individual department, or employee (Hyten). Rummler and Brache (1995) have expanded on TPS to provide a more comprehensive and efficient method for charting

organizational interactions. They analyze performance at the three specific levels and consider relationships neural, or in other words, across all departments and levels within the organizational hierarchy. In their analysis, business evaluation exists for strategy, processes, and behavior, with emphasis on fundamental analyses that contribute to the system as an interacting agent, serving functions for leaders who build them, and consumers left to rely upon them for their livelihood. Processes described here and the evaluations of such provide a means by which essential growth and organizational movement may be identified and accounted for in the organizational hierarchy. Business administrators and OBM consultants provide essential examples of such processes being utilized to better the already efficient services contained within the organizational infrastructure initial quality and planning.

Since its introduction roughly three whole decades ago, behavioral systems analysis has been the subject of many conceptual and introductory research articles, and the applicability of its construction has been reviewed in an objective, critical manner by skilled behavioral psychologists and OBM consultants (Abernathy, 2009; Brethower & Smalley, 1998; Diener, McGee, & Miguel, 2009; Gilbert, 1996; Hyten, 2009; Keller, 1968; Krapfl & Gasparatto, 1982; Malott, 2003; Malott, Vunovich, Boettcher, & Groeger, 1995; Mawhinney, 2000; Williams, Di Vittorio, & Hausherr, 2003). In a more recent article, Abernathy (2009) describes a future for behavioral systems analysis and relates it to early fictional work of Skinner (1948/1976), which describes the use of contingency management in creating and maintaining a successful utopian community. Reawakening the idea of horizontal systems viewpoints and the need for systems analysis, and as a means to promote potential future contributions to the experimental analysis upon which it was based, Abernathy (2009) stresses the importance of organizational contingencies and interactive effects occurring at all levels. Though Skinner's *Walden Two* was a fictional account of behavioral technology's presumed application, the apparent applicability should not be lost in translation as foci of

research interests continue to morph into consumer behavior analysis (Foxall, 2010; Hantula & Wells, 2010) or other recent trends.

The Nature of Human Service

Caregivers of consumers in human service agencies may consist of one person, or many people, but all share the common characteristic as someone upon whom the consumers of services inherently rely to respond appropriately given various life encounters (Riley & Frederikson, 1984). Caregivers of individuals with developmental disabilities often consist of a team of medical and clinical therapists, few or many residential direct care staff, and members of the consumer's immediate family (or a state-designated caregiver, hired by and paid for with federal or state funds) (Odom, Horner, Snell, & Blacher, 2007; Reid & Parsons, 2006). The demonstrable range of services deemed appropriate for a consumer and their family, and execution of service delivery to individuals with disabilities becomes apparent, especially when one considers the implications surrounding the fact that consumers may potentially interact with a minimum of five different caregiving individuals on any given day (potentially more if the consumer resides full time in the agency providing 24-h services). Caregivers may even diverge further according to an array of trait variables that relay crucial information to relevant others in the lives of consumers. Caregiver traits may be categorized and described in terms of experience level, knowledge of the consumer's needs, educational influence on the expected and demonstrated comprehension of caregivers, and degree to which the caregiver demonstrates motivation to provide services in the client's best interests (Odom et al., 2007; Reid & Parsons, 2006; Sulzer-Azaroff & Mayer, 1991). The nature of human services staff and the nature of human service tasks are often at fault for an unwarranted decline in service quality rendered, and outcomes for obtaining the personally identified goals become meager, unlikely to be met given such expectations (Reid & Parsons, 2006).

Behavioral Challenges Faced by Consumers and Caregivers

Individuals with disabilities often present some level of maladaptive behavior associated with consumer-specific functional limitations impeding on consumer livelihood and expectations for habilitation throughout the course of treatment. Self-injurious behavior, aggressive behavior, impulsive decision-making, and various other maladaptive behaviors commonly exhibited by individuals with intellectual and developmental disabilities require precise definition and measurement, and further, sufficiently effective and least restrictive behavioral support plans to ensure the consumers are subjected to least potential harm, through implementation of interventions which properly address the varying issues as they arise. These and other features shared with populations served by human service agencies provide rationale for thorough support planning, regardless of the severity or frequency upon which the behaviors occur, and the organizational system must therefore demonstrate some preplanned level of preparedness upon which responding to emergencies may rely. For this reason, proper planning and support for the unexpected lay at the forefront of any operation, and the need for a solid infrastructure becomes more apparent.

Constructing a Support Plan

One essential component of organizational preparedness includes the construction of predetermined responses to behavior as it occurs, which anyone and everyone in the consumer's life may adopt and implement. Behavioral targets may include adaptive features, identified as more likely to advance a client toward relevant goals. Contrastingly, maladaptive behaviors (self-injury, impulsive decision-making, disruptive behavior, and others) are more often identified for behavioral reduction due to the implications of engaging in such behavior for the consumer and those who interact with that individual. Behaviors that impede on the implementation of

rehabilitative services are likely to occur with developmentally disabled populations and are determined as high-potential targets for intervention. In doing so, physicians and clinicians first address medication and organic causes for a behavior to allow for clinicians in other areas (e.g., behavior analysts, cognitive therapists) a better chance to eliminate variability in performance. Resulting expectations focus on increasing the consumer's ability to meet goal-directed objectives likely inhibited previously due to disturbances in normal behavioral functioning.

Key factors commonly identified in any effective response to problem behavior identified in disabled populations include (a) proper identification of variables responsible for the occurrence and foregoing maintenance of maladaptive behavior (functional analyses; Iwata, Dorsey, Slifer, Bauman, & Richman, 1982/1994; Mace, Lalli, & Lalli, 1991), (b) function-based antecedent strategies and behavioral interventions (deemed necessary and appropriate given the frequency and severity of the target behavior) (Bailey & Burch, 2005; Cunningham & Schreibman, 2008), and (c) consistent, reliable implementation and follow-up analyses of rate and severity over the course of treatment by direct care staff members and clinicians. This ensures probable, beneficial outcomes for the client based on individualized goals and person-focused objectives.

Implementation and Process of Support

In human services, consumers are often provided with a guarantee that essential needs are met, with services provided in a vast array of modalities, contingent on factors likely to determine a best course of treatment. A variety of factors are said to influence the services received, and most often, each may be directed back to the infrastructure devised by the agency serving the client. Factors alluded to here may include, but are not limited to, proper identification and evaluation of needs, accessibility to services in less-populated areas, and adequate funding for services from a variety of clinicians trained to enhance personal abilities (psychological/cognitive abilities, activities of

independent living, emotional and behavioral support, physical and occupational skill sets—which may require retraining if bodily injury is apparent and/or mobility is compromised—and medical monitoring for ongoing treatment evaluation of factors likely to affect all other areas addressed).

Services provide a basis of support for the individual to accomplish personalized goals and objectives, increase access to reinforcing items and activities, and engage in behavior that will allow the consumer to progress through life unaffected to the best possible degree. This, and other information, is summarized in the consumer's person-centered plan, which essentially provides an in-depth depiction of all relevant variables in the consumer's personal life.

Later in this book, the construction and implementation of function-based intervention strategies will be presented, with considerations that ensure the least variability in how processes are carried out. Behavioral support plans may be viewed in this way, as a mini-infrastructure that sets a foundation for responding to a consumer, given the necessity for action, which is directly related to the personal history and contingencies surrounding behavior. Building upon each other, each of these mini-models of responding comprises a larger model, and the overall preparedness of the organization excels to ensure solid service delivery.

Implications for Human Service Organizations

Consumers of human service agencies include individuals affected by disability and their families and relevant others who care for and support the individual as he or she progresses through life. Additional supports afford individuals the opportunity to experience life to the fullest extent possible, a luxury that those living without the effects of disability may often take for granted. Great care must be taken when working with consumers, and agencies supporting the advancement of those living with disability take on an important task which requires immediate intervention and

ongoing support to ensure the clients receive the best care with the most effective outcomes.

Human service specialists and the agencies providing supports for consumers are often faced with behavioral issues demonstrated by individuals whom they serve, which often require the use of emergency-intervention procedures. To ensure procedures are implemented with the consumer's best interests intact and addressed, processes and planning are required in the previously described identification, intervention, and follow-up of behavioral support plans expected to maintain advancements in the consumer's behavioral repertoire, thus inducing the need for an organizational infrastructure worthy of supporting the implementation and maintenance of best-practice procedures. Each level of support provides a foundation from which consumers and their families can better their lives, and human service agencies allow them to realize their goals of a brighter future.

Current Trends: Building an Organizational Culture That Shines

A buzz phrase in the behavioral and business literature in the past decade is the concept of organizational *culture*. Culture is defined broadly as a set of behaviors that have been consistently reinforced (or previously punished) over time (Tosti & Herbst, 2009). According to these authors, a common view held by organizations and consultants specializing in organizational culture is that establishing a strong organizational culture requires a common vision, a vision likely outlined at the inception of any organization and promoted publicly via organizational slogans or mission statements. Whether the organization holds a vision to obtain perfect customer and employee satisfaction or higher qualities of life for the individuals they serve, organizations need to set these and remain consistent in all actions contributing to the overall missions, thus branding their promise to consumers.

Oftentimes large established agencies run into the issue of staff who show a blatant disregard for, or to the contrast, only a slight incongruence between their mission and actual behavior surrounding that mission (Daniels & Daniels, 2006).

Most often a drifting effect occurs over time. At first, minor behavioral discrepancies pass without notice, until after enough time has passed, visions are misaligned and behavior is inconsistent with obtaining those missions. At this point, when noticed, a means of reorganization is required, and having anticipated such shifts and needs in the outset of organizational planning will help with remedying the circumstances. Culture, taken as the organization views it, occurs regardless of planning. Without proper planning, leaders and administrators end up with a culture that is not highly preferred or even insufficient for effective processing and performance. Leaders are called upon to clarify expectations, and reinforcement must be provided for employees when the right things are getting done. This "catch 'em being good" strategy is a technique identified in managers most effective and most active in the day-to-day operations of their agencies (Daniels & Daniels, 2006). Importantly, managers must identify that culture is tied to performance, so the most important thing a company can do is tie a desired outcome to objective measures likely to be identified in daily employee performance (Dakens, 2009a, 2009b).

Behavior Analytic Applications in Human Services

Professionals in OBM and ABA have long since demonstrated the need for organizational planning and procedural implementation for effective services in various agencies and with a large scope of individual types. Riley and Frederikson (1984) set the case for application to human services because of the inherent need for a different kind of evaluation in these settings, stemming most directly from the general nature of limited resource availability, and constant staff turnover resulting from burn out and other job-related issues (Lawson & O'Brien, 1994). Interventions in behavior analysis allow for cost-effective and simplistic delivery when building a strong system upon which service delivery lies. Research findings in behavior analysis and OBM have proven worthy when working to resolve issues

within human service organizations. The research presented here includes such interventions that allow behavior analysts to fulfill the promise of socially valid and effective procedures, such qualities that founded the behavior analytic tradition (Wolf, 1978). General application and potential future avenues are outlined to a greater degree in sections that follow.

Skills Training

With little hesitation, one can state with great confidence that staff training is conducted best when done so in an orderly and well-structured manner (Chapter 5 of this volume describes empirically supported staff training techniques in greater detail). Years of behavior analytic research on performance show that training is most effective when initial planning and eventual training processes link behavior to the natural context in which skills and knowledge are expected to be applied (Brethower & Smalley, 1998; Methot, Williams, Cummings, & Bradshaw, 1996). In a way, just the training component can be treated as a total system discussed previously and may be structured and carried out in the same fashion expected as the overarching organizational system would. Benefits of doing so include the idea that remote contingencies likely to contribute to behavioral maintenance, despite their delayed effects (Michael, 2004) could be anticipated and better controlled. Further, interactive and almost pyramidal effects of training may likely be identified for the most efficient dissemination of knowledge across departments and within residential units to individual contributing to the greater team of skilled professionals working with multiple individuals. OBM researchers conduct a wide array of training, whether training staff to work directly with individuals with disabilities, or training them to conduct assessments, such as preference assessments prior to delivering instruction. Roscoe, Fisher, Glover, and Volkert (2006) examined the role of variables likely to promote or demote effective training with human service staff. The authors trained the staff members to identify client preference by conducting behavior

analytic assessment of reinforcing items in the natural environment. Other incentives and reinforcement were available during training and were deemed important when enhancing the likelihood that staff would maintain their skills following training. Importantly, consideration and application within the natural setting were granted to the individual being trained, with transfer of skills, and discriminative functions appropriately demonstrated throughout (Roscoe et al.).

Feedback

Performance feedback, described previously as a common component of the effective behavioral skills training, is said to be the one component likely to contribute a high impact as a stand-alone treatment, independent of all other components of the package intervention (Balcazar, Hopkins, & Suarez, 1985). Feedback delivery may occur in a variety of ways, including (a) visual or graphic presentation, (b) post hoc review of video clips produced while performance occurred in the natural setting, (c) written feedback in the form of memos and progress summaries or reports, and (d) direct face-to-face, spoken feedback, delivered from an observer to the performer either immediately as behavior occurs or some time thereafter (Daniels & Daniels, 2006). Major benefits afforded by the use of performance feedback include a varied array of delivery methods and the ability to creatively tailor delivery according to the specific settings and individuals receiving feedback. Recent work in human services demonstrates the usefulness of feedback on staff performance, with methods that can be used across settings and with varying individuals with little need for alteration (Cook & Dixon, 2006; Guercio & Dixon, 2010). Guercio and Dixon delivered feedback to direct care staff members of a rehabilitation facility that serves individuals with traumatic brain injury as a means to improve the quality of client and staff interactions. Feedback delivery consisted of video modeling and was paired with further behavioral skills training to enhance the impact on less-sufficient staff performance, thus demonstrating the flexibility

of feedback, given the necessary resources. Just prior to this study, Cook and Dixon (2006) demonstrated substantial gains in performance when staff members in the same facility were provided feedback, but also had the opportunity to earn additional, albeit probabilistic bonus reinforcement for meeting their established observational performance criteria.

Other researchers assessed the impact of intervention in general, which often includes feedback as a major component, in similar complex settings. Brackett, Reid, and Green (2007) assessed the reactive effects of observation on the performance of job support coaches responsible for ensuring clients completed assigned duties independently rather than having coaches complete forgotten or incomplete tasks for them. Using a multiple probe design that included follow-up, results suggested reactivity to observation and performance feedback may have been responsible for improved performance. The authors then showed it is possible to decrease such reactivity and maintain improved performance over time. The study noted various limitations, however, which are subject to future research for clarity and conclusive effects yielded by intervention.

In an attempt to demonstrate the effects of feedback systems on performance in rehabilitative settings (Coles & Blunden, 1981), the addition of feedback, including private staff performance data and public display of client engagement, was said to have contributed to the increase in materials offered and activities provided to individuals with limited mental capacity. Both targets and improved performance scores demonstrated maintenance multiple weeks following initial implementation with little variation. Left unanswered in each of the aforementioned studies, however, is the question of how much each component of packaged interventions contributes toward progress and maintenance, given the fact that formal analysis of the problem plays an important role already. Uncertainty arises with regards to relative effectiveness due to the concurrent implementation of feedback and a structured recording system, with no additional analyses to separate and confirm the added value of each (Coles & Blunden). Even still, research since then has

shown the valuable effects feedback alone provides in performance management with individual and group behavior (Alvero, Bucklin, & Austin, 2001; Balcazar et al., 1985).

Performance Checklists

Checklists have become one of the least complex, and perhaps most efficient way of ensuring ends are being met and tasks are completed, leaving a positive impact on the people and processes affected by their use. Development of checklists that sustain complex or large-scale behavior requires consideration with planning, and methods for doing so are outlined within the works of behavior-based safety, a subfield in behavior analysis and OBM most sensitive to critical description of work tasks (McSween & Matthews, 2001). Early works in OBM afford the checklist many positive contributions in terms of behavior change and maintenance of interventions (LaFleur & Hyten, 2005) in a variety of settings to increase behavior of individuals and groups alike (Bacon, Fulton, & Malott, 1982). In a recent work, Gwande (2009) describes the varied use of checklists that have helped to improve effectiveness and safety within settings that range from architecture to hospitals, during routine survey work, or while in the surgical room with patient lives depending on their use. Checklists may be implemented to increase accountability and decrease the number of mistakes made due to human error in memory or other distractions, and in all settings, require little effort of skill on the part of those utilizing them. The need for simple interventions that cost the least amount in resources is especially great in the realm of human services and implementation of care and thus should be expanded to the realm of human services.

Differential Reinforcement of Desirable Performance

A variety of methods have been developed and adopted to positively reinforce appropriate staff behavior that can lead to increased adaptation

and willingness to act, even when situations are new or pose some degree of uncertainty. Positive reinforcement strategies repeatedly demonstrate their worth in human services, with reinforcing stimuli including tangible, social, nonsocial, or sensory consequences for appropriate performance (see Daniels and Daniels (2006) and Reid and Parsons (2006) for an exhaustive list of reinforcer types and delivery methods). Evaluating staff preference for varying forms of functional reinforcement is essential before implementing reinforcement systems in any agency, and though varying methods of observation, interviewing, and trial and error may be attempted (Cook & Dixon, 2006; Wilder et al., 2007, 2011), research shows it may be more efficient and equally effective to simply ask employees what they like. Asking, in this case, may consist of providing staff with a list of items and having them rate items in order of preference, or perhaps, asking staff to generate the list of preferred items themselves (Wilder et al.). Further ways of manipulating the means of contacting reinforcement in the organizational setting may involve the inclusion of lottery systems or bonus contingencies (Cook & Dixon, 2006) or manipulating compensation to mimic the successful pay-for-performance systems (Murphy, 1995). Of course, in doing so, careful consideration should be granted to devising and defining desirable performance of staff members, to ensure objective, unbiased performance criterion that staff members are capable of meeting.

Contextual Behavioral Contributions

Contextual behavioral psychology, known to the behavior analytic community as the “third wave” of behavior therapy (Hayes, 2004), stems from the empirical works of behavior analysis and traditional psychological endeavor. As the title suggests, contextual behavioral psychology adds a variable of context to the already investigated, first- and second-order, form and function of behavioral phenomenon. In this way, third-wave therapies seek to address specific, psychological functions intertwined within broad psychological and behavioral repertoires that have emerged through the ongoing interactions between the

whole organism and environmental contexts over time (Hayes). From the expanded scope of experience, therapists attempt to reduce functions via experiential change strategies (often by use of metaphor and visual imagery tasks) that may be linked to functionally similar, yet formally unrelated situations. In this way, new wave therapists work to expand the scope of therapeutic subject matter to experiential and indirectly accessible experience. In turn, unobservable psychological phenomena may be directly applicable to investigation, and interventions may simultaneously address many broad, functionally related response repertoires to enhance greater flexibility in responding.

In third-wave therapies, personal values, goals, and past experiences become relevant components of the psychological and behavioral analysis and may be used to directly relate one or more formally dissimilar situations with functionally or contextually related equivalents. Third-wave principles and techniques are often mistakenly interpreted by novice behavior analysts and are considered a highly complex area of behavioral science—complex in terms of technological understanding, application, and delivery of services—and thus are often approached with hesitation or abandoned before they can be adopted. Despite the hesitation surrounding the perceived complexity, contextual-based therapies offer a variety of simple interventions that are easily adopted by novice therapists and delivered by way of experientially based strategies to expanded circumstances.

Third-wave behavior therapies lend methods to a systems application that expands the scope of OBM and traditional behavioral intervention options. Though not as simple to grasp and implement as organization-wide interventions described previously (i.e., the checklist), methods from contextual behavioral psychology have led to great advancements in single-subject research and application and only recently have been demonstrated empirically effective with use in large organizations.

Pingo (2010) examined the role of personal values as they relate to performance improvement in a treatment facility for individuals with intellectual and developmental disabilities.

Measurements from various psychometric analyses were administered pre- and post-intervention, which consisted of brief sessions of Acceptance and Commitment Therapy (ACT), focusing on employee values and psychological flexibility in relation to assigned employee roles. Employee performance following brief sessions of ACT was objectively evaluated compared to a control group receiving no such therapy. Results yielded vast improvements in the performance of those individuals participating in the therapeutic group. Employees demonstrated greater proactive service planning, increased interaction with individuals at the facility, and an increased provision of materials for instruction available, all targets that previously lacked in all participants. Moreover, with improved employee psychometric ratings, objective observation concluded that not only were materials available for use, but in addition, consumers were provided with more frequent, meaningful, and relevant task materials throughout treatment than they were prior to intervention. Further, outcomes enhanced post-training were never specifically targeted in the ACT sessions, which, as the ACT model suggests, is common with use of experiential reduction techniques. The study provides great implications for use of alternative training methods and interventions that allow for skills gained by participants to be related and applied to other areas of the work environment that function in similar manner for the employee and also for improvements in active treatment delivery in the absence of specific, often costly training.

Future Directions

Since Riley and Frederikson (1984) proposed the need for OBM in human service agencies, many accomplishments continue to improve the functions upon which services are based, and effectiveness, as determined by the number of individuals now residing in the community compared to those housed under institutional care (Odom et al., 2007). In the way of OBM application in behavioral systems analysis, and the application of behavior-based interventions to large-scale organizations in the past four

decades, there exists still an abundance of research not yet conducted in the field, and more specifically, demonstrated in the realm of human services. No set boundaries dictate the future direction for work in behavior analysis within a human service framework, though avenues introduced in ABA and behavior therapy with typically developing individuals may be readily applied and subject to examination in the organizational setting, expanding the breadth of such interventions to that of disabled populations or the staff members responsible for their care (e.g., Pingo, 2010).

One avenue of future research may consist of the experimental analysis of behavior systems analysis. Although numerous studies show improvement in systems when a systems analysis procedure, such as process mapping is conducted, no study to date examines its effectiveness in comparison to basic contingency management as used in single departments for small-scale problems. Behavioral systems analysis is a lengthy, and oftentimes complicated, procedure which requires the expertise often a behavioral consultant fluent in conducting such analyses, so examining the true applicability and benefit it brings in comparison to brief, informal performance functional assessments (Austin et al., 1999) and A-B-C contingency management (Daniels & Daniels, 2006) is warranted. If less-complicated methods are equally effective, valuable resources may be saved and performance gains likely to continue.

Consumer motivation and choice have grown as interest and research in consumer behavior become more accessible (Fagerstrøm, Foxall, & Arntzen, 2010). OBM professionals have adopted and expanded the analysis of consumer behavior, practiced in later years of Watson's career, and maintained under the umbrella of interests that comprise behavioral economics (see Buckley (1982) and Kreshel (1990) for a review of Watson's contributions to the study of consumer behavior and advertising). A recent special issue in the *Journal of Organizational Behavior Management* (see introductory work by Foxall, 2010, and Hantula & Wells, 2010) is home to many groundbreaking articles for organizational analysis. Each of the included works speaks to

consumer behavior, and the value of environmental manipulation and behavioral observations within the consumer sector is expressed. Still, an analysis of consumer behavior as it relates to consumers of human services may likely enhance the insight afforded to administrators and managers when determining the allocation targets for the already-sparse resources, or as described in traditional consumer analysis, inputs, for most desirable and effective outcomes in service for consumers, even if meaning across settings for input and output can vary substantially (Riley & Frederikson, 1984).

Another avenue likely to improve methods in organizational management resides in the study of complex human behavior from a contextual behavioral viewpoint, particularly in human services. As previously identified, recent work derived from Relational Frame Theory demonstrates the utility of ACT used in a human service agency to improve the type and quality of active treatment afforded to individuals with disabilities (Pingo, 2010). A common outcome of contextual psychological methods is additional benefits in the absence of training specific targets, and this work demonstrates vast improvements obtained without direct training. Work in human services requires some degree of investment toward the betterment of others, particularly, in terms of the clients with whom one works and in the quality of life experienced by such individuals. Direct care staff members and clinicians are responsible for such influence, so interventions derived from this type of research may afford employees and clients a greater flexibility in day-to-day activities and increase their ability to cope with issues as they arise.

Further research and potential application of contextual psychology may come from the analysis of mindful behavior of direct care staff. Langer (1989) suggests that repetitive, structured, familiar tasks lead to mindless behaving or an equivalent sort of mental laziness. Mindless behaving may be observed in those who conduct many repetitive tasks seemingly without demonstrating the need to think about it. This type of performance may often be identified in the roles adopted by staff working with individuals in human

service settings. Bathing clients, delivering sequenced instruction, or teaching structured tasks to children and adults with developmental impairments may follow this sort of repetitive, mindless activity, so demonstrating the ability to complete tasks in this way often allows for more efficient task completion. Langer asserts that because of this mindlessness, difficulties arise when the repeated task is slightly modified or a new step is introduced (or in the case of disability, crises arise). At this point in time, the once-proficient professional may become less adaptive and unable to respond in the same efficient manner. Instead, novice performers may outshine those who have many years of experience in their ability to cope with these unexpected procedural complications, thus enhancing the complexity of the interacting organizational system.

Conclusions

Human service organizations and the professionals working with individuals with developmental disabilities and other disorders face a major task of improving the lives of those suffering from detrimental conditions while providing services deemed appropriate by society and research in that area. With the continuously increasing rates and varying degrees of disability reported each year (Falvo, 2009), the job of human service professionals continually changes, with unique challenges faced on a daily basis—some with life-threatening consequences. Unlike traditional organizations, human service organizations face a consumer demand for effective services, which means something entirely different than the consumer market of traditional business and economics. Effective organizational operation means not that any clearly defined “inputs” result in specific products, or “output,” through some form of organized process; rather, inputs may refer to a blend of time, energy, knowledge, and other personal traits of a service provider, and outputs then refer to constructs describing client progress (e.g., independence, intellectual growth, and increased ability to lead a normal life) which are hard to define and clearly measure uniformly across

individuals. Despite the fact that tangible outputs are not as easily categorized and measured for effectiveness, constraints and regulations required of such service providers increase just as expectations for accountable, reputable services are demanded by insurers and families of those in need (Falvo). For this reason, organizations specializing in human services have a unique task of providing services and accounting for the progress in others, with data to support their efforts.

In the beginning of this chapter, examples were provided of organizations that began as a means to improve the human experience. Human services for individuals with intellectual or developmental disabilities may just fit as one of these organizations, with specialization in disabilities that arise quite early in life. Every organization begins small but can have large influences on people in many unique ways. Ideas proposed by founders of human service organization giants such as Goodwill Industries and United Way were constructed by individuals continually thinking outside the box to develop a better means by which services could be delivered to the consumer market necessitating such services (Townsend, 2006). Human service agencies today continue this trend, with lessons from predecessors providing the building blocks of efficient planning.

In many ways, and throughout this chapter, one can see the very need for organizations to enhance services and assume from inception, a proper infrastructure upon which it may stand as a means to maintain progress and further develop over time. Especially sensitive to the needs of infrastructure are those organizations specializing in the evaluation and treatment of developmental disabilities, considering the maximal likelihood of unexpected behavior and high-risk populations in such settings. Such organizations require a procedural foundation capable of ensuring the appropriate processes and performance that have come to be expected by consumers influenced by the agency or organization, which allows them to handle emergency situations that call for immediate, direct action on the part of the employees. In human service organizations, a firm infrastructure will ensure that services are being delivered in a safe, efficient, and effective

manner, limiting the sudden procedural changes often resulting when plans fail to meet expectations during execution. Such preparedness occurs if processes are developed and properly implemented as planned during initial stages of organizational development. Further, data, materials, and supplies that enhance employee roles will likely provide the necessary means by which employees may contribute to the attainment of organizational goals and objectives, maintaining optimal status with funding agencies.

Demonstrating a Need for Infrastructure

Human service organizations that demonstrate the ability to produce a solid performance infrastructure should find that they continually meet and exceed overall expectations with constant monitoring and shaping of job, department, and organizational goals and objectives to ensure success, with or without the aid of consultation services that ensure smooth operation and advancement of the organization during difficult times. It may be assumed that administrators under which these organizations operate possess the skills necessary to identify and establish the correlating variables between processes and people within the organizational hierarchy to directly enhance and contribute to goal attainment and realize the missions of the provider. When organizational goals are achieved, and missions upon which the organization was founded are met, consumers can be confident they are receiving efficient, consistent care, leading to positive outcomes and sensitive to changing life situations.

Becoming successful in providing services for humans with disabilities is no easy task and demands leaders a search for constant improvement. Improvement requires the use of new tools for adaptation, beyond the initial planning stage, and behavioral technologies may intervene when infrastructure and execution become weak. Even still, beginning with a solid (clearly defined and comprehensive) infrastructure will undoubtedly raise the ability of staff and clinicians to perform to their best.

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Some children and adults who have intellectual and developmental disabilities (IDD) and display challenging behaviors (e.g., self-injury, aggression, property destruction) receive extended treatment in residential settings. The professionals responsible for such treatment have to design and evaluate intervention plans that effectively reduce and eliminate these behaviors. As well, persons in residence frequently require crisis management, notwithstanding periods of relative stability and positive response to intervention. Periodic behavioral crises demand immediate clinical attention, may be prolonged, and usually drain staff resources. Indeed, preventing and quickly resolving crisis events are critical objectives within most human services and behavioral healthcare organizations.

A related clinical concern is children and adults who are *temporarily* admitted for residential treatment because they have one or more behavioral crises at school, home, or in the community. For example, a child attending public school may display episodes of self-injury in her classroom, causing bodily harm and compromising instruction with other students. School administrators and the child's parents may decide that appropriate intervention cannot be offered at school and at home, where intermittent episodes

of self-injury are also encountered. In such a case, the behavioral crisis leads to a referral for short-term residential treatment, stabilization, and eventual return to home and the less restrictive school setting.

Human services and behavioral healthcare organizations that provide residential treatment for people with IDD usually have policies and procedures for implementing intervention, training staff, supervising care, reporting outcome, and meeting regulatory guidelines imposed by external accreditation agencies (Federal statutes, regulations & policies governing the ICF/MR program, 2003). However, policies and procedures vary widely among organizations. Relative to crisis management, the methods also are different among organizations, including use of therapeutic restraint (protective holding), specialized staff-to-client ratios, environmental modifications, seclusion, and medication, to name just a few. Although organizational policies and procedures governing behavioral intervention would be expected to fluctuate dependent on the characteristics of the people served, nonetheless it is desirable to have uniform protocols that are carefully planned, clinically justified, closely monitored, and revised routinely based on outcome evaluation.

This chapter addresses the topic of peer review within human services and behavioral healthcare organizations for children and adults who have IDD and behavioral crises that demand extended and short-term residential treatment.

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My premise is that systematic peer review can contribute to organizational systems development for ensuring that policies and procedures are informed by evidence-based and empirically supported practices, coordinated at all levels of care, prevention focused, and socially valid. I, first, define the process of peer review and then describe several peer review objectives common to most human services and behavioral healthcare organizations. Later in the chapter, I present several systems-level intervention projects that my colleagues and I have evaluated in addressing some of these objectives.

Peer Review Models and Practices

Most readers are familiar with peer review in the context of academic publishing: expert referees (editorial board members, ad hoc reviewers) make recommendations about the publication worthiness of manuscripts that prospective authors submit for publication. As used in this chapter, “peer review is designed to determine the extent to which a service program or specified treatment procedure is consistent with the prevailing professional standard of care for the client being served and the behavior being treated” (Christian et al. 1982, p. 353). More specifically, through *organizational peer review* (Luiselli & Russo, 2005), professionals who have requisite expertise scrutinize the practice standards of administrators, psychologists, behavior analysts, and allied staff. Peer review is then expected to produce recommendations for performance improvement and to evaluate results accordingly.

Organizations can approach peer review from several perspectives. Commonly, experts external to the organization are retained and scheduled for on-site consultation. The advantage of external peer review is objectivity—the reviewers are not formally associated with the organization, do not function as employees, and accordingly, should not have biased perspectives. But, there are limitations. For one, most individuals that would be considered for external peer review have busy schedules, making it difficult for them to routinely visit organizations. The time individuals commit

to peer review may also have to be curtailed. Furthermore, organizations may not have the necessary financial resources to compensate external reviewers and pay their travel and lodging costs.

Acknowledging the difficulties with external peer review, Luiselli and Russo (2005) proposed a system of internal (“in-house”) peer review that “dedicates senior level clinicians within the organization to regularly assess multiple facets of service delivery, identify corrective action plans, initiate performance improvement projects, conduct systematic evaluation, and document outcome” (pp. 472–473). We commented further about the benefits of internal peer review. First, the review process can be continuous and not limited to infrequent contacts from outside professionals. Second, the feedback and recommendations from peer review can be integrated at all levels of an organization, thereby ensuring that staff faithfully adopts desirable action plans. Third, systematic internal peer review is a powerful staff training strategy. And fourth, there is no additional cost to an organization because peer review is conducted by salaried employees.

Before presenting some of the clinical areas that should be considered within a model of internal peer review, I suggest another avenue alluded to earlier, namely, submitting manuscripts for publication in professional journals. When human services and behavioral healthcare organizations are able to establish a program of applied research, dissemination efforts through publication capitalize on a reliable source of peer review. Put another way, clinicians can get “free advice” from a network of professionals who have editorial advisory expertise. The publication peer review process, regardless of a manuscript’s eventual outcome, gives authors direction and recommendations about clinical standards, evaluation methodology, research-to-practice translation, and similar topics. How to build and maintain a productive applied research program requires its own chapter, as does writing for publication in nonacademic settings (Luiselli, 2010), but neither concern should detract from the positive influence publication peer review can have on an organization’s quality of care and practice parameters.

Peer Review Objectives

Designing a model of internal peer review begins by assessing an organization’s personnel resources and how they are equipped to handle behavioral crises. The number of staff clinicians must be sufficient relative to their caseload assignments. Clinical expertise is another obvious concern as judged by a person’s educational background, supervised training, credentials, areas of expertise, and years of practice. Personnel deficiencies have to be remedied in order to create an effective peer review system. For example, residential treatment settings for children and adults experiencing behavioral crises should have specialization in applied behavior analysis (ABA), extensive staff training, family support services, and medical professionals in psychiatry, nursing, and psychopharmacology.

To illustrate the operation of internal peer review, Fig. 3.1 shows a hypothetical organizational structure at a residential setting for children and youth. As depicted, there is a school component, comprised of 12 classrooms, and supervised by three mid-level behavior specialists. The setting also has a residential director in charge of four community-based group homes where the children live. In this structure, there are two supervising clinicians: one responsible for

the classrooms and one responsible for the group homes. A senior clinician is designated as Director of Peer Review—this person oversees the system and is linked to allied health services comprised of nursing, psychiatry, occupational therapy, and family support disciplines.

The model of internal peer review presented in Fig. 3.1 will function most successfully if the following guidelines are in place:

1. Each person involved with peer review should have a clearly articulated scope of responsibility and respective work performance standards. In effect, there must be behaviorally specific job descriptions which include reporting functions in a “chain of command” format.
2. Peer review participants should have regularly scheduled meetings with both standing and flexible agendas according to active and future action plans. The Director of Peer Review should record, summarize, and distribute meeting notes.
3. It is useful to have immediate, short-term, and long-term peer review objectives. Figure 3.2 is a representative documentation and tracking form. There would be one such form for each “performance area,” designating general objectives, principal participants, effective dates, priority tasks and action plans, responsible staff, and target completion dates. This

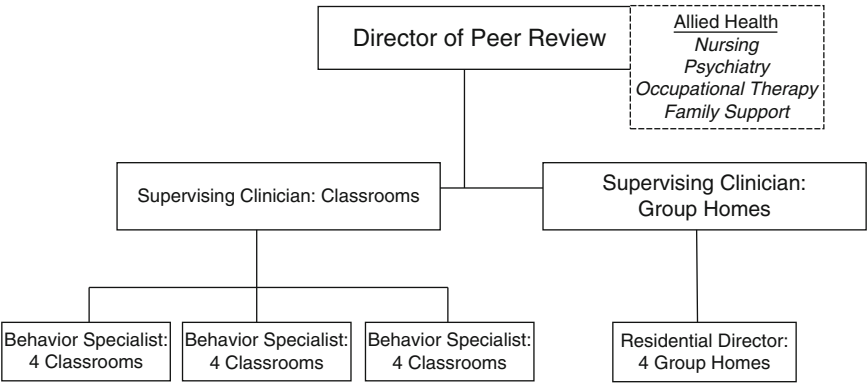


Fig. 3.1 Hypothetical organizational structure of clinical services at a residential setting for children and youth

Performance Area:		
General Objective(s):		
Principal Participants:		
Effective Date:		

Priority Tasks and Action Plans	Responsible Staff	Target Completion Date
1:		
2:		
3:		
4:		
5:		
6:		

Fig. 3.2 Peer Review Documentation and Tracking Form

type of form is particularly useful for monitoring progress toward performance improvement projects.

4. Organizational leaders must be closely aligned with the clinical staff that design, implement, and evaluate internal peer review. Referencing Luiselli and Russo (2005) again, meetings should be arranged with leadership so that “all decision makers in the organization receive information about the findings from peer review” and “with knowledge and understanding of the issues, there is greater assurance that the recommendations from peer review will be approved” (p. 479).

Among many objectives of internal peer review, organizations devoted to behavioral crises should be concerned about several priority areas.

Recording, Reporting, and Evaluating Clinical Incidence Data

How staff intervenes in a behavioral crisis and the effects of this intervention must be measured objectively. As one example, if therapeutic restraint is implemented with a child or adult, incidence data should be reported, including (a) frequency and duration of each restraint episode, (b) conditions associated with restraint, (c) method of restraint that was used, (d) staff responsible for restraint implementation, and (e) occurrence of injury or other untoward events (Luiselli, 2011b). One function of peer review would be to analyze these data to ensure that staff applied restraint correctly, that restraint should be continued as intervention, or that because of poor

results, other procedures should be substituted for restraint. Similar clinical incidence data include frequency of high-risk behaviors (aggression, self-injury, elopement, pica), PRN medication administration, community events posing a threat to bystanders, and behavior-induced physical problems.

Clinical incidence data should be reviewed for individual children and adults and aggregated to reveal organizational patterns and trends. In Luiselli, Sperry, and MaGee (2011), we described a large-scale evaluation of therapeutic restraint among 448 adults with IDD attending 4-day habilitation settings and living in 52 community group homes. Direct-care providers were taught to record and report restraint implementation for every adult using a standardized incident form that tracked several clinical measures. Through a system of internal peer review, these data were submitted to senior supervisors who (a) approved the reports, (b) clarified information as warranted, and (c) evaluated that data according to frequency, duration, clinical context, and trend analysis indicators. We found that this organizational approach to recording, reporting, and evaluating therapeutic restraint revealed that staff applied restraint with a small proportion of adults; implemented restraint exclusively as a consequence for self-harming, aggressive, and environmentally disruptive behaviors; and initiated restraint as a planned intervention 91 % of the time.

Intervention Policies and Procedures

Effective management of behavioral crises demands that organizations have written intervention policies and procedures. Ideally, the policies and procedures should be informed by the contemporary research literature. Methods of intervention must also be classified according to their restrictiveness, normalization, risk, and acceptability by care providers and the lay public. Peer review would be instrumental in drafting intervention policies and procedures as well as revising them accordingly. For example, regulatory agencies for human services and behavioral healthcare organizations issue guidelines that

must be followed in order to maintain accreditation status. These regulations are not always consistent with clinical “best practices” and must be reconciled adroitly. Dedicated internal peer review should enable senior clinicians to establish a collaborative relationship with regulators, meeting all necessary policy and procedural requirements, without sacrificing therapeutic guise and sophistication. A key issue here is that both clinical “best practices” and accreditation guidelines change over time—in consequence, peer review is best conceived as a fluid, rather than a static, process of “checks and balances.”

Intervention Integrity

Even evidence-based and properly formulated intervention plans will not be successful if care providers implement them inconsistently or inaccurately. Intervention integrity assessment refers to a three-step process by which (a) care providers are observed interacting with clients, (b) implementation accuracy is quantified, and (c) integrity feedback is presented to the care providers. Within the purview of peer review, a supervising clinician would conduct scheduled or unannounced intervention integrity assessments using a data recording form (DiGennaro Reed & Coddington, 2011). To illustrate, in the case of a child or adult who has a ten-step behavior support plan, the steps would be listed on a form, and during intervention integrity assessment, the observing clinician would record the steps as “implemented as written,” “not implemented as written,” or “no opportunity for staff to respond.” The percentage of steps that a care provider implemented accurately serves as a global measure of integrity. Analysis of each step is also required to isolate procedures in need of further training.

The importance of *performance feedback* during intervention integrity assessment should not be overlooked. In most cases, feedback to care providers does not have to be lengthy (e.g., 10–15 min) but initially should occur immediately following daily observations. As care providers learn to implement plans more proficiently,

performance feedback can be delayed and provided less frequently. With respect to content, supervisor-delivered performance feedback combines positive reinforcement (praise, approval) contingent on accurately implemented steps and correction (reminders, rehearsal) contingent on inaccurately implemented steps. Performance feedback can also be supplemented with graphic displays of data and written recommendations (Coddington, Feinberg, Dunn, & Pace, 2005; Hagermoser-Sanetti & Kratochwill, 2008; Hagermoser-Sanetti, Luiselli, & Handler, 2007).

Through internal peer review, organizations can design systems-level approaches to intervention integrity assessment by specifying the assessment procedures, designing recording forms, establishing a reasonable assessment schedule (see Reed, Feinup, Luiselli, & Pace, 2010), and monitoring outcome. Keep in mind that conducting intervention integrity assessment functions as in vivo and competency-based staff training, which is a productive approach to personnel performance enhancement (Ricciardi, 2005) and is ideally suited to crisis intervention settings.

Prevention-Focused Intervention

Most clinical specialists agree that preventing a behavioral crisis instead of reacting to it is the recommended choice for intervention. Although prevention is not always easy, the area of antecedent assessment and intervention is a rich source of strategies and procedures (Luiselli, 2006, 2008a, 2008b; McGill, 1999; Smith & Iwata, 1997). An antecedent perspective first identifies interpersonal and environmental conditions that reliably precede challenging behaviors and then, manipulates those conditions so that they no longer have a provoking effect. Clinically, these behavior-altering procedures focus primarily on changing features of discriminative stimuli and motivating operations (Friman & Hawkins, 2006).

As outlined in this chapter, internal peer review should be committed to integrating ante-

cedent-based assessment and intervention within an organization's clinical landscape. Some necessary steps are making sure that antecedent procedures are prominent in written behavior support plans and that the plans are conceived on the results of antecedent functional behavioral assessment and analysis (Cipani & Schock, 2011; Luiselli, Dunn, & Pace, 2005; Luiselli, Pace, & Dunn, 2003). It may also be prudent to conduct specialized training about antecedent assessment and intervention with possibly one or more seminars combined with "on-the-job" training that is provided during in vivo supervision.

Another objective of prevention-focused crisis intervention is carrying out a risk-benefit analysis of proposed procedures. As background, my involvement with peer review at several organizations helped create the *Protective Holding Screening and Review Form* shown in Fig. 3.3. The purpose of the form is to assess several areas whenever protective holding (therapeutic restraint) is recommended for a child or adult. Section I of the form documents the type of proposed hold, preparation of a written behavior support plan, informed consent, organizational approval, and staff training designations. Section II asks that a physician evaluate the child or adult to rule out medical contraindications for implementing protective holding with that person. Section III rates severity and risk associated with protective holding, and Section IV projects level of resistance and likelihood of injury during application. By completing the *Protective Holding Screening and Review Form*, clinicians and administrators can determine the relative advantages and disadvantages of using therapeutic restraint during a behavioral crisis or whether avoiding restraint is a more desirable option.

Staff Training

Staff training in behavioral crisis prevention and management should be a priority for internal peer review. At the most basic level, organizations

Child/Adult:	Age:
Diagnosis:	
Service Center:	
Supervising Clinician:	
Date:	

SECTION I: Status Checklist	
Guidelines	Completed (√)
(1) Designate the type of protective hold used with the child/adult: Basekethold [] Team Control: Seated [] Team Control: Standing [] Floor Control: Supine [] Other:	
(2) The protective hold is included as an intervention procedure in a written behavior support plan.	
(3) Informed written consent to use the protective hold has been granted by the child's/adult's parent or guardian.	
(4) The child's/adult's behavior support plan has been reviewed and approved by the following senior staff: Senior Supervising Clinician [] Program Director [] Director of Peer Review []	
(5) Only staff having completed physical management training implements the protective holding procedure.	
(6) The written behavior support plan designates a staff person to serve as "physical monitor" during implementation of the protective hold.	

Fig. 3.3 Protective Holding Screening and Review Form

SECTION II : Physical Evaluation		
Physical Locus	Categories	(√)
Muscle Integrity/Tone	Within Functional Limits	
	Hypotonic	
	Hypertonic	
	Abnormal Condition	
	Other:	
Neurological	Within Functional Limits	
	Seizures	
	Other:	
Range of Motion	Within Functional Limits	
	Contractures	
	Limitations	
	Other:	
Orthopedic	Within Functional Limits	
	Prior Surgeries	
	Joint Abnormalities	
	Other:	
Respiratory	Within Functional Limits	
	Asthma	
	Other:	
Cardiovascular	Within Functional Limits	
	S/P Heart Surgery	
	Heart Murmurs	
	Bradycardia	
	Tachycardia	
	Hypertension	
	Hypotension	
	Other:	
Gastrointestinal	Within Functional Limits	
	S/P Surgery	
	Ulcers	
	Reflux	
	Organ Abnormalities	
	Other:	

Fig. 3.3 (continued)

SECTION III: Severity and Risk Assessment		
Index	Categories	Rating
Body Parts: Indicate the body parts contacted during implementation of protective holding	☐ Head	Enter the total number of body parts:
	☐ Shoulders	
	☐ Arms	
	☐ Hands	
	☐ Upper Torso	
	☐ Legs	
	☐ Feet	
Staff: Indicate the number of staff implementing protective holding	☐ 1	Enter the total number of staff:
	☐ 2	
	☐ 3	
	☐ 4	
Resistance: Indicate the degree of resistance demonstrated during implementation of protective holding	☐ No resistance: 0	Enter the number code:
	☐ Minimal Resistance: 1	
	☐ Mild Resistance: 2	
	☐ Moderate Resistance: 3	
	☐ Extreme Resistance: 4	
Injury Risk: Indicate the potential for injury to the student/consumer during implementation of protective holding	☐ No Risk: 0	Enter the number code:
	☐ Unlikely Risk: 1	
	☐ Slight Risk: 2	
	☐ Increased Risk: 3	

Date of Assessment	Total Severity and Risk Score (Sum of body part/staff/resistance/injury risk ratings)

Fig. 3.3 (continued)

SECTION IV: Resistance and Injury Risk Ratings	
Rating	Description
0: No Resistance	The child/adult remains passive during implementation of protective holding and does not demonstrate resistance. There is an absence of agitation and distress.
1: Minimal Resistance	The child/adult may tug or pull gently against the physical contact, usually for 1-3 seconds, several times during the implementation of protective holding, but staff do not have to apply more intense pressure to maintain the hold. There are no discernable signs of agitation and distress.
2: Mild Resistance	The child/adult pulls and tugs against the physical contact, staff occasionally must apply more intense pressure to maintain the protective hold, and resistance occurs for durations not exceeding 5 seconds. The child/adult may demonstrate low-level and infrequent agitation and distress.
3: Moderate Resistance	The child/adult pulls and tugs against the physical contact, staff must apply more intense pressure to maintain the protective hold, and resistance occurs for durations lasting 5-10 seconds. Such resistance may occur several times when the procedure is applied. The child/adult may break contact with the protective hold, requiring re-implementation by staff. The child/adult demonstrates periodic agitation and distress.
4: Extreme Resistance	The child/adult pulls and tugs against the physical contact, staff must apply more intense pressure to maintain the protective hold, and the resistance occurs for durations that exceed 10 seconds. Such resistance may occur several times when the procedure is applied. The child/adult breaks contact with the protective hold, one or more times, requiring re-implementation by staff. The child/adult demonstrates frequent and lengthy periods of agitation and distress.

Fig. 3.3 (continued)

Injury Risk Ratings	
Rating	Description
0	There is no risk of injury to the child/adult.
1	Despite the display of minimal to moderate resistance, the risk of injury to the child/adult is unlikely.
2	There is a slight risk of injury to the child/adult due to the presence of moderate resistance.
3	There is an increased risk of injury to the child/adult due to the presence of extreme resistance.

Fig. 3.3 (continued)

must train direct-service providers to properly administer first aid, CPR, infection control, and similar occupational safety procedures. There should also be a comprehensive training program that teaches staff acceptable physical management techniques for preventing, de-escalating, and controlling crisis episodes (Lennox, Geren, & Rourke, 2011). Behavioral intervention training, of course, is a prerequisite both for understanding learning principles and implementing procedures correctly. I add that most staff will need concentrated training that deals with recording data, reporting incidents, and compiling clinical statistics.

The goals, direction, and format of staff training depend on identified skill and performance deficiencies. On one hand, staff may behave poorly because they do not know what to do (i.e., a skill deficit or a “can’t do” problem). In such cases, skills must be taught to them. Conversely, staff may have the necessary skills but do not display them properly because they are either unmotivated to do so or conditions interfere in some way (i.e., a performance deficit or a “won’t do” problem). Effective training in these cases must arrange contingencies to better support staff-acquired but inconsistently demonstrated skills.

Basic knowledge competencies and fundamental skills can be taught to staff initially through instructional sessions that include didactic presentations, reading materials, and video

training media (LeBlanc, Gravina, & Carr, 2009; Luiselli, Bass, & Whitcomb, 2010; Luiselli & St. Amand, 2005). However, this format seems to be most effective when it provides staff with role-playing opportunities, behavior rehearsal, and direction from trainers (Fleming, Oliver, & Bolton, 1996). The skills that staff learn in these sessions are developed further by evaluating performance under natural conditions and when necessary, training more intensely “in the moment.”

When poor performance is not caused by skill deficits but instead, environmental or motivational influences, peer review can structure remedial systems to overcome the problem. For example, as illustrated in the next section of the chapter, staff behaviors can improve with task-specific and contingent feedback from supervisors. Adding incentives to supervisor management can also fortify performance (Alevero, Bucklin, & Austin, 2001; Komaki, Desselles, & Bowman, 1989). Austin (2000) revealed further that environmental constraints such as not having adequate materials and scheduling too many contemporaneous competing activities are negative influences on staff performance. Training care providers to make environmental modifications can be effective in such cases (Casella et al., 2010; Schmidt, Urban, Luiselli, White, & Harrington, 2013; Shore, Lerman, Smith, Iwata, & DeLeon, 1995).

Child/Adult:	
Clinical Director:	
Day Setting:	Residence Setting:
Review Meeting Date:	

Presenting Problems and Current Status	
1:	
2:	
3:	
4:	

Administrative and Clinical Action Plans	Responsible Staff and Timeline
Behavior Support Plan:	
Staffing:	
Classroom Issues:	
Residence Issues:	
School District Issues:	
Family Issues:	
Nursing/Medical/Psychiatric Issues	
Discharge Planning Considerations:	
Other Considerations:	

Fig. 3.4 High-Risk Clinical Case Review Form

Multidisciplinary Collaboration

One purpose of this book is to detail the need for multidisciplinary collaboration when addressing behavioral crises regardless of the treatment setting. Within an organization that provides residential services, relevant disciplines would be psychiatry, nursing, family support, and counseling.

Coordinating recommendations among these disciplines is another objective of internal peer review. One approach is to schedule high-risk clinical case conferences in which members of a multidisciplinary team comprehensively review children and adults that have reached a priority status. Figure 3.4 is a *High-Risk Clinical Case Review Form* to record topics and action plans that

are presented and decided during conferences. Each of the items listed on the form is discussed, and respective administrative and clinical decisions are recorded. Additionally, the conference chairperson documents the names of responsible staff and associated timelines for their assigned tasks. High-risk clinical conferences work best when they are purposefully scheduled (e.g., weekly or biweekly), produce written summaries, and report follow-up results of implementation recommendations.

Multidisciplinary collaboration as a peer review function requires a cooperative working environment among professionals who may view behavioral crisis prevention and management from different perspectives. I suggest that team cohesion will be promoted when the constituents are comfortable with a few operational guidelines. First, regardless of discipline, a multidisciplinary team should be able to agree that objective measurement of clinical indices is essential for quantifying and evaluating intervention outcomes. Another basis for building consensus is that crisis intervention plans always attend to a person's medical status. That is, formulation with a child or adult must consider possible physical causes for challenging behaviors and rule them in or out accordingly. Third, the philosophy of least restrictive intervention should guide clinical decision-making. Collaboration is enhanced further when team members agree to design intervention plans according to the evidence-supported practices that apply to their discipline. In fact, it is desirable to have multidisciplinary team members share relevant publications and other information that are pertinent to peer review.

Peer Review Systems Projects

This section describes several systems-level projects that I designed and implemented with colleagues at human services and behavioral healthcare organizations for children and adults with IDD. These projects emanated from peer review teams and committees that we initiated to improve staff performance in specific areas that impacted behavioral crisis prevention and management.

Clinical Supervision

I discussed previously how ongoing supervision of direct-care service providers is essential for ensuring that they implement intervention plans correctly. Several methods of supervision have been evaluated in institutional and community-based settings, combining elements of direct observation, competency training, and performance feedback (Fleming & Sulzer-Azaroff, 1994; Parsons & Reid, 1995; Reid, Parsons, & Green, 1989; Sturmey & Stiles, 1996). Of significance, supervision must be integrated with other clinical activities, time-efficient, and conducted regularly.

Luiselli (2008a) reported a performance management intervention for increasing the frequency of supervision by four behavior specialists at a residential school for children with IDD. Two of the participants had a masters degree, two had a doctoral degree, and all were board certified behavior analysts. In their role as behavior specialists, each participant supervised 2–6 assigned classrooms of the 17 classrooms at the school. The expectation was that they observe staff-to-student interactions in their assigned classrooms and train staff to implement instructional and behavior support plans. Each participant was scheduled to complete one 30-min supervision observation per classroom each week. The time of the observations (e.g., 10:00–10:30 a.m.) was written on a master schedule that was distributed to the participants and was posted in the classrooms. Although not required, the participants were encouraged to conduct additional supervision whenever possible.

The participants recorded their scheduled supervision observations, and any additional classroom supervision, on a classroom “sign-in” sheet. The recorded information included the date of supervision, time of supervision, and participant's signature. The primary dependent measure was the number of classroom supervision observations each week. These data were computed by summing the “sign-in” sheets completed by the participants. In addition, the percent of weeks the participants conducted the minimum standard of one supervision observation per

assigned classroom each week was also measured. These data were computed by dividing the number of times the standard was achieved by the total weeks comprising the study and multiplying by 100.

During a baseline phase, the previously described classroom supervision schedule was distributed to the participants. In the first week of the phase I reviewed the schedule, the expected supervision standard, and the “sign-in” recording procedure. Thereafter, the participants were reminded about the supervision requirements during clinical review meetings each month. However, specific performance feedback and supervision data were not presented.

After baseline, I introduced *supervision performance management* with the participants, a multicomponent intervention, as follows:

1. The supervision data were summarized in a visual display (bar graph) and reviewed with the participants each month during a group meeting. Acceptable performance was defined as the participants achieving the expected standard and exemplary performance was defined as the participants exceeding the expected standard. I praised and acknowledged these levels of performance. Additional reminders were given to participants with below-standard performance.
2. In addition to signing in for each supervision observation, the participants also completed a respective one-page “activity log.” The activity log had sections for them to enter the date and time of supervision (similar to the “sign-in” sheet), check-off mandatory activities that were completed, and write a brief narrative summarizing the observation. This procedure was intended to standardize the content of supervision by listing activities required of all participants.
3. The participants submitted their completed “activity logs” to me by 5:00 p.m. on Friday of each week. I reviewed each “activity log” and delivered feedback to the participants as warranted. The date and time documented on each “activity log” also were compared with the information recorded on the “sign-in” sheet.

I also implemented *supervision performance management and personalized feedback* with one participant who did not respond consistently to supervision performance management alone. This intervention consisted of sending the participant an electronic communication (email) on Monday of each week depicting her supervision data for the previous week. The data were displayed successively (week to week) in a line graph. Embedded in the graph was a distinctively colored box that had the following entries: *below standard*, *at standard*, and *exceed standard*. One of the entries was highlighted with an accompanying statement based on the participant’s performance. For example, if the participant exceeded the supervision expectation for the previous week, the *exceed standard* entry was highlighted with a comment such as, “Fantastic-thank you for the extra effort!” I confirmed each week that the participant had received and reviewed the email communication.

Figure 3.5 shows the percent of weeks each participant achieved the minimum one-time-per-week supervision observation standard for their assigned classrooms. *Participant 1* had virtually identical results, averaging 75 % and 76 % during baseline and performance management phases, respectively. *Participant 2* achieved the standard on only 12 % of weeks during baseline but 71 % of weeks during performance management. *Participant 3* also improved significantly, moving from 0 % at baseline to 81 % during performance management. Finally, *Participant 4* never achieved the standard during baseline, increased to 25 % during performance management, and reached 86 % during performance management combined with personalized feedback.

In summary, Luiselli (2008a) found that relatively simple performance feedback procedures increased the frequency of classroom observations by supervising behavior specialists. As I acknowledged in this publication, the study was not an experimental analysis nor did it measure explicitly the content of supervision activities. Nonetheless, the results documented that clinical supervision could be improved by realigning existing personnel resources and administering individually tailored performance feedback.

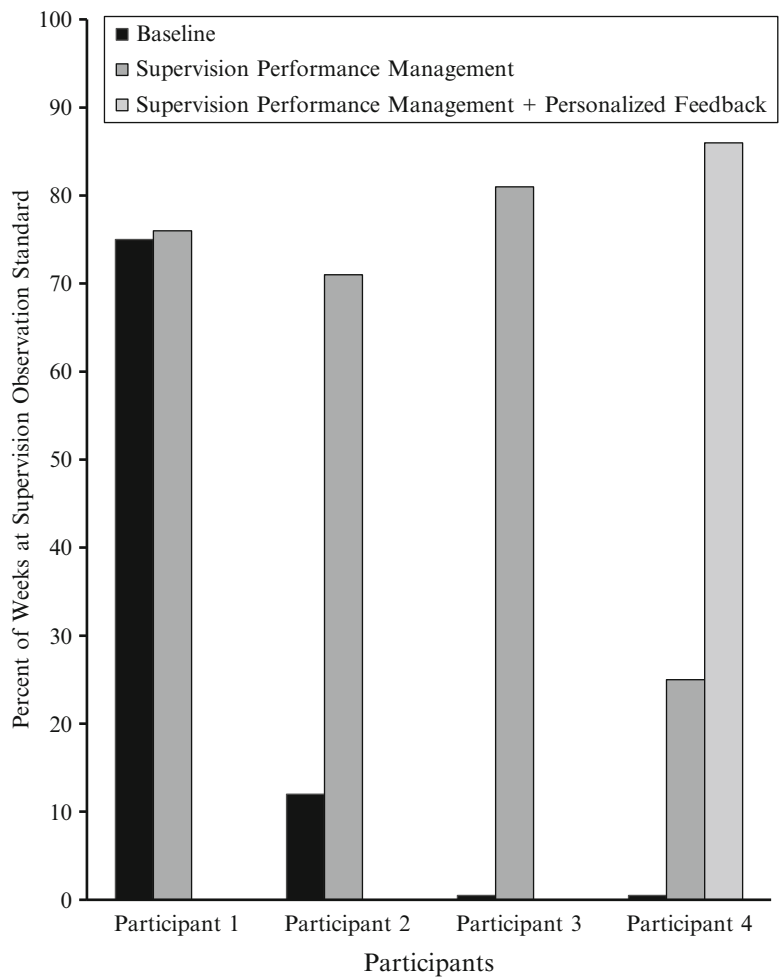


Fig. 3.5 Percent of weeks that participants achieved the minimum one-time-per-week supervision observation standard (from Luiselli, J. K. (2008). Effects of a performance management intervention on frequency

of behavioral supervision at a specialized school for students with developmental disabilities. *Journal of Developmental and Physical Disabilities*, 20, 53–61)

Training Critical Staff Skills

Garrity and Luiselli (2005) implemented an *administrative supervisory protocol* to train behavior support plan preparation skills to seven program managers at a day school for children with IDD. Through internal peer review, we determined that three components of behavior support plans were often prepared inconsistently because they did not include (a) a signed parent consent form, (b) a “sign-off” form indicating that staff read and understood

the plan, and (c) a single document that integrated all intervention procedures.

Each month we evaluated newly prepared behavior support plans by recording the percentage of plans that featured the three components. In a baseline phase, classroom staff prepared plans without intervention. During intervention, the administrative supervisory protocol was introduced simultaneously in all of the classrooms but sequenced in a multiple baseline design across each behavior support plan component. We conducted training with the program managers,

assigned specific classrooms to them, and requested that they monitor behavior support plan preparation, respectively. One element of training was *goal specification*, by which we identified the three behavior support plan components, defined each one operationally, and selected them as goals that the program managers should address during classroom supervision. Using *action directives* we instructed the program managers on how to complete the three behavior support plan components. The final training procedure, *performance feedback*, was introduced during a monthly meeting with the program managers by presenting the behavior support plan component data in a summary table. We acknowledged improved performance with praise and approval and corrected procedural misapplication as warranted.

During baseline, none of the classrooms completed the behavior support plan components. With intervention, percent completion increased, achieving near 100 % for both the parent consent and staff “sign-off” components and near 65 % for the single intervention document component. Thus, the administrative supervisory protocol successfully trained program managers to improve the quality and expected standards of written behavior support plans by classroom staff.

In a similar study, Garrity, Luiselli, and McCollum (2008) sought to improve data recording practices of eight teachers at a school for children with IDD, specifically their routine assessment of interobserver agreement (IOA). The dependent measure was the percentage of skill acquisition plans and behavior support plans that had IOA assessment conducted at least one time per month. As per school guidelines, classroom teachers were responsible for scheduling IOA assessment with their staff. Each time IOA assessment was conducted for a student’s skill acquisition and behavior support plan, the classroom teacher plotted the data on a line graph with the date of assessment and percent agreement between staff. These data were summed to compute the percentage of skill acquisition plans and behavior support plans that achieved the minimum one-time-per-month IOA assessment criterion.

We evaluated the supervisory intervention in a multiple baseline design across skill acquisition and behavior support plans. Baseline conditions were identical to those preceding the study, that is, there was no performance improvement intervention in place. During intervention, we implemented three procedures simultaneously with the classroom teachers.

Action Directives

Assigned classroom supervisors met with the teachers, explaining that a performance improvement project would be implemented to increase frequency of behavior support plan IOA assessment. A similar meeting was convened preceding intervention for skill acquisition plans. The supervisors informed the teachers that they would have an active role instituting and documenting the project, explained the relevant procedures, and answered questions.

Public Posting

At the start of each month, supervisors posted an *IOA Checklist* in each classroom. Consistent with the multiple baseline design, the checklist included only the behavior support plan measure during the first 2 months of intervention. At the third month of intervention and for the remainder of the study, both behavior support plan and skill acquisition plan measures were included on the checklist. Teachers were told to enter their IOA assessment data on the sheet each time it was recorded. The sheet featured the name of each student in the classroom, the respective behavior support plan and skill acquisition measures, and spaces to enter the date and percent of each IOA assessment. As in baseline, teachers continued to plot the IOA data on each student’s monthly summary graph.

Performance Feedback

This component of intervention was applied sequentially to behavior support plan and skill acquisition plan IOA assessments. Supervisors made scheduled visits to classrooms each week, at which time they reviewed the *IOA Checklist* with teachers and delivered performance feedback consisting of verbal praise (e.g., “This is

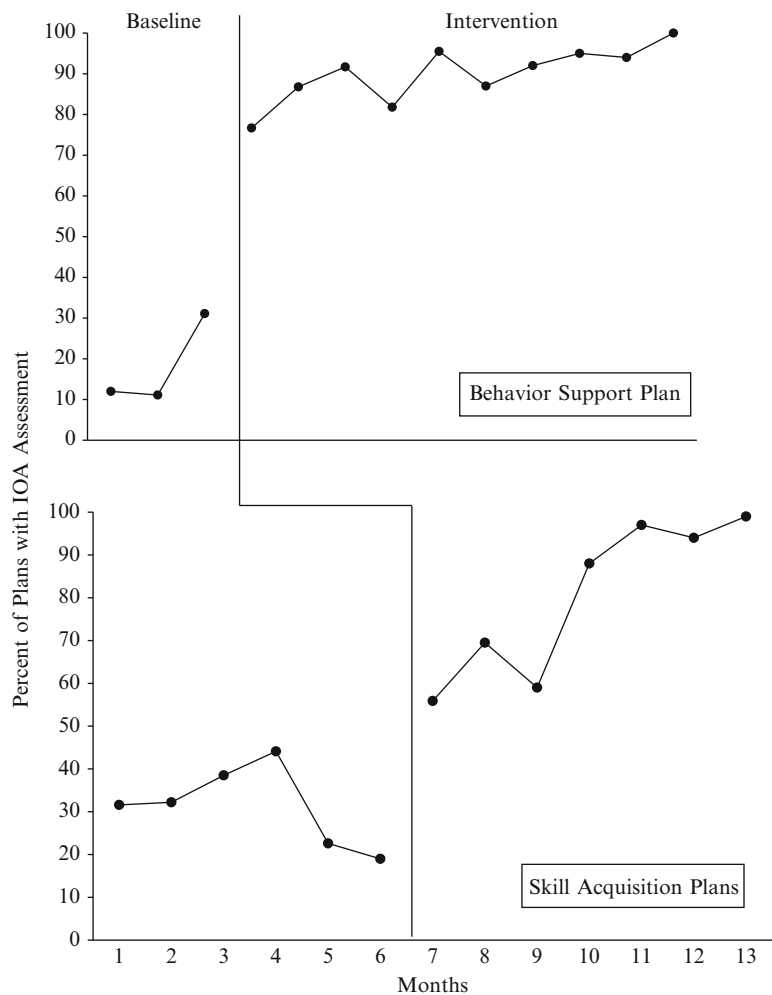


Fig. 3.6 Percent of behavior support plans and skill acquisition plans with IOA assessment conducted at least one time per month (from Garrity, M. L., Luiselli, J. K., & McCollum,

S. A. (2008). Effects of a supervisory intervention on assessment of interobserver agreement (IOA) by educational service providers. *Behavioral Interventions*, 23, 105–112)

great, your IOA assessments have increased!”) or correction (e.g., “Remember, IOA must be assessed with all your students.”). Feedback from the supervisors was presented in the same way to individual teachers. Supervisors also gave performance feedback to the teachers during a biweekly group meeting. The supervisors provided additional feedback by summarizing each teacher’s monthly IOA assessment data and presenting it to them in a bar graph. The graph depicted results for all classrooms, enabling teachers to see

within-classroom and between-classroom data trends.

Figure 3.6 is the percent of behavior support plans (top panel) and skill acquisition plans (bottom panel) with IOA assessment conducted at least one time per month. At baseline, average IOA assessment for behavior support plans was 18 %. Intervention produced a steady increase in IOA assessment, averaging 92.4 % for the phase and culminating at 100 % during the final month of the study. For skill acquisition plans, the

baseline average was 31.3 %. With intervention, IOA assessment increased progressively, also reaching near 100 % in the final month. The average IOA assessment during the intervention phase for skill acquisition plans was 80.3 %.

The studies by Garrity and Luiselli (2005) and Garrity et al. (2008) represent one approach to staff training that can be coordinated through internal peer review. In effect, permanent administrative systems can be designed for continuously supporting staff and teaching them critical skills.

Staff Injury Prevention and Reduction

Service providers are sometimes injured during interactions with children and adults (Sanders, 2009; Spreat, Lipinski, Hill, & Halpin, 1986; Williams, 2009). The possibility of injury is apparent when staff must intervene during a behavioral crisis, either trying to manage a problem such as aggression, interrupting an escalating episode of agitation, or applying therapeutic restraint. On other occasions injuries are sustained because staff did not recognize that a person's actions were dangerous or perhaps, had a lapse of judgment. Whatever the cause, injury to care providers is physically harmful and can be financially costly to organizations due to worker's compensation claims and filling staff vacancies (Lennox, 2007). Furthermore, the potential for injury creates apprehension among staff who must work in an unsafe environment.

Recently, my colleagues and I have conducted research to prevent and reduce injury to care providers within human services and behavioral healthcare organizations for children and adults with IDD. Two single-case studies evaluated the effects of staff-worn protective equipment on frequency and intensity of injuries from child aggression (Lin, Luiselli, Gilligan, & DaCosta, 2012; Urban, Luiselli, Child, & Parenteau, 2011). On a larger scale, Luiselli (2011a) designed a clinical safety performance improvement project with care providers at a child and youth residential school. Approximately 220 staff at the school was responsible for implementing instructional

and behavior support plans within 18 classrooms and 8 group homes. The project measured frequency of bite and non-bite injuries that staff reported each week. Staff documented injuries on a standardized *Accident Report (AR)* form that was submitted to the school's Human Resources Department.

During a 20-week pre-intervention phase, administrative personnel at the school conferred with staff about their injuries, reviewed the *AR* forms with them, and had the nursing department administer medical treatment if required. As an initial step toward developing an injury prevention and reduction program, I analyzed the pre-intervention injury data, which revealed that (a) bite and hits to the body accounted for 76 % of injuries, (b) four students were responsible for 60 % of injuries, and (c) the clinical context associated with injuries was not described in 33 % of submitted *AR* forms. With this information, we formed a clinical safety committee dedicated to implementing a four-component injury prevention and reduction program over 44 weeks:

1. *Clinical Incident Report Form*. A new measurement tool, the *Clinical Incident Report Form*, was added to the *AR* form in order to identify more clearly the conditions associated with staff injury. The form had staff enter injury and related information but additionally, describe the context in which the injury was sustained. Also, a designated supervisor reviewed the completed form with staff, "debriefed" the incident, and entered a brief analysis of the injury. The *Clinical Incident Report Form* was filled out simultaneously with the *AR* form and subsequently, routed to the author for further analysis.
2. *Focus on High-Risk Students*. Intervention planning and focus centered on the four students who caused the most frequent staff injuries, as well as other students responsible for more than one reported injury. The clinical safety committee supervised implementation of several strategies that targeted this segment of the student population.
 - (a) Each student's behavior support plan was reviewed to ensure that all procedures were formulated based on functional

assessments that confidently identified antecedent and consequence sources of control. In particular, these reviews concentrated on environmental “triggers” for problem behaviors that were associated with staff injury and methods to prevent them. The clinical directors at the school were responsible for revising the behavior support plans and training staff to properly implement the respective procedures.

- (b) The clinical safety committee conducted a detailed analysis of any physical intervention procedures that comprised a student’s behavior support plan, for example, response blocking, guided compliance, and therapeutic restraint. These procedures were scrutinized with staff, checking on their application of proper technique. In some cases modified procedures were introduced to provide greater staff protection during their physical interactions with students.
 - (c) Having staff wear protective equipment such as arm guards and padded gloves was considered as another injury prevention strategy. Decisions about protective equipment were made on a risk-benefit analysis. That is, the potential advantages of staff wearing protective equipment had to be balanced against possible negative outcomes such as a student displaying novel injury-provoking behaviors directed at a non-protected area of the body. Judgments about protective equipment were also based on range-of-motion restriction, appearance, and acceptability by staff.
3. *Implementation Integrity and Coordination.* Clinical directors conducted implementation integrity observations during their routine supervision of staff. These observations were intended to document accurate application of all behavior support plan components during scheduled activities with students. An additional objective was ensuring proper behavior support plan implementation across classroom and group-home settings. Cross-setting implementation integrity was addressed through

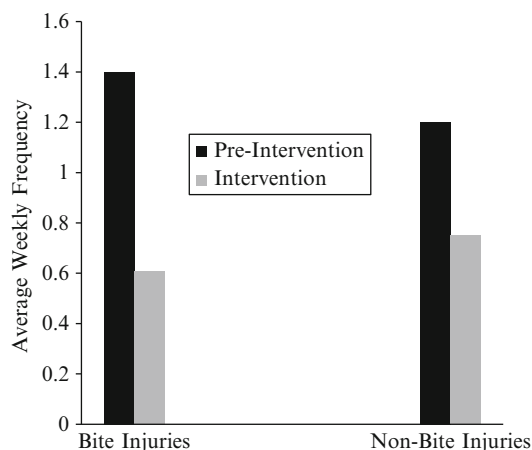


Fig. 3.7 Average bite and non-bite staff injuries during pre-intervention and clinical safety intervention phases (from Luiselli, J. K. (2011a). Staff injury prevention and reduction: Behavioral systems analysis and intervention in a human services setting for youth with intellectual disability. Manuscript submitted for publication)

observations, staff meetings, and in situ performance feedback.

4. *Continuous Clinical Quality Improvement.* As noted previously, I chaired a clinical safety committee which met weekly to review intervention data for the high-risk students and performance improvement objectives school-wide. Relevant data were distributed to committee members as graphic feedback to guide decision-making. Results were also conveyed to the school’s HR Department. The review of injury data, procedural adjustments, and outcome dissemination were considered components of a continuous clinical quality improvement plan.

Referencing Fig. 3.7, average bite injuries were 1.4 per week during pre-intervention and 0.61 per week during intervention. For non-bite injuries, the average was 1.2 per week during pre-intervention and 0.75 per week during intervention. We further analyzed the percentage of weeks without a reported staff injury. Bite injuries did not occur in 45 % of weeks during pre-intervention and 64 % of weeks during intervention. Non-bite injuries were absent in 25 % of weeks during pre-intervention and in 50 % of weeks during intervention.

I suggest that staff injury prevention and reduction is a high-priority peer review objective of behavioral crisis intervention and management within residential treatment settings. The research I cited indicates that human services and behavioral healthcare organizations can design effective clinical safety programs which decrease staff injuries and create a less risky work environment.

Summary

Designing a system of internal peer review allows humans services and behavioral healthcare organizations to maintain continuous clinical quality improvement of crisis intervention practices for children and adults who have IDD. Effective peer review has clinicians and allied specialists identify organizational strengths and weaknesses, plan performance enhancement projects, evaluate programmatic success, and revise policies and procedures on an ongoing basis. Furthermore, internal peer review must be supported by organization leaders who, in turn, enlist other departmental resources (e.g., finance, facility operations, human resources). Finally, those responsible for peer review should pursue models that integrate the highest quality clinical, organizational behavior management (OBM), staff training, and behavioral systems analysis expertise (McGee & Diener, 2010).

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Lindsay Maffei-Almodovar and Peter Sturmey

In 1952, Eysenck provocatively declared that, “The figures fail to support the hypothesis that psychotherapy facilitates recovery from neurotic disorder,” but later, Smith and Glass (1977) reached the opposite conclusion when they stated that “Findings showed psychotherapy to be effective and that the different varieties of therapy do not produce differential effects.” This conclusion is echoed in the “dodo bird hypothesis” (Luborsky, Singer, & Luborsky, 1975) that “all have won and all shall have prizes.” Despite the controversy that has ensued over the effectiveness of psychotherapy, the academic industry of evaluating psychotherapy is no dodo bird: It has been vigorously alive and well and continues to produce hundreds of studies every year (Hersen & Sturmey, 2012; Sturmey & Hersen, 2012). The adoption of systematic reviews and meta-analyses by government agencies, such as Britain’s National Institute for Health and Clinical Excellence, as the rational basis for investing in evidence-based practice (EBP) and guiding clinical practice attests to the continuing importance of EBP in psychological treatment and professional training. The adoption of EBP guidelines by many professional organizations, such as the American Psychological Association

(APA, 2000), further attests to its importance. Publicly funded mental health services, with an eye to the economics as well as ethics of mental health treatment, have also interested themselves in identifying common, treatment-responsive mental health problems that have economic benefits to society. These benefits include returning people to work, reducing their consumption of mental health services, and increasing the number of people paying income tax. Professional organizations have emphasized the ethical obligation of practitioners to maximize client benefits from therapy by selecting the most effective treatment. Also emphasized is the practitioners’ obligation to be honest with clients and others who pay for treatment as to the likely benefit from psychotherapy. Thus, over 50 years of psychotherapy, outcome research has changed the landscape from an absence to a mountain of evidence.

Despite its vigorous pursuit with other populations, EBP has had a more modest impact in the field of developmental disabilities. An exception to this generalization is in the area of autism. Here the question of the effectiveness of intensive early behavioral intervention (Eldevik et al., 2009; Peters-Scheffer, Didden, Korzilius, & Sturmey, 2011; Reichow & Wolery, 2009; Virués-Ortega, 2010) and more recently the effectiveness of specific behavioral and nonbehavioral interventions (National Autism Center [NAC], 2009) has received greater attention. The apparent relative absence of evidence in the field of developmental disabilities led King (2005) to declare

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balefully that it is best to proceed “with compassion while awaiting the evidence” while comparing the current state of knowledge with prescientific magic, alchemy, astrology, and witchcraft. Clinical practice may indeed have much in common with magic, alchemy, astrology, and witchcraft, but has the science of psychological treatment of people with developmental disabilities advanced beyond that yet? This chapter and other publications (Hassiotis & Sturmey, 2010; Sturmey & Didden, *in press*) contend that while certain interventions, including some psychological interventions, have not yet been evaluated, in fact, there is sufficient evidence on effectiveness to draw conclusions that some forms of treatment have been shown to be promising or effective, while others have been shown to be ineffective or even potentially harmful.

Criteria for Evidence-Based Practice

Since Eysenck’s (1952) provocation, many narrative reviews of psychotherapy outcome studies have been published and have often reached divergent conclusions about a treatment because of sampling different types of literature and applying imprecise criteria for effectiveness. In response to these limitations, the growing size of the evidence-base for many disorders, and the availability of on-line databases of publications, researchers developed systematic reviews and meta-analyses. These approaches are characterized by transparency in the methods used and, in the case of meta-analysis, quantitative methods to estimate treatment effect size, which aggregate data from more than one study and sometimes disaggregate those data to answer specific research questions.

One influential approach to meta-analysis of psychotherapy comes from Chambless and Hollon (1998), who proposed criteria for established EBP. These criteria included (a) the identification of acceptable experimental designs, such as randomized clinical trials (RCTs), comparisons with other treatments or placebos, and small *N* experimental designs, including ABAB reversal designs, multiple baseline designs, and

component analyses of combination treatments; (b) reduction of bias and complication of participant selection by involving clear definitions of the populations for which experimenters designed and tested treatments in terms of a diagnostic system such as the *Diagnostic and Statistical Manual of Mental Disorders*, cutoff scores on reliable and valid questionnaires, or interviews identifying the problem or focus of interest; (c) maximization of treatment integrity through the use of treatment manuals or treatment intervention that is relatively simple and is adequately specified in the procedure section of the journal article with effective therapist training and monitoring based on actual samples of therapist behavior; (d) accurate data analysis and interpretation of results controlling for differential attrition from treatment groups; (e) outcome assessments with demonstrated reliability and validity in previous research and not based on self-report; (f) assessment for the clinical significance of an effect which might be determined on the basis of attainment of some societal or personally important goal; (g) external validity shown through replication of results by independent research teams; (h) social validity; (i) collection of follow-up data; (j) generalizability across populations and settings; (k) treatment feasibility; (l) patient acceptance and compliance; (m) ease of dissemination; and (n) cost-effectiveness. Further, Chambless and Hollon formalized the definition of EBP by proposing explicit criteria for *effective* and *promising* interventions. For an intervention to be considered *effective*, it must prove efficacious in at least two well-conducted RCTs by independent research teams. If there is only one RCT supporting a treatment’s efficacy or if one team has conducted all of the research, the findings are *promising* and *possibly efficacious*, pending replication. Chambless and Hollon also proposed similar criteria for the number of well- and independently conducted small *N* experiments: A sufficient small *N* experiment with at least three participants constitutes a “possibly efficacious” treatment, while sufficient small *N* experiments with at least nine participants and conducted by at least two independent research groups constitute an “efficacious” treatment.

Although these are not the only criteria for EBP, they illustrate one of the most cited examples of criteria for EBP.

Before going on to review the evidence for effective psychological and educational interventions in people with developmental disabilities, the next section will briefly review the nature of behavioral crises. Subsequent sections will review the evidence for both prevention and treatment related to behavioral crises before making recommendations.

Nature of Behavioral Crises

Behavioral crises occur for different reasons: Sometimes client behavior changes in ways that caregivers can no longer tolerate; at other times, client behavior changes little or not at all, but services and families change in their capacity to deal with existing problems; at other times, both phenomena may occur simultaneously. Increases in topography, frequency, duration, intensity, or some other dimension of challenging behavior occur naturally. For example, several authors have speculated how stereotyped behavior might develop into self-injurious behavior (SIB) (Guess & Carr, 1991; Kennedy, 2002), although the number of studies to support such speculation is limited (Symons, Sperry, Dropik, & Bodfish, 2005). For example, Oliver, Hall, and Murphy (2005) observed that increases in SIB in 16 children with intellectual disabilities, aged approximately 2–10 years, were correlated with increasingly tight contingencies between SIB and parental attention. This finding suggests that parents inadvertently shaped increases in SIB and that termination of child SIB negatively reinforced parental attending. Such changes in topography and other dimensions of SIB might be the basis for subsequent behavioral crises.

Direct studies of longitudinal development of challenging behavior are understandably rare (Symons et al., 2005), but the literature on stressful life events and challenging behavior also hint at some of the learning processes that may occur as behavioral crises develop. Several studies have reported modest correlations between stressful

life events involving losses, such as bereavement, and challenging behavior (Hulbert-Williams & Hastings, 2008). Although such correlations are indeed modest, hidden within them may be relationships between independent and dependent variables that are meaningful and important for case formulation and functional assessment/analysis of individual cases (Haynes & O'Brien, 1990, 2000). Behavioral crises that involve loss or which occur during periods of transitions from one setting to another or from one phase of life to another are reminiscent of Skinner's (1953) description of transitions and depression which involve two kinds of losses. First, certain behavior is no longer possible—we can no longer go to the movies with the person who had died, and hence, reinforcement previously associated with that behavior is no longer physically possible. Second, although certain behavior is still possible, the schedules of reinforcement associated with the new environment may no longer support such behavior. For example, the skills that were reinforced in a previous job may now result in extinction or punishment: Now that we have calculators and computers, almost no one operates comptometers anymore. Similarly, some losses and transitions for people with developmental disabilities involve loss of opportunity to engage in adaptive operant behavior that may compete with challenging behavior. For example, a teenager who was successful in school may not have the skills to be successful in a work setting. Some stressful life events involve social losses, such as losses of friends, family members, and favorite staff. Again, one aspect of such transitions is that behavior that was effective in the first environment may be ineffective in the new setting. For example, behavior that family members used to find charming may irritate new residential staff. This may represent a change from an intermittent schedule, to an extinction or punishment schedule resulting in weakening of adaptive behavior. If we conceive of adaptive and challenging behavior as being reinforced on two or more concurrent schedules (Herrnstein, 1961), then we might predict an increase in challenging behavior in such circumstances. Finally, other concurrent schedule effects may occur related to changes in effort for

adaptive and challenging behavior. For instance, when a sheltered workshop changes the furniture and workers must reach further to obtain materials, their adaptive behavior may be weakened and challenging behavior may be more likely. Alternatively, if engaging in the challenging behavior becomes easier, as when a new peer sits next to the client who does not defend themselves from aggression, then challenging behavior may be more likely.

Concurrent operant schedules provide a useful model for how behavioral crises can arise through changes in client behavior. Concurrent schedules of reinforcement not only point to the potential mechanisms of how behavioral crises may arise through changes in client behavior, but they also focus attention on the relevant variables that control challenging and alternate behavior. These variables include parameters such as reinforcement schedule value, reinforcement quality, delay to reinforcement, and response effort for both adaptive and challenging behavior.

As noted earlier, behavioral crises may also occur, not because of a true increase in challenging behavior, but rather because of a change within the system that responds to such behavior. For example, a loss of capacity to manage a challenging behavior may occur when there are fewer social resources available to manage the behavior or when additional demands are placed on an existing system. For example, teenagers may play a key role in managing the behavior of a sibling with a developmental disability. A family may be able to manage their child's aggression effectively when a teenage child plays a key role in directly or indirectly managing their sibling's challenging behavior—perhaps the teenager provides a rich schedule of reinforcement for adaptive behavior. If that teenager leaves, the family may no longer be able to manage their child's aggression and a behavioral crisis may ensue—perhaps because the schedule of reinforcement maintaining the child's adaptive behavior is now too weak to maintain it. Likewise, when service cuts occur or greedy services expand rapidly, they may no longer be able to provide preventative or intervention services and behavioral crises may ensue.

These two different types of reasons may have different implications for evaluating the literature

on EBP and behavioral crises. Although EBP may guide practitioners as to which treatment is most likely to be effective, it does not guide practitioners on other questions, such as whether or not the system has the capacity to implement an effective treatment. Researchers often frame questions concerning EBP in terms of “what works,” “what works best,” or “what works best for whom for what kind of problem?” Such questions focus our attention on psychological and other professional treatments. When treatment teams and administrators respond to behavioral crises, they do many more things than to simply implement professional treatment plans. They may increase staffing, reassign different staff to work with the client, instruct staff to leave the person alone, or keep them busy as much as possible. They may reassign the person to alternate programs, suspend programming, and/or send the person back to their family or other residential home. They may add restrictive management practices, such as restraint, time out, seclusion, preventing access to personal property, or home visits, in the hope that these practices may prevent or reduce the challenging behavior or at least prevent its resultant harm. Caregivers and professionals may declare a medical emergency: “Call a Doctor!”; “Call ten doctors and some dentists too!”; and “Call the psychiatrist to adjust psychotropic medication or provide some temporary sedation!” In response to behavioral crises, individual caregivers may also implement their own intuitive or informal intervention plans. They may attempt to get the client in a good mood, remove irritating peers or staff, provide preferred activities, leave the person alone, and so on. Thus, there are a range of interventions other than professional treatment plans that commonly occur during behavioral crises. EBP should also consider what is known about these other approaches to managing behavioral crises.

Prevention

Most meta-analyses and systematic reviews have not focused explicitly on prevention of crises, but there are meta-analyses and systematic reviews on outcome research related to problem behavior, and these address questions that relate to prevention.

We conducted a research review on interventions for problem behavior including the use of engagement, choice, and functional communication training (FCT) in order to determine whether these interventions could be considered as evidence based in the prevention of crises.

Search Strategies

We completed three searches of PsycInfo, ERIC, PubMed, and MEDLINE®. Our first search included the terms “(engagement) AND (meta-analysis OR systematic review OR literature review or review of research) AND (disabilit*).” Our second search included the terms “(choice) AND (meta-analysis OR systematic review OR literature review or review of research) AND (disabilit*).” Our third search included the terms “(communication training) AND (meta-analysis OR systematic review OR literature review or review of research) AND (disabilit*).” We retained articles that were reviews examining the effects of engagement, choice, or communication training in decreasing challenging behavior among individuals with intellectual or other developmental disabilities. We excluded articles exploring decreasing challenging behavior among typically developing individuals or examining interventions for behavior problems other than engagement, choice, or communication training.

Our search identified 184 abstracts. After application of exclusion criteria, five articles remained for review. A hand search of these five articles identified an additional four articles. Of the nine review articles remaining after the application of exclusionary criteria, none examined engagement specifically as a treatment to reduce problem behavior, six explored choice, and three explored communication training. Although we did not find any reviews specific to increasing engagement as an intervention for problem behavior, reviews on choice, communication training, and a few other types of interventions, such as activity schedules and instructional fading, indicated increases in engagement in addition to decreases in problem behavior as behavioral targets. We coded each included review according whether it was (a) a

Table 4.1 Table for summary of identified reviews

<i>General reviews on interventions to reduce problem behavior</i>	
Meta-analyses	Didden, Duker, and Korzilius (1997) Denis, Van den Noortgate, and Maes (2011) Harvey, Boer, Meyer, and Evans (2009)
Systematic reviews	Kahng, Iwata, and Lewin (2002) Lang, White, et al. (2009)
Narrative reviews	Munk and Repp (1994)
<i>Choice</i>	
Meta-analyses	Shogren, Faggella-Luby, Bae, and Wehmeyer (2004)
Systematic reviews	Kearney and Mcknight (1997) Kern et al. (1998) Lancioni, O'Reilly, and Emerson (1996) Stalker and Harris (1998) Romaniuk and Miltenberger (2001)
<i>Communication training</i>	
Systematic reviews	Mancil (2006)
Narrative reviews	Mirenda (1997) Snell, Chen, and Hoover (2006)
<i>Activity schedules</i>	
Systematic reviews	Banda and Grimmer (2008)

systematic review, (b) a meta-analysis, or (c) some other type of review; most often these other types were narrative reviews. Results of the coding procedure are displayed in Table 4.1.

Although relevant narrative reviews are referenced briefly in the following sections, only systematic reviews and meta-analyses were considered thoroughly as they provide more complete and pertinent information when it comes to identifying EBP. Systematic reviews and meta-analyses were considered according to how thoroughly they addressed the Chambless and Hollon (1998) criteria in their conclusions about whether certain treatments are EBP.

Choice

Although there had been several earlier traditional narrative reviews of choice-making procedures

(Kearney & McKnight, 1997; Lancioni et al., 1996; Romaniuk & Miltenberger, 2001; Stalker & Harris, 1998), one of the first systematic reviews was conducted by Kern et al., (1998) who searched PsychLit for studies published between 1975 and 1996. They included studies that (a) used choice making as an independent variable, (b) used choice making as an antecedent procedure, (c) offered choices in a similar manner, and (d) examined the effect of choice making on adaptive or challenging behavior. Fourteen studies that met inclusion criteria were in three general areas: (a) vocational or domestic activities (six studies); (b) academic activities (five studies); and (c) leisure, recreational, or social activities (three studies). Choice-making procedures were carried out in a variety of applied settings such as group homes, vocational training centers, and community-based residential facilities. Choice making resulted in behavioral improvements for some participants across all three areas of choice making; however, the authors did not calculate effect sizes, and there was no systematic method to identify particular characteristics of participants or circumstances best suited to choice-making interventions.

A more recent meta-analysis of choice research comes from Shogren et al. (2004). They evaluated the impact of choice interventions on reducing challenging behavior. The authors searched PsychInfo and ERIC to identify small *N* experiments that (a) had experimental participants with identified disabilities, (b) implemented a choice intervention as an independent variable to reduce problem behavior, (c) measured problem behavior as a dependent variable, and (d) reported the effect of an intervention on problem behavior graphically and with identifiable baseline and intervention phases. Thirteen studies with 30 participants met inclusion criteria. Shogren et al. coded included studies according to (a) type of choice intervention used; (b) type of activity in which choice procedures were embedded; (c) whether choice-making training was provided to participants prior to intervention; (d) type of experimental design; (e) whether a functional assessment or analysis of the participant's problem behavior was conducted prior to and used to design the intervention; and (f) participant

characteristics including gender, age, diagnosis, setting, and type of behavior. Sixty-two percent of included studies examined interventions where participants chose the order in which they completed assigned tasks, and 38 % examined interventions where participants chose between two activities. Thus, all included studies examined some type of *activity* choice intervention as the independent variable which included academic (46 %), daily living (31 %), vocational (0 %), or combination (23 %). Only 15 % of included studies included pre-intervention training in how to make choices. As for experimental design, 69 % were ABAB reversal designs, 23 % were multiple baseline designs, and 8 % were other experimental designs. Twenty-seven percent of participants were females, and 73 % were males aged 4–50 years (mean = 10.4 years); most were aged 5–21 years. Participant diagnoses were emotional disturbance (17 %), autism (23 %), developmental disabilities (13 %), attention deficit/hyperactivity disorder (13 %), and intellectual disability (ID) (33 %) with the exception of one participant diagnosed with Down syndrome and ID. Settings included general education classrooms or community settings (20 %), self-contained classes or resource rooms in public schools or group homes (40 %), and institutions or inpatient facilities (40 %). Most of the studies used the term *problem behavior* to include aggression, noncompliance, elopement, off-task behavior, and destruction of property. The authors classified most problem behaviors into two categories: problem behavior that involved aggression to self or others (50 %) and problem behavior that did not include aggression (33 %); problem behavior could not be coded for individual participants for one included study. Five participants were excluded from these analyses because their specific target behaviors were not described.

Shogren et al. (2004) calculated the proportion of nonoverlapping data points (PND) and proportion of zero data points (PZD) to examine the effect of the included and coded activity choice interventions. The mean PND for all studies was 65.7 % and the mean PZD was 42.3 %. Effect sizes for participants who engaged in aggressive behavior were large (PND = 78 %, PZD = 60 %),

whereas effect sizes for nonaggressive behavior were small (PND=54 %, PZD=40 %). Effect sizes also varied according to whether a functional assessment was conducted. A mean reduction over baseline of only 53 % was found when experimenters had not conducted functional assessment or analyses. Additionally, studies that utilized functional assessments or analyses demonstrated a 77 % mean reduction over baseline in escape-maintained problem behaviors when choice-making interventions were implemented compared to only a 33 % mean reduction over baseline in problem behaviors maintained by other contingencies.

Based on these findings, Shogren et al. (2004) suggested that future research should investigate the degree to which functional assessment or analysis results affect efficacy of activity choice interventions. Shogren et al. concluded that providing these choice opportunities resulted in clinically significant reductions in the number of occurrences of problem behavior; however, these results provided only preliminary support for the benefit of providing activity choice opportunities as an intervention or prevention for problem behavior, since they fell in the “questionable” range with regard to efficacy (Scotti, Evans, Meyer, & Walker, 1991).

Given the shortcomings of the above systematic review and meta-analysis, it seems prudent to classify activity choice as “promising” in terms of reducing and possible in terms of preventing problem behavior in the populations described according to the Chambless and Hollon (1998) criteria for EBP.

Language Interventions

Functional Communication Training

FCT teaches communicative behaviors that are functionally equivalent to an individual's problem behavior. This intervention relies on the assumption that if an individual is taught an efficient way of accessing the same consequences maintaining problem behavior, use of the alternative behavior will increase and problem behavior

will decrease (Durand, 1990; Durand & Carr, 1991). FCT may include teaching communication using vocal speech, communication boards, signs, gestures, or high-tech devices.

Mancil (2006) conducted a systematic review that identified eight studies where experimenters applied FCT as part of an intervention package to reduce problem behavior in children with ASD. Mancil accounted for many of the limitations of previous narrative reviews on FCT (Mirenda, 1997; Snell et al., 2006) by identifying participant characteristics, research environments, experimental designs, behaviors, interventions, major findings, reliability, and treatment integrity. Studies were included for review when (a) at least one participant in the study was a child with an ASD diagnosis; (b) the function of the problem behavior was assessed and determined by a functional behavior assessment (FBA); and (c) the primary intervention was FCT combined with either extinction, punishment, or both.

Although some studies reviewed by Mancil (2006) included adults and child participants with diagnoses other than ASD, the author only analyzed results for children with ASD. There were 22 participants across eight included studies (18 males and 4 females) aged 2.7–13 years (mean=8 years). Participants' use of language varied ranging from nonvocal, without signs or gestures, to vocal, with full sentences that were not always functional. Research environments were fairly stable across the studies reviewed. Six of eight study settings were clinical rooms containing only a table and chairs. Only two studies were conducted in natural settings including one in a classroom and one in a participant's home. Experimenters applied most interventions, with the exception of one intervention applied by a teacher and one applied by parents. In four studies, experimenters used a reversal experimental design, and in four studies, experimenters used a multiple baseline experimental design. Topographies of problem behaviors included aggression, property destruction, tantrums, body rocking, hand flapping, oppositional behavior, and walking away. Fourteen participants engaged specifically in aggression, SIB, or property

destruction, and 14 out of 22 participants engaged in more than one problem behavior. Experimenters conducted interviews, direct observations, and functional analyses to determine functions of problem behaviors. Out of the 22 participants, only one engaged in problem behavior where the function was determined to be undifferentiated. Twelve participants engaged in escape-maintained problem behavior, eight engaged in attention-maintained problem behaviors, and three engaged in tangible-maintained problem behaviors. Of the 12 participants who engaged in escape-maintained problem behavior, four also engaged in attention-maintained problem behavior, and one also engaged in attention- and tangible-maintained problem behaviors. Responses taught during the FCT interventions were all mands (i.e., requests) designed to match functions assessed and included (a) vocal language, (b) sign language, (c) picture-/icon-based language, or (d) augmentative devices. All study teams reported high levels of treatment integrity and high interobserver agreement ranging from 80 % to 90 %.

Mancil (2006) reported that FCT consistently reduced problem behavior and increased communication across various topographies, functions, and communication modes; however, the reviewer did not apply statistical analyses to determine the effect sizes of FCT, and Mancil's review also pointed out that the majority of study settings were clinical where experimenters applied interventions and most focused on only one communication mand. These limitations pose important threats to maintenance and generalization of communication and behavioral results and may decrease the effects of FCT over time and in settings different from the study settings. Additionally, all studies reviewed included FCT combined with extinction, punishment, or both as a package intervention. FCT alone has not often been evaluated as an independent intervention, and when it has, it was shown that for some individuals, FCT was insufficient to produce even clinically significant reductions in problem behavior without the addition of extinction or punishment procedures (Fisher et al., 1993). Thus, FCT, even when combined with extinction, punishment, or

both, can only be categorized as "promising" for reducing and "possible" for preventing problem behavior according to the Chambless and Hollon (1998) criteria. In order for FCT to qualify as an EBP, future research should show statistically significant results demonstrating maintenance and generalization of communicative responses taught and should conduct component analyses to show that FCT is a necessary component of the treatment packages evaluated.

Regardless of whether FCT qualifies as an EBP, it is a popular intervention for reducing problem behavior, particularly aggression. For example, Matson, Dixon, and Matson (2005) assessed current methods of assessing and treating aggression in children and adolescents with developmental disabilities. The authors reviewed studies on assessment and treatment of aggression and found that the most commonly used treatments for aggression are FCT and differential reinforcement of other behavior (DRO). Additionally, Lang, Rispoli, et al. (2009) conducted a systematic review of interventions to reduce elopement in individuals with developmental disabilities and found that functional analysis procedures and function-based treatments, including FCT, may be the most effective in producing clinically significant decreases when compared with other popular interventions. Finally, studies examining participant preference for particular types of interventions have shown that participants prefer FCT over other types of interventions. For example, participants in Hanley, Piazza, Fisher, Contrucci, and Maglieri (1997) showed a clear preference for a combination of FCT and extinction over either noncontingent reinforcement (NCR) and extinction or extinction alone when these interventions were applied to decrease their problem behaviors.

Picture Exchange System

The Picture Exchange Communication System (PECS; Bondy & Frost, 1993, 1994) is a behavioral approach to teach language skills which focuses on teaching requesting through exchange of picture icons and subsequently teaching initiating requests, discriminating icons, elementary grammar, responding to requests, and commenting in a six-

phase program. PECS might be helpful for some individuals related to behavioral crises in that it may teach communication skills to compete with challenging behavior and may also be used as a direct treatment for challenging behavior.

In addition to earlier narrative reviews (Lancioni et al., 2007; Millar, Light, & Schlosser, 2006; Mirenda, 2003), there are now at least four meta-analyses of PECS (Hart & Banda, 2010; Flippin, Reszka, & Watson, 2010; Gantz et al., 2012; Preston & Carter, 2009). These meta-analyses vary modestly in terms of which papers were included, whether they only included participants with autism spectrum disorders, and the methodologies they used, such as search strategies, choice of effect size measure, and whether they included RCTs of PECS. Despite these differences, they agree on a number of key points. First, the effect sizes for acquisition of simple requesting skills are large. For example, Preston and Carter reported a PND of 78.5 % (range 50–100 %) based on nine small *N* experiments, indicating that PECS was “effective” for acquisition of picture exchange skills. These meta-analyses also concur that PECS has varied, small, or no effects on acquisition of other language skills, such as speech. Gantz et al. (2012) also found that PECS had large effect sizes similar to speech-generating devices, but larger than for other picture communication systems. Again, based on four small *N* experiments, Preston and Carter (2009) reported a mean PND of only 49.8 % (range 19.5–100 %) which they described as “non-effective or at best very mildly effective with wide variation” (p. 1478). Data on more advanced phases of PECS are generally lacking at this time. Thus, we can conclude that PECS is a highly effective program for teaching the basic mand/icon exchange procedure, but an ineffective or weakly effective procedure to produce speech or other related outcomes.

Augmentative and Alternative Communication Systems

As part of their meta-analysis, Gantz et al. (2012) reported effect sizes for speech-generating devices and picture-based systems other than PECS. The effect size measurement tool that

Gantz et al. used was the improvement rate difference (IRD), which is the difference in percent of high scores from baseline to intervention. A high score is a baseline point which overlaps with treatment data, and a low score is a treatment point that overlaps with baseline data. For example, if there are 20 % high and 60 % low scores, the IRD is 0.4. One of the advantages of IRD over other effect size metrics for small *N* experiments is that it is possible to calculate confidence limits; hence, it is easy to compare effect sizes.

Of a total 24 papers with 58 participants, nine evaluated PECS, seven evaluated other picture-based systems, and eight evaluated speech-generating devices. The IRDs were 0.99 (84 % CI=0.98–1.00), 0.61 (84 % CI=0.57–0.64), and 0.99 (84 % CI=0.99–1.00), respectively. IRDs were 0.99 (84 % CI=0.99–0.99), 0.90 (84 % CI=0.84–0.95), 0.79 (84 % CI=0.76–0.82), and 0.80 (84 % CI=0.76–0.84) for communication, social skills, academics, and challenging behavior, respectively. Parker, Vannest, & Brown (2009) suggested that IRDs be classified as small/questionable if they are less than 0.5, moderate if they are from 0.5 to 0.7, and large if they are greater than 0.7 or 0.75. Thus, almost all effect sizes here were large, except for non-PECS picture-based systems. Thus, this meta-analysis confirms the findings of other meta-analyses of PECS in reporting large effect sizes, at least in terms of initial acquisition of picture exchange. It also extends these findings by demonstrating large effect sizes for PECS and speech-generating devices and moderate effect sizes for non-PECS picture-based systems. Further, it reported large effect sizes for all dependent variables, although the effect sizes were significantly smaller for academic outcomes than for other outcomes.

Activity Schedules

An activity schedule is a group of photographs, videos, computer images, drawings, symbols, or text, sequentially arranged on a display for individuals to follow. They can include single or multiple items in sequence. Activity schedules can be used between routines as a transitional

tool or within routines to cue specific steps of an activity (Banda & Grimmer, 2008).

Banda and Grimmer (2008) conducted a systematic review by searching *ERIC* and *PsycInfo* for studies using activity schedules to improve social interaction skills and decrease problem behaviors. Inclusion criteria specified that studies must (a) be conducted with individuals with autism, (b) involve an activity schedule as an intervention, (c) present data in graphical form, and (d) be published in a peer-reviewed journal. If studies met all inclusion criteria, but included participants with autism as well as participants with other diagnoses, the authors included only results for the participants with autism for review. These criteria led to the inclusion of 31 participants across 13 studies aged 3–40 years (mean=8.8 years). Twenty-eight were male and female children aged 14 years or younger (mean age=6.53 years). The remaining three participants were adult males ranging in age 22–40 years. There were 28 males and 3 females in total. Seven studies took place in either general or self-contained classrooms, four were in the participants' homes, one was in a group home, and one was in an adult service program building. Behaviors targeted for increase included social exchanges and initiations, on-task and on-schedule behavior, independent daily living skills and independent play skills. Behaviors targeted for decrease included tantrum behaviors, such as hitting, kicking, biting, crying, and screaming, other undefined problem behaviors during transitions, and long latencies in completing transitions. While most studies focused exclusively on either increasing or decreasing a target behavior, four focused on increasing on-task behavior while simultaneously decreasing problem behaviors. Nine studies utilized photograph, computer, or video activity schedules, two used line drawings, one used PECS icons (Bondy & Frost, 1993, 1994), and one used text. All interventions were applied by psychologists, teachers, and/or graduate assistants. As for experimental design, nine studies were conducted with a multiple baseline design, three were reversal designs, and one was matrix training.

Banda and Grimmer (2008) reported that activity schedules enhanced social interactions

and on-task behavior and decreased tantrums and other problem behaviors during transitions. The authors noted that several studies reported generalization of behavior changes across settings and persons. In five studies reporting social validity measures, caregivers indicated that activity schedules were beneficial and efficient in improving participant behavior. Limitations to this review included that effect sizes for interventions were not calculated and that it was not indicated whether studies included for review used treatment integrity measures.

Koyama and Wang (2011) reported a second meta-analysis of activity schedules using broader inclusion criteria. They searched *Psychinfo*® and *Google Scholar*® for articles on activity schedules for people with any disability and articles that combined activity schedules with other interventions. They found 23 experiments with 69 participants of whom approximately three-quarters were children and adolescents and one-quarter were adults. Sixty percent had autism and 20 had cognitive impairment. Most articles did not specify the degree of participants' intellectual functioning. Dependent variables included engagement (15 studies, 65 %), disruption and/or SIB (8 studies, 35 %), task initial/transition (7 studies, 30 %), and learning to self-schedule (7 studies, 30 %). Twenty-six percent of studies reported maintenance, 39 % reported generalization data, and 30 % reported social validity data.

Both meta-analyses reached the same conclusion that activity schedules were effective interventions. Since Koyama and Wang (2011) reported many more than three experiments with more than nine participants, we can conclude that according to the Chambless and Hollon (1998) criteria, activity schedules are an *effective* treatment.

Instructional Fading

Munk and Repp (1994) completed a narrative review of studies that used instructional variables as non-aversive interventions for problem behaviors. Instructional fading is one way of possibly manipulating establishing operations to decrease the momentary value of escape from instructional

demands. Instructional fading consists of drastically decreasing the rate or difficulty of instructions identified as antecedents to escape-maintained problem behavior and then systematically increasing the rate or difficulty of instructions to a predetermined acceptable level (Horner, Day, Sprague, O'Brien, & Heathfield, 1991; Pace, Iwata, Cowdery, Andree, & McIntyre, 1993; Weeks & Gaylord-Ross, 1981; Zarcone et al., 1993). Instructional variables include student's choice of task, task variation, pace of instruction, interspersal of high-probability tasks, partial- vs. whole-task training, instructional fading, and multicomponent packages. Instructional fading is typically applied to reduce escape-maintained problem behaviors (Butler & Luiselli, 2007; Horner et al., 1991; Pace et al., 1993; Weeks & Gaylord-Ross, 1981; Zarcone, Iwata, Smith, Mazaleski, & Lerman, 1994) including SIB maintained by task avoidance (Iwata, Pace, Kalsner, Cowdery, & Cataldo, 1990; Repp, Felce, & Barton, 1988; Steege, Wacker, Berg, Cigrand, & Cooper, 1989).

We did not find any meta-analyses or systematic reviews related to instructional fading while conducting searches on engagement, choice, or FCT; however, a search of ERIC, MEDLINE, PsycARTICLES, and PsycInfo with the search terms "instructional fading AND disability*" did return several single-subject experiments, including six that utilized instructional fading to decrease dangerous problem behavior. In order to include studies for review, we insured that they (a) were published in English and in peer-reviewed journals, (b) included participants with identified developmental or intellectual disabilities, (c) utilized a reversal or multiple baseline design to allow for percentage of all nonoverlapping data calculations (PAND), and (e) targeted a dangerous problem behavior. Dangerous problem behavior is defined as a behavior likely to result in injury to the individual or to others in the immediate environment such as various forms of SIB, aggression, elopement, and property destruction. After application of inclusion criteria, we were left with four studies with ten participants.

We reviewed and coded all included experiments according to Chambless and Hollon's (1998) criteria in order to determine whether

instructional fading qualified as an EBP for reducing dangerous problem behavior. We also coded studies by participant characteristics (age, gender, and diagnosis), setting, target problem behavior, and specific instructional fading intervention (instructional fading alone, with extinction or with noncontingent escape). We found effect sizes for each study by utilizing the PAND calculation to identify both PND and Pearson Phi scores (Parker, Hagan-Burke, & Vannest, 2007). Table 4.2 displays all coding for included studies.

Participants included seven females and three males aged 2–40 years. Nine out of ten participants were diagnosed with moderate to profound intellectual disabilities and one was diagnosed with autism. Experimental settings included a therapy room, two state residential facilities, and one private school for children with developmental disabilities. All ten participants engaged in escape-maintained SIB, and one also engaged in escape-maintained aggression. Instructional fading interventions varied across studies to include instructional fading plus extinction (Pace et al., 1993; Zarcone et al., 1994), instructional fading plus noncontingent escape (Butler & Luiselli, 2007), and a comparison of instructional fading plus extinction with extinction alone (Zarcone et al., 1993).

After coding each study according to Chambless and Hollon (1998) criteria for EBP, we found that no study met all criteria, although each met the following three criteria: (1) acceptable experimental designs, (2) participant selection that involves clear definitions of the populations for which experimenters designed and tested treatments, and (3) outcome assessments with demonstrated reliability and validity. Only one study accounted for treatment integrity (Zarcone et al., 1994), while one other reported training interventionists, but did not provide treatment integrity data (Pace et al., 1993). Additionally, only one study reported collecting follow-up data, but these data were not displayed (Zarcone et al., 1993). Last, no study reported social validity.

There were large effect sizes across all four studies (see Table 4.2); however, since each study utilized a slightly different variation of the

Table 4.2 Table for instructional fading mini review

	Pace et al. (1993)		Zarcone et al. (1993)		Zarcone et al. (1994)		Butler and Luiselli (2007)
Dependent variable	SIB		SIB		SIB		SIB and aggression
Setting	Therapy rooms		State residential facility		State residential facility		Private school for children with developmental disabilities
Independent variable	Instructional fading + extinction		Extinction with AND without Instructional fading		Instructional fading *extinction applied and rate of instructions held constant when SIB remained high across 10 sessions		Combination of noncontingent escape and instructional fading
Functional analysis	X*		X 2/3		X		X
	Escape		2 escape 1 descriptive analysis escape		Escape		Escape
Acceptable experimental design	X		X		X		X
Treatment manual/treatment integrity	Multiple baseline		MBD, multiclement		MBD		reversal
Identified participant characteristics	Staff trained, but no samples of staff behavior taken				X		
	3 (2 females, 1 male) moderate to profound MR Ages: 2–17		3 (females) profound MR Ages: 26–39		3 (1 female, 2males) profound MR Ages: 27–40		1 female autism Age: 13
Used acceptable outcome measures	X		X		X		X
Demonstrated statistically significant effects	% of intervals		Rate = responses per minute		Rate = responses per minute		% of intervals
	X		X		X		X
Follow-up data	PAND = 94 % (Pearson Phi = 0.74)		PAND EXT = 85 % (Pearson Phi = 0.6)		PAND = 82 % (Pearson Phi = -0.89)		PAND = 100 % (Pearson Phi = 1.00)
			PAND EXT + IF = 94 % (Pearson Phi = 0.67)				
Reported social validity	None		Reported data not displayed		None		None

* An X entry indicates that the study has met the Chambless and Hollon (1998).

instructional fading intervention, effect sizes will be reported separately for each study. Pace et al. (1993) applied instructional fading plus extinction to significantly reduce SIB across three participants (PAND=94 %). Zarcone et al. (1993) compared instructional fading plus extinction vs. extinction alone and found that both interventions significantly reduced SIB. Zarcone et al., however, also found that extinction alone produced less reduction in SIB (PAND=85 %) than instructional fading plus extinction (PAND=94 %). Zarcone et al., (1994) also utilized instructional fading only applying extinction (with the rate of instructions held constant) when SIB remained high across ten sessions. Effect sizes for Zarcone et al. were less robust (PAND=82 %) indicating that instructional fading alone may be less effective than instructional fading plus extinction. Finally, Butler and Luiselli (2007) implemented noncontingent escape plus instructional fading and reduced problem behavior with the most robust effect size (PAND= 100 %).

Experimenters in all four studies also reported increases in appropriate responses to instructions as instructional difficulty and frequency were faded in during interventions. In this way, studies also reported increases in participant engagement. In spite of the large effects sizes related to reduction of SIB and aggression across studies, it is premature to categorize instructional fading as an EBP for reducing problem behavior across individuals with developmental disabilities due to the included studies' failure to meet all of Chambless and Hollon's (1998) criteria and the variability of the intervention across studies. Additionally, the range of participant characteristics was narrow, thereby potentially limiting the external validity of these observations. Nonetheless, instructional fading shows promise as a component in a treatment package to decrease and possibly prevent dangerous problem behavior when combined with either extinction or noncontingent escape for the populations described above.

Treatment

Expert Panels

There have been a number of expert panels on issues related to crisis intervention. This section will focus on two such panels, one that reported on both adults and children (Rush & Frances, 2000) and one that focused on children and adolescents with ASD (NAC, 2009).

Rush and Frances (2000) developed a series of expert consensus guidelines for treatment of psychiatric and behavioral problems in ID for both psychotropic medication and psychosocial treatments. Of 48 psychosocial experts, 86 % replied to a survey that asked them to rate the effectiveness of 7 psychosocial treatments including applied behavior analysis (ABA), managing the environment, client and/or family education, cognitive behavior therapy (CBT), supportive counseling and psychotherapy, and 13 ABA interventions including behavioral parent and teacher/staff training, social skills and communication training, response cost, and contingent noxious stimulation on a nine-point scale. These experts rated the appropriateness of each treatment for a variety of problems, including mild and persistent aggressive behavior and self-injury, a range of comorbid psychiatric disorders, such as depression and substance abuse disorder, and a range of target behaviors, such as public masturbation, social withdrawal, and pica. They made these ratings separately for people with mild/moderate ID and people with severe/profound ID.

Across all ratings, there was almost uniform ranking of the appropriateness of the seven ABA treatment modalities, with managing the environment and client/family education being rated as first-line treatments (i.e., "usually extremely appropriate treatments") and CBT, classical behavior therapy, supportive counseling, and psychotherapy being ranked lowest and often as second or third line (i.e., "usually extremely

inappropriate treatments”). Often there was clear separation between the top three treatments and other treatments. Among ABA treatments, behavioral parent and staff training, social skills and communication training, and accelerating differential reinforcement procedures were uniformly ranked as first-choice treatments, whereas punishment-based interventions were consistently rated as least appropriate. Thus, this expert panel consistently rated behavioral interventions as more appropriate than other interventions and positive behavioral interventions as more acceptable than punishment-based interventions.

As with other expert panels, much of the expert panel process is unclear. For example, it is unclear how Rush and Frances identified their experts. Similarly, it is unclear what evidence, if any, the experts used to make their ratings. Despite these limitations, it is interesting to note that the results of this expert panel largely agree with the broad conclusions of the NACs National Standards Report (2009) who reported 10 years later on a different population using a very different methodology.

In order to identify the level of research support for educational and behavioral interventions, help parents and professional integrate research findings into decision making, and identify the limitations of research, the NAC conducted an extensive systematic review of evidence for treatment efficacy for ASD published between 1957 and 2007 (NAC, 2009). Building on earlier expert panels (NRC, 2001; New York Department of Health, 1999), the NAC assembled a pilot team and several panels of experts to develop a process to identify EBPs. The team identified 7,038 abstracts of which 5,978 were retained for further review. Using a manual and trained, reliable raters, they retained articles of both RCTs and small *N* experiments that included participants with ASD, Asperger syndrome, or pervasive developmental disorder—not otherwise specified—and were peer-reviewed empirical articles reporting change in the behavior of children or adolescents aged less than 22 years. They excluded articles that were not empirical; only reported data on caregivers; were not in English; included participants with

rare comorbid conditions, such as severe health issues; or addressed pharmacological, nutritional, or alternative medical treatments, although they retained articles on special diets. Application of these criteria resulted in 724 retained papers with 775 total studies. The team then rated each article according to quality of research using a standard six-point rating scale. They rated the treatment effects as beneficial, ineffective, adverse, or unknown. Finally, the team grouped treatments into 38 treatment types and rated the strength of evidence for each treatment type as established, emerging, unestablished, or ineffective/harmful. At each stage, they trained raters using manuals and demonstrated that inter-rater reliability was at least 80 %.

The NAC identified 11 established treatments of which five—antecedent package, behavioral package, comprehensive behavioral treatment for young children, modeling, and self-management—were established treatments for problem behavior. Further, of 22 emerging treatments, only two—imitation training and multicomponent package—were emerging treatments for problem behaviors. Most of the 11 established treatments were effective for increasing skills potentially related to prevention or treatment of crises, such as communication skills, self-regulation, and other alternate behaviors.

The NAC noted that “approximately two-thirds of Established Treatments were developed exclusively from the behavioral literature [and] of the remaining one-third, 75 % represent treatments for which research support comes predominantly from the behavioral literature ...” (p. 52.) notably absent from both established and emerging treatments were cognitive, sensory, dietary, counseling, and psychotherapeutic interventions. The NAC noted several limitations in the literature including smaller numbers of studies with adolescents, the exclusion of studies of adults and children who are *at risk* for ASD, and the exclusion of literature on people with related developmental disabilities. Another limitation was that the treatment categories were relatively broad so that the manner in which they presented the results did not permit conclusions about specific treatment strategies.

Systematic Reviews and Meta-Analyses

Since the publications of Lennox, Miltenberger, Spengler, and Erfanian's (1988) meta-analysis, there have been 20 or more systematic reviews or meta-analyses related to developmental disabilities published, including meta-analyses of intensive early behavioral intervention reporting data on reduction in problem behavior. These articles have varied a great deal in terms of research questions asked, populations studied, definitions of target behavior, and methodological features. For example, some reviews have focused on broad research questions such as "Are psychological interventions effective?," whereas others have asked more focused questions, such as "Is one form of psychological treatment more effective than another?" or "What is the impact of behavior reduction procedures on inclusion?" (Embs, Brown, & Fortain, 2011). Some studies have included a broad range of disabilities and ages (Didden et al., 1997; Scotti et al., 1991), whereas others have focused on specific populations, such as people with mild intellectual disabilities (Didden, Korzilius, van Oorsouw, & Sturmey, 2006) and children with autism (Campbell, 2003; NAC, 2009). Additionally, some have focused on problem behavior broadly defined, including psychiatric disorders (Didden et al., 1997), while others have focused on specific problems, such as SIB (Christiansen, 2005, 2009; Kahng et al., 2002; Sturmey, Maffei-Almodovar, Madzharova, & Cooper, 2012), pica (Hagopian, Rooker, & Rolider, 2011; McAdam, Breidbord, Levine, & Williams, 2012), rumination (Lang et al., 2011), or bruxism (Lang, White, et al., 2009). Some have reviewed many kinds of psychological, behavioral, or pharmacological treatment (Harvey et al., 2009), whereas others have reviewed only one form of treatment, such as multisensory environments (Wai-Chi et al., 2010), active support (Hamelin & Sturmey, 2011) or positive behavioral support (Carr et al., 1999). Finally, these papers have varied widely in terms of methodological features including (a) the type and number of measures of effect size; (b) inclusion or exclusion of nonexperimental studies, such as those using quasi-experimental designs or AB

small studies; (c) the literature search strategies used; (d) inclusion and exclusion criteria; (e) whether the unit of analysis is a published manuscript (which might include more than one experiment), the experiment, or the participant; (f) reporting of reliability of inclusion and coding features; (g) inclusion or exclusion of group or small *N* experiments; (h) inclusion of behavior reduction and/or increases in other relevant behavior, such as replacement behavior or side effects; (i) included or excluded years of publication; (j) the manner in which target behaviors were aggregated; (k) the manner in which individual treatment procedures were coded and aggregated; (l) the use of quality of study measures to include or exclude studies in analyses or sub-analyses; and (o) types of inferential statistics used, if any. A comprehensive and systematic review of all of these is beyond the scope of this chapter; thus, we only highlight certain features of this literature to illustrate some of the more prevalent trends and conclusions.

Four early systematic reviews and meta-analyses related to intellectual disabilities (Lennox et al., 1988; Lundervold & Bourland, 1988; Matson & Taras, 1989; Scotti et al., 1991) were limited by small samples of journals reviewed, limited range of years sampled, limited range of treatments considered, and/or failure to use quantitative methods to synthesize effect sizes. Thus, Didden et al. (1997) addressed these problems by hand searching 30 journals from 1968 to 1994 yielding a database of 482 studies. Their main finding was that approximately 27 % of studies resulted in a PND of greater than 90 % ("quite effective"), 47 % of papers resulted in a PND of 70–90 % ("fairly effective"), 24 % of papers resulted in a PND of 50–70 % ("questionable"), and only 3 % of papers resulted in a PND of less than 50 % ("unreliable"). Most primary treatments were "quite" or "fairly" effective, although some 20 % of treatments were "unreliable." Contingency management procedures were associated with the largest PND, whereas pharmacotherapy was associated with the smallest PND. Finally, treatments based on functional assessments and analyses were associated with larger effect sizes than treatments that did not use a functional

assessment. In response to the possibility that behavioral treatments were ineffective with persons with mild ID and the relatively high proportion of people with severe and profound ID in earlier meta-analyses, Didden et al. (2006) conducted a meta-analysis of 80 studies which provided 133 treatment comparisons using both PND and PZD. The mean PND and PZD were 75 % (0–100 %) and 35 % (range 0–100 %), respectively. Experimental functional analyses produced significantly larger effect sizes (PND=83 %) than descriptive analyses (PND=62 %) and experimental designs, such as reversal designs and multiple baseline designs, produced larger effect sizes than AB designs (PNDs=87 %, 91 %, and 68 %, respectively). The majority of the studies ($N=58$) used differential reinforcement, antecedent control, extinction plus reinforcement, and response cost plus reinforcement. Only five studies utilized anger management.

A different approach to conducting meta-analyses comes from Heyvaert, Maes, and Onghena (2010), who conducted a meta-analysis of group designs of biological, psychotherapeutic, and contextual treatments. They searched four on-line databases and selected 30 of 80 potential articles for meta-analysis. The standardized mean difference was 0.671 ($SD=0.051$). Most RCTs were of atypical antipsychotics, a range of behavioral, cognitive, and other psychological treatments, or contextual interventions, such as evaluations of different service arrangements. No differences between these treatments types were found perhaps because of the relatively small number of studies in each treatment category.

Reflecting the increasing interest in ASD, Campbell (2003) conducted a meta-analysis of small N experimental studies that reduced behavior problems in children and adults with ASD. The authors identified 117 articles with 181 participants from 15 journals published between 1966 and 1998. They calculated mean baseline reduction (MBLR), PND, and PZD for each participant. Overall effect sizes were relatively large with MBLR being 76 % ($SD=29$ %), PND=85 % ($SD=24$ %), and PZD=43 % ($SD=36$ %). Like earlier meta-analyses, Campbell also found that functional analyses and experimental analyses of

behavior were associated with larger increases in effect sizes than other interventions. Thus, behavioral interventions were associated with large effect sizes regardless of treatment type and target behavior. In addition, effect sizes were much larger if experimental functional analyses were conducted.

A small number of studies have reported the effects of PECS and other communication-based interventions on challenging behavior. Two meta-analyses of PECS specifically reported effect sizes for reduction of challenging behavior. Preston and Carter (2009) reported a mean PND of 92.5 % for two small N experiments (PNDs=85 % and 100 % for each experiment), and Hart and Banda (2010) reported that of four participants in three experiments (two of which were included in Preston & Carter, 2009), “PECS was a highly effective intervention for one of four participants, moderately effective for two participants, and minimally effective for one participant” (p. 483). Thus, due to insufficient numbers of participants, PECS only meets the criteria for a “promising” rather than “effective” treatment (Chambless & Hollon, 1998). Recall also that Gantz et al. (2012) reported large effect sizes of PECS, other picture-based interventions, and speech-generating devices on challenging behavior. Future research should focus on increasing the number of participants and topographies while evaluating the effects of FBA on the effectiveness of PECS to reduce challenging behavior and should also focus on the effects of functional assessment on communication-based interventions using non-PECS language-based interventions.

Several systematic reviews have provided descriptions of the treatment literature related to specific research and practice questions without providing quantitative measures of effects size. For example, Snell, Voorhees, and Chen (2005) conducted a systematic review of team involvement in assessment-based interventions with problem behavior in people with an intellectual, emotional, learning, or sensory disability aged less than 21 years published between 1997 and 2002. They searched Eric, Ingenta, and PsychLit, searched the reference lists of relevant literature reviews, and hand searched 22 journals. Inclusion

criteria were that studies had (a) group or small *N* designs (including AB designs); (b) at least one independent variable involving educational behavioral and/or psychological interventions, but not pharmacological interventions alone; and (c) at least one dependent variable that included student inappropriate behavior. After applying inclusion criteria, they identified 111 relevant studies. They found that only half reported increases in replacement behaviors. Most interventions used positive strategies, such as positive reinforcement, antecedent interventions, and skill training. Interventions utilizing parents, peers, and teachers were rare, as were self-management interventions and comprehensive lifestyle outcome measures. Thus, Snell et al. concluded that the majority of studies did not conform to most of the features of PBS. Wood, Blair, and Ferro (2009) reported similar results for the period 1990–2007 adding that most FBAs were conducted in analog rather than naturalistic settings.

This chapter reviewed the evidence for effective psychological and educational interventions for people with developmental disabilities, by reviewing the nature of behavioral crises and the evidence for both prevention and treatment related to behavioral crises. The most promising prevention strategies available according to the current research in this area include activity choice, activity schedules, FCT when combined with extinction, punishment, or both, and instructional fading when combined with either extinction or noncontingent escape. As for treatment, robust evidence was found for the effectiveness of behavioral interventions based on functional assessments and analyses including differential reinforcement, antecedent control, extinction plus reinforcement, and response cost plus reinforcement to address target behaviors directly relevant to crises, including aggression, tantrums, noncompliance, and SIB in people with developmental disabilities.

Conclusions

We can now put witchcraft behind us: Let us proceed with compassion and replace medieval superstitions with evidence from the behavioral

sciences. There is a large psychotherapy outcome literature that we can use to guide professional practices and services that addresses many common problems related to both prevention and treatment of behavioral crises. In order to prevent behavioral crises, we should implement strategies to promote child/client engagement, choice making, FCT, activity schedules, and instructional fading. Some of these treatments may not yet meet the Chambless and Hollon (1998) criteria for “effective” psychotherapy; however, they are the most promising prevention strategies available according to the current research, and at this time, research does not support any alternative approaches. At this time, there is no evidence that sensory treatments, counseling, and psychotherapy are evidence-based treatments. There is no justification for their use at this time: Limited resources would be better invested in strategies that have been shown to work, and the onus is upon those who use these unresearched, ineffective, or possibly harmful practices to demonstrate positively that they are effective in those cases where they implement them.

With respect to treatment, meta-analyses and systematic reviews described here find robust evidence for the effectiveness of behavioral interventions with people with developmental disabilities to address target behaviors that are directly relevant to crises, including aggression, tantrums, noncompliance, and SIB. When meta-analyses have addressed increases in replacement behavior, they also have supported the effectiveness of behavioral approaches. Further, several of these meta-analyses reported that the largest effect sizes were associated with functional assessments and analyses, and in some cases, experimental functional analyses resulted in larger effect sizes than functional assessments. Over time, these papers have documented a shift away from punishment and other contingency approaches to greater use of antecedent-based approaches and complex treatment packages and to a lesser extent a shift toward assessment and treatment in naturalistic settings conducted by caregivers. Some papers indicated that generalization was indeed often addressed. These papers also indicated several important limitations with

behavioral interventions. These include failure to document increases in replacement behavior and maintenance data, reliance on research staff as change agents, reliance on analog settings, and failure to meet all the criteria for positive behavior support. Thus, over the last 50 years, research has shifted away from simple questions that have now been robustly answered—such as whether behavioral approaches can reduce problem behavior—to more complex questions related to broader behavioral change and dissemination from research to applied settings. The potential for such application is illustrated by a recent, well-conducted randomized controlled trial which showed that these strategies can be implemented by community-based behavioral teams for adults in community settings and result in reductions in challenging behavior, as well as cost reductions (Hassiotis et al., 2009). Behavior reductions were maintained at a 2-year follow-up, but cost reductions were not (Hassiotis et al.). Additionally, these reductions did not result in a reduced caregiver burden of care (Hassiotis et al., 2012).

It is notable that several commonly used interventions were absent from this literature. This may have been because there were no studies on these methods or no studies that met inclusion criteria. Thus, although there was limited evidence for the effectiveness of CBT reported in a few studies (Didden et al., 2006), none of the meta-analyses demonstrated that sensory treatments, psychotherapy, or counseling were EBPs for behavioral crises. Similarly, many of the practices that service providers commonly use, such as one-on-one staffing, prn (“as needed”) medication, and staff counseling after behavioral crises, have not been evaluated at this time. Future research should address these as well as formal treatment strategies.

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Empirically Supported Staff Selection, Training, and Management Strategies

5

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Effective delivery of high-quality services to individuals with disabilities depends, in part, on a well-trained workforce of educators, paraprofessionals, clinicians, and other staff. Poor staff training practices and infrequent follow-up contribute to a variety of negative outcomes including compromised rate and quality of staff-consumer interactions (Finn & Sturmey, 2009; Reid, Parsons, Green, & Schepis, 1991; Szczech, 2008), low consumer task engagement (Szczech, 2008), reduced opportunities for choice making (Reid, Green, & Parsons, 2003), decreased teaching opportunities (Schepis, Reid, Ownbey, & Parsons, 2001), low quality of life (Jahr, 1998), and suboptimal treatment integrity (Catania, Almeida, Liu-Constant, & DiGennaro Reed, 2009; DiGennaro Reed, Coddington, Catania, & Maguire, 2010).

Despite a rich literature on evidence-based intervention practices, knowledge about empirically supported treatment does not always translate to effective implementation by the staff delivering services (Jahr, 1998; Parsons, Reid, & Green, 1993; Reid & Green, 1990). The extent to which behavioral interventions are implemented as designed is termed *treatment integrity*

(Gresham, 1989; Yeaton & Sechrest, 1981). Other terms also refer to the same concept including *procedural fidelity*, *implementation integrity*, and *instructional fidelity*. A number of researchers have documented that lack of consumer improvement is related to or directly caused by poor treatment integrity (DiGennaro, Martens, & Kleinmann, 2007; DiGennaro, Martens, & McIntyre, 2005; Northrup, Fisher, Kahng, Harrell, & Kurtz, 1997; Rhymer, Evans-Hampton, McCurdy, & Watson, 2002; Wilder, Atwell, & Wine, 2006). Researchers have also shown greater student learning when staff are adequately trained (e.g., Downs, Downs, & Rau, 2008). DiGennaro Reed, Reed, Baez, and Maguire (2011) showed that errors committed during discrete trial training of three children with autism were directly responsible for the degree of skill acquisition. That is, learning occurred only when integrity errors were not committed. Relatedly, Wilder et al. (2006) discovered that lower levels of treatment integrity resulted in lower preschooler compliance to adult instructions. Studies have also reported significant negative correlations between levels of treatment integrity of function-based behavior support plans and student problem behavior. Across two studies, lower levels of treatment integrity were correlated with higher levels of problem behavior (DiGennaro et al., 2005, 2007).

Consumers' rights to effective behavioral treatment (Van Houten et al., 1988) cannot be protected if treatment is implemented with poor

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integrity or if well-qualified staff are not adequately trained. Effective training practices and ongoing monitoring of staff are critical features of evidence-based practice (Detrich, 2008). As such, preparing staff to interact with and support consumers is a worthwhile expenditure of resources for service-delivery organizations. The purpose of this chapter is to present antecedent- and consequence-based strategies to maximize staff performance including (a) effective personnel selection practices, (b) research-supported practices with respect to initial staff training, (c) ongoing staff management and follow-up techniques, and (d) crisis management preparation.

Overview of Effective Staff Training Practices

Personnel Selection

The acquisition of personnel is vital to any organization's survival. Staff are the means through which organizations deliver services to clients and consumers. The quality of direct care and supervisory staff is a limiting factor for the quality of these services. Thus, it behooves the administration of an organization to adopt the best and most empirically supported practices in the screening and hiring of personnel. Although literature searches of research conducted within applied behavior analysis and organizational behavior management return surprisingly sparse results, the body of literature within business and industrial and organizational psychology (I/O) contains nearly 100 years of research on this subject. It is outside the scope of this chapter to provide a comprehensive review of this literature, so this section will focus on the most recent and relevant research on personnel selection. It is important to note that not all measures are applicable or predictive of performance in all occupations or criteria of performance. As a result, the information we summarize is meant to direct readers to consider possible measures applicable to their own needs.

Predictive Measures of Performance

Work sampling—being the most behavioral and best predictor of future performance—will be discussed first. Although work samples carry a high cost of administration and scoring, they offer promising predictive ability. The assessment of work samples is the practice of directly measuring performance on a criterion. A primary benefit for the use of work sampling is that they offer relatively high predictive validity ratings with correlations ranging from 0.33 (Roth, Bobko, & McFarland, 2005; Schmitt, Gooding, Noe, & Kirsch, 1984) to 0.54 (Hunter & Hunter, 1984).

A study by Campion (1972) provides recommendations for the procedure for constructing a work sample test. First, job experts were asked to list all tasks that are performed during the performance of a specific job. The frequency of each task was also noted. The experts discussed and decided upon the critical dimensions of a job that would differentiate effective performance of the job from ineffective performance. Tasks were selected that would be representative of the tasks required to perform the job and were used as work samples. Finally, a weighted scoring system was developed by specifying the logical methods an applicant could use to perform the task and weighted them according to the judgment of the job experts. The materials present during the work sample were selected such that the opportunity for an unqualified applicant to make errors was maximized.

On a larger scale, this practice is referred to as an Assessment Center (AC) approach. ACs are designed to simulate a work environment for the purposes of assessing applicant performance through a battery of tests and work samples comparable to an internship or tryout in an analogue setting. The general procedure for developing an AC includes a job analysis, representative skill identification, the development of exercises to assess those skills, and training assessors to evaluate applicant performance (Cohen, 1980). Assessment Centers have, however, been the focus of some debate over validity. The skills and dimensions measured in ACs have been predominantly personality and cognitive ability constructs,

which are plagued by issues of validity. It may be that the predictive validity of an AC is related to the relevance and predictive validity of the dimensions assessed.

There is, however, an ethical consideration for the use of work sampling, especially in human service or educational settings. It may be inappropriate to place applicants in a tryout or internship position as a sole means of selection. Organizations could be liable for any errors or inappropriate behaviors exhibited by unqualified applicants during the selection process. It may be more feasible for human service organizations to use analogue scenarios and simulations, such as role-playing or situational judgment tests (SJTs), rather than to allow contact with vulnerable populations prior to training. SJTs are typically series of questions about the action an applicant would take in either job-related or interpersonal scenarios. They are similar to work samples in that they are designed to assess applicant behavior in context, but they rely on self-report rather than direct observation. A benefit to this approach, however, is a significantly lowered cost of administration. SJTs can be developed to fit the organization's specific needs. There are also prepackaged tests that primarily only measure interpersonal skills rather than job-specific skills. An important consideration in selecting a test is its validity in the specific selection context (see Christian, Edwards, and Bradley (2010) for a treatment of the constructs measured by published SJTs).

An overarching theme in this section is the importance of verifying the relevance and applicability of measurement instruments to the specific job and organization when integrating these instruments into a selection system. Research suggests that the use of inappropriate tests during selection may hinder the predictive validity and incremental validity of a selection process. Adverse reactions stemming from a lack of face validity may influence outcomes such as job performance, job satisfaction, and organizational citizenship behavior, although the evidence on these findings is still somewhat sparse (Sackett & Lievens, 2008).

Interview Structure

Another broad category of research on personnel selection practices is structured interviewing. According to Macan (2009), there is much variability in the meaning of this term when researchers describe an interview technique as structured. Some studies make only a dichotomous distinction of either structured or unstructured, whereas others refer to "level" of structure according to nomenclature offered by Huffcutt and Arthur (1994). Other nomenclatures for structured interviewing include situational, behavioral, conventional structured, and structured situational interviews (Macan, 2009).

There appear to be three common dimensions of a structured interview across descriptions in the literature including job-relatedness of the interview, standardization of the questions, and standardization of scoring with the lower "levels" of structure containing a lesser degree of standardization (see Campion, Pursell, and Brown (1988) for a procedure for conducting a highly structured [level 4] interview). The job-relatedness of an interview procedure is accomplished through a job analysis or competency modeling. A job analysis is a survey of the knowledge, skills, abilities, and other characteristics (KSAOs) required to perform a job. Personnel who have performed the job typically are asked to collaborate with managers to develop a list of the KSAOs an applicant should have. More reflective of the changing organizational climate, competency modeling includes a job analysis but also incorporates more future-oriented KSAOs or skills and abilities that will be required as an employee moves through the ranks of an organization and cross-job competencies (see Campion et al. (2011) for a review and discussion of best practices). This may be especially beneficial for human service settings as high turnover or absenteeism may require that staff cover responsibilities outside their own job. Organizations may benefit from hiring personnel capable of performing multiple jobs when needed. Structured interviews also involve the standardization of the questions asked of each applicant. That is, all applicants are asked the same questions, and follow-up questions are

avoided such that each applicant's performance during the interview can be directly compared to others. Each response is also scored according to a preestablished benchmark developed for each question, standardizing each applicant's score for comparison to those of other applicants. There is evidence for the validity of structured interviewing with correlations ranging from 0.34 (Campion et al., 1988) to 0.57 (Huffcutt & Arthur, 1994). For example, Campion et al. (1988) reported that structured interview ratings predicted performance appraisals conducted 6 months after initial hire. There is also evidence of a "ceiling effect" for level of structure. Huffcutt and Arthur (1994) reported that the difference in predictive ability of level 4 and level 3 structured interviews (with level 3 described as allowing variability in questions asked of each applicant but still using preestablished benchmarks for rating responses) was minimal with correlations of 0.57 and 0.56, respectively. This suggests that adding additional structure above a certain point does not add to the effectiveness of an interview procedure.

Conclusion

The goal of this section was to provide a summary of recent research on personnel selection while providing resources for further information. When selecting instruments to include in a selection system, preference should be given to instruments and procedures that have been demonstrated to be effective, especially if evidence has been shown in similar settings or with similar populations to the organization. The use of empirically supported practices is of growing importance with escalating expectations for accountability. The literature has demonstrated that work samples are among the best predictors of job performance and can be developed for any job, while other selection methods have lesser predictive ability or limited generalizability across applicants or contexts. It is also important to consider the costs associated with the development of complex selection systems. One consideration is whether the addition of multiple instruments actually contributes to the predictive validity of the system (i.e., incremental validity).

It may be the case that the addition of another measurement tool does not actually provide any benefit over the system without it. As previously mentioned, considerations of the face validity of the selection system are also important. If a selection system has little perceived relevance to the job for which an applicant is applying, the system may elicit an adverse reaction, which may influence job performance.

The majority of businesses still do not use structured interviews or may use testing batteries that have limited validity (Macan, 2009). One reason, among others, may be that the development of a selection system that is empirically supported is a resource-intensive process. In order to justify such an expense at the front end, organizations should also consider protecting their investment by taking steps to improve personnel retention. One method of improving retention is to improve employee training and support, which will be discussed below.

Initial Staff Training

Even when choosing the most qualified applicants, it is unlikely that new hires will enter an organization with the requisite knowledge necessary for working effectively within the organization and for optimal service delivery. Furthermore, the danger of providing interventions with poor treatment integrity suggests that organizations have a vested ethical interest in ensuring that staff are well trained to implement prescribed behavioral procedures with high integrity (Stein, 1975). A period of front-end (i.e., initial or antecedent-based) staff training is necessary to orient the new hire to the organization and provide them with necessary working skills. While it is beyond the scope of this chapter to provide a meta-analysis or comprehensive review of the vast body of staff training literature, this section attempts to summarize the types of training available. Specifically, the considerations involved in developing staff training, the strengths and weaknesses of the different methods of staff training, and suggestions for making the most of training resources will be described.

Developing Staff Training

Staff training is used to produce a variety of outcomes including, but not limited to, improving reports of staff opinion and perception (Dowey, Toogood, Hastings, & Nash, 2007; Hahn & Cadogan, 2011; Probst & Leppert, 2008), increasing written knowledge of training material (Luiselli, Bass, & Whitcomb, 2010; Luiselli, St. Amand, MaGee, & Sperry, 2008), and improving the skill with which staff use procedures (Lavie & Sturmey, 2002; Moore & Fisher, 2007; Wallace, Doney, Mintz-Resudek, & Tarbox, 2004), implement treatment plans (Burgio, Engel, Hawkins, McCormick, & Jones, 1990), and record data (Kissel, Whitman, & Reid, 1983). The first step in developing staff training is to determine the goal of the training—that is, operationalizing target skills that will be acquired once training is complete (stated simply, identifying what success “looks like” at the conclusion of training). It is worth mentioning that an improvement in one type of outcome may not necessarily translate into improvements in all outcomes. For example, increasing a staff member’s confidence that he or she *can* correctly use a procedure does not mean that the staff member *will* correctly use a procedure. Relatedly, a staff member’s knowledge about what to do in a particular situation does not always translate into effective in vivo implementation. To that end, it is vital that the goal of training is identified before designing the program in order to select the best training methods for the desired outcome.

Training Methods

The aim of much of the applied research in staff training is to maximize staff acquisition of knowledge and/or skill, often as quickly or as efficiently as possible. As a result, researchers typically employ packages and combinations of training methods (Roscoe & Fisher, 2008; Sarokoff & Sturmey, 2004, 2008; Sepler & Myers, 1978). In spite of frequent recommendations for component analysis, few published articles empirically investigate the comparative effectiveness of isolated training methods. Meta-analytic research suggests that training comprised of more than one method/technique may be *more* effective

than a single method in isolation (van Oorsouw, Embregts, Bosman, & Jahoda, 2009). This conclusion is likely influenced by statistical comparisons of research designed as component analysis with research aimed at maximizing staff acquisition of skill and/or knowledge, with the former more likely to have a small effect size than the latter. Nevertheless, it may be wise to combine a variety of the following methods when designing training for staff.

Written and/or Didactic Instruction

The cornerstone of many training programs is some combination of written or didactic (verbal) instruction. This method of training offers many advantages: it is easy to use, relatively inexpensive for the organization, can be easily standardized, and in an era of modern technology, can be implemented remotely with ease in the form of word processing documents, podcasts, or webinars. The effectiveness of written instructions is influenced by a number of staff variables, including skill level prior to training and reading competency. This method of training leads to increases in verbal fluency, but also produces the least robust increase in skillful performance (Fixsen, Naoom, Blase, Friedman, & Wallace, 2005; McClannahan & Krantz, 1993; Moore, Edwards, Sterling-Turner, Riley, Dubard, & McGeorge, 2002; Roscoe, Fisher, Glover, & Volkert, 2006; Sterling-Turner, Watson, & Moore, 2002). For example, in a seminal article comparing training methods, Gardner (1972) found that staff who received traditional lecture (i.e., didactic instruction) were more successful on written tests of knowledge than their peers who participated in role-plays, but were relatively incapable of performing basic behavior analytic procedures consisting of reinforcement and extinction. This method of instruction is also rated less effective and less desirable to staff than other more interactive forms of instruction (Sexton et al., 1996). Training that relies on written or didactic instruction alone is less effective than training that incorporates other empirically supported procedures (Adams, Tallon, & Rimell, 1980; Ducharme & Feldman, 1992). We encourage readers to adopt one or more of the training

procedures described below in lieu of or in combination with written or didactic instruction.

Modeling

Beyond simply describing how to perform a skill as with written or didactic instruction, modeling involves: (a) correct demonstration of the skill by the trainer, and (b) imitation of the modeled skill by the trainee. In vivo modeling can be an effective procedure when adopted as part of a training package (Nigro-Bruzzi & Sturmey, 2010; Sarokoff & Sturmey, 2004); however, a number of considerations must be made. First, research suggests that multiple examples of the model correctly implementing the procedure being trained produce more skillful performance than training with few (Ducharme & Feldman, 1992) or limited (Moore & Fisher, 2007) examples. The quality and consistency of the model may also directly impact the effectiveness of the training, and it may not always be feasible to provide staff with high-quality models. For example, the organization may lack access to a qualified trainer, space for staff training may be limited, or personnel time and financial resources may not be available. In these circumstances, video modeling may be an option worth considering.

Video modeling makes use of technology to create a prerecorded training tool to model skills trainees/staff are expected to imitate and demonstrate in their respective work settings. Advantages include the ability to standardize the training curriculum for staff, a lower probability of inadvertent use of poor or inadequate models that may occur in vivo, and flexible use of self-paced instruction (i.e., trainees may repeatedly watch the video models until they can perform the skill accurately). In addition, disseminating the training materials is relatively easy and may be less expensive than other forms of training for organizations with staff dispersed from one central location. Staff training that incorporates video models has been shown to be effective in a number of studies (e.g., Catania et al., 2009; Lavie & Sturmey, 2002; Moore & Fisher, 2007); however, DiGennaro et al. (2010) documented that, while improvements were noted, trainees prefer a combination of video modeling with performance

feedback over video modeling alone. In addition, performance improvements were greatest when video modeling was combined with feedback.

Role-Play/Rehearsal

Another common training technique is role-playing or behavioral rehearsal. This method involves creating occasions for staff to practice implementation of the learned skills in analogue situations. For example, during training, trainees may be asked to demonstrate how they would use a target skill as if they were in the clinical setting. This method of training is likely made effective by creating opportunities for the trainer to provide constructive feedback to the trainee. This method is rarely used alone and is more often included as an element of a training package (Roscoe & Fisher, 2008; Schepis et al., 2001; Wallace et al., 2004).

Peer Training

A relatively innovative approach to staff training involves the use of trained direct care staff functioning as trainers of their peers. This method, also called train-the-trainer or pyramidal training, has the potential to be incredibly advantageous for organizations in that it is a potentially cost- and resource-efficient method of training. Equipping direct care staff with the skills and resources to train new staff could help alleviate the burden of staff turnover and reduce the costs associated with hiring a credentialed, professional trainer for each new hire. While results indicate that peer training can be effective to increase correct implementation of target staff behavior under experimental conditions (e.g., Finn & Sturmey, 2009), there are drawbacks. First, providing ancillary training to the direct care staff responsible for training is a necessary prerequisite for staff to provide training or feedback to their peers (Parsons & Reid, 1995) and, thus, introduces a significant cost to the organization adopting a train-the-trainer approach (Finn & Sturmey, 2009). Second, although peer trainers indicate acceptability of this approach on surveys, findings indicate that they also decline additional opportunities to train their peers (van den Pol, Reid, & Fuqua, 1983). Other research has shown

that some staff abdicate from participation because the opportunity to provide feedback to their peers is undesirable (Fleming & Sulzer-Azaroff, 1992). There is evidence to suggest that a self-selection bias exists in the peer training literature; thus, this method of staff training should be approached with caution.

Training and Technology

Improvements in modern technology, including the wide dissemination of personal computers and high speed internet, have made the provision of high-quality training easier and more accessible to organizations and their staff. Meta-analytic review of studies comparing computer-based instruction with other teaching and training methods for typically developing adult learners showed that computer-based instruction was as good or better than other instructional formats in 95.2 % of studies (Johnson & Rubin, 2011). Online training modules and courses can be made available to staff or organizations that might not otherwise have access to quality trainers for a small fee. Sailor et al. (1999–2000) describe a number of these online training methods in detail, including Online Academy, an online, interactive, self-paced instructional format.

Job Coaching

While performance feedback will be covered extensively in the following section, it is worth briefly mentioning the role that feedback plays in front-end staff training. Many studies have found that training is more effective when an on-the-job coaching or a performance feedback element is added to the initial training package (Jones et al., 1999; Salmento & Bambara, 2000; van Oorsouw et al., 2009; Wood, Luiselli, & Harchik, 2007). Beyond simply making initial staff training more effective, planning for coaching and support in the working environment may make all the difference in staff using the skills and knowledge they have learned where these skills are needed most—in the service setting.

Evaluating Training

One final consideration we would like to highlight is that behavioral variability is inevitable in

the applied setting. While the training methods described above have been shown to be effective under experimental and applied conditions, we cannot guarantee that these methods will work in *all* situations to teach *all* skills for *all* staff (see Campbell, 2007). Furthermore, skills learned in a training setting may not generalize to the working environment without support (Hall, Grondon, Pope, & Romero, 2010). Administrators should consider evaluation of the training to be part of the training process to promote wise investment and use of limited resources (Quilitch, 1975). Training should not be considered complete until staff can demonstrate mastery of the material as evidenced by correct implementation of procedures or treatment plans across multiple observations (Reid & Parsons, 2002). That is, we encourage trainers to adopt a competency (mastery) criterion based on actual performance rather than performance on written knowledge tests.

Staff Management and Follow-Up Support

Front-end (i.e., antecedent-based) training strategies (e.g., didactic instruction, information, video modeling, role-playing) are common features of programs designed to orient newly hired staff to their jobs and responsibilities (Jahr, 1998). These strategies may also be used to train staff during organizational changes or as part of annual “refresher” training mandated by funding agencies. Providing this form of education and training may be a *necessary* condition for appropriate on-the-job performance; however, research suggests it is not a *sufficient* condition (Reid & Green, 1990). Traditional in-service training (i.e., didactic instruction, provision of information) does not consistently produce high levels of staff performance (e.g., Jahr, 1998; McClannahan & Krantz, 1993; Reid & Parsons, 2002). Other antecedent strategies, such as video modeling, have evidence to suggest initial effectiveness, but long-term maintenance of job skills has not been empirically evaluated. Relatedly, behavioral skills training packages (i.e., modeling, in vivo coaching, and immediate performance feedback)

can produce dramatic staff behavior change initially (Sarokoff & Sturmey, 2004); however, studies have documented performance decrements over time and as early as one session post-training (DiGennaro et al., 2005; 2007). Rather, *ongoing* staff support is commonly required to maintain high levels of performance over time (DiGennaro Reed & Coddling, 2011; Reid & Parsons, 2002). A growing body of literature supports the use of follow-up strategies to improve or maintain employee performance including (1) progress monitoring, (2) performance feedback, (3) programmed reinforcement, (4) directed rehearsal, and (5) participative staff management. In some instances, progressive discipline (i.e., punishment) may be warranted. A brief summary of each of these strategies is offered below. Note, however, that most of these procedures are used as part of a training package with antecedent-based techniques or in combination with other follow-up strategies. For example, Schepis et al. (2001) adopted a packaged training program consisting of classroom-based instruction, role-playing activities, on-the-job training, and on-the-job monitoring and feedback. As a result, we are unable to determine the unique contribution of each procedure on observed outcomes because component analyses were not conducted.

Progress Monitoring

Although the term progress monitoring commonly refers to assessment of *student* progress in order to evaluate effects of instruction (<http://www.studentprogress.org/>), the performance of *staff* should be systematically measured and monitored as well. These data are especially important in the delivery of evidence-based practices and documenting that instructional practices improve the skills of and quality of life for service recipients. In addition, staff performance data will inform supervisors/managers of the need for additional training and other follow-up support activities (offered below). Using task analyses, progress monitoring tools can be individually tailored to specific job responsibilities (e.g., behavioral intervention implementation, appropriate delivery of instruction, data collection practices, timely attendance). Note that

developing an organization-wide system for monitoring staff performance requires leadership commitment—administrators must allocate resources to this important task. Resources are necessary initially to develop progress monitoring tools (e.g., determining which behaviors will be measured and how) and policies and procedures surrounding this activity. Moreover, specific training and follow-up for management/supervisory staff will likely be necessary to ensure the system is implemented as designed (Williams, Di Vittorio, & Hausherr, 2011).

Performance Feedback

Performance feedback is the most commonly used procedure in managing staff (Arco, 2008) and refers to providing information to staff about their previous performance (Wilder, Austin, & Casella, 2009). Note that measuring and monitoring staff behavior is an important prerequisite to delivering effective feedback. A large body of research supports the effectiveness of this staff management procedure. For example, Schepis and Reid (1994) showed that both immediate and delayed (2–7 days) verbal feedback following a brief instructional session were effective in increasing staff interactions with individuals with disabilities. Salmento and Bambara (2000) used a training package consisting of a consultation meeting during which information was provided, in vivo modeling with praise and feedback, and ongoing feedback to increase the number of choices offered to individuals with disabilities by their paid caregivers (i.e., staff). They documented improvements in choice offerings and generalization across staff-consumer dyads and routines. The effects of video feedback (supervisor and staff watch video together) combined with positive feedback for correct behaviors and conversation about appropriate implementation for errors on staff performance during teaching were evaluated in a nonconcurrent multiple baseline design (van Vonderen, de Swart, & Didden, 2010). Results support the effectiveness of this training package.

As noted above, feedback can be delivered in a variety of ways including the following: (a) by a particular source (supervisor, researcher,

self-generated), (b) private delivery versus public posting, (c) about individual versus group performance, (d) against different comparison standards, (e) delivery medium (verbal, written, graphic), and (f) frequency of delivery (Alvero, Bucklin, & Austin, 2001). Alvero et al. reviewed the published literature to identify the most effective and most common aspects of feedback. Interestingly, the most common method (feedback delivered verbally by a supervisor to an individual about individual performance) is not the most effective method. When aggregating their data, they found maximal effectiveness when monthly written, verbal, and graphic feedback about individual and group performance was delivered in both a public and private forum by a supervisor and researcher. Although feedback is highly effective, it can also be intensive with respect to time and labor demands. As a result, organizations may opt to deliver less-intensive forms of feedback such as public posting or written and graphic feedback.

How acceptable is performance feedback to staff receiving this information? In their study of human service personnel, Reid and Parsons (1996) found that staff prefer feedback to a no-feedback condition and immediate feedback is preferred over delayed feedback. A growing body of literature supports these findings; researchers have documented the acceptability of feedback procedures by staff implementing behavioral interventions with individuals with behavior disorders (DiGennaro et al., 2007; DiGennaro Reed et al., 2010), educators implementing token systems in public school classrooms (DiGennaro et al., 2005), prevocational staff (Hrydowy & Martin, 1994), and others (Parsons, 1998).

Programmed Reinforcement

Multiple forms of programmed or engineered reinforcement including delivery of monetary rewards (e.g., Luiselli et al., 2009; Pommer & Streedback, 1974), additional privileges (e.g., a letter of commendation, parking space, free lunch, or an extra work break; Green, Reid, Perkins, & Gardner, 1991), increased vacation days or schedule changes (e.g., Iwata, Bailey, Brown, Foshee, & Alpern, 1976; Reid, Schuh-Wear,

& Brannon, 1978), and other tangible items (e.g., coupons or meals; Reid & Whitman, 1983) have been used to improve staff performance. For example, Luiselli et al. (2009) delivered a financial incentive in combination with public posting (a form of feedback) to reduce staff absences. This incentive involved entering the names of staff into a weekly lottery contingent upon completion of scheduled shifts for their entire duration (i.e., were not absent from work for any portion of their scheduled shifts). Eligible participants had the opportunity to win a weekly monetary reward if they met the experimental criterion. Reid et al. (1978) also used a group contingency to reduce staff absences from a state institution. In their study, the frequency of days off was used as a reinforcer. That is, if staff absences remained below a set criterion, staff were scheduled to receive days off every other weekend. If absences exceeded this criterion, staff resumed their typical schedule consisting of days off every third weekend. Negative reinforcement has also been effectively applied contingent upon satisfactory performance in human service settings in the form of canceling a meeting to role-play poorly implemented intervention steps (e.g., DiGennaro et al., 2005, 2007).

While effective, organizational leaders and administrators may be reluctant to rely on programmed reinforcement given the cumulative costs of delivery over time and across staff. In addition, policies set by unions or labor groups may impede nonuniform delivery of reinforcers or privileges to staff (Reid, Parsons, & Green, 1989; Szczech, 2008). As a result, supervisors and administrators may avail low- or no-cost reinforcers such as verbal praise, public recognition, electronic mail of appreciation, letter of commendation, or others.

Directed Rehearsal

Directed rehearsal consists of a role-play scenario involving repeated practice of intervention steps inconsistently or inaccurately implemented by staff in the work setting. Studies have shown improvements in performance when rehearsal involves as many as ten opportunities for practice (Ward, Johnson, & Konukman, 1998) or as few

as three opportunities (DiGennaro et al., 2005, 2007). An advantage of this procedure is that it provides repeated practice in needed areas (i.e., skills for which staff exhibit poor performance) and also establishes a putative negative reinforcement contingency for high levels of on-the-job performance. That is, staff can avoid directed rehearsal if they meet the expectations of their job. However, to our knowledge, there are no studies that have examined the long-term drawbacks of programmed negative reinforcement contingencies in the workplace. As a result, if directed rehearsal is adopted, we recommend its use with other effective follow-up strategies and encourage close monitoring of staff acceptability of this procedure.

Participative Staff Management

Participative staff management procedures are informed by social learning theory and incorporate a variety of techniques that involve direct care staff in an active role of self-management. The most common techniques include self-recording, goal setting, and self-reinforcement (Burgio, Whitman, & Reid, 1983; Reid et al., 1989). Self-recording involves staff monitoring and graphing their own behavior rather than relying on a supervisor to accomplish these tasks. Goal setting involves comparing present performance against performance goals (Miller & Kelley, 1994). Self-reinforcement involves the staff delivering him- or herself a consequence (i.e., a reinforcer) contingent on a previously identified behavior or performance standard being met (Goldiamond, 1976). The goal of participative staff management procedures is to increase acceptability and ongoing use of these effective procedures.

Progressive Discipline

Occasionally, staff do not respond to training and management techniques described in this chapter and elsewhere and, instead, continue to perform poorly or inconsistently at work. In these instances, staff performance might impede client learning and progress, but it could also jeopardize the welfare and safety of the clients, themselves, or their colleagues. Moreover,

organizations risk these individuals inadvertently serving as models for other employees, which has the potential outcome of creating a negative work culture or workplace. To protect the organization and its employees and clients, policies and procedures that clearly outline the circumstances which lead to progressive discipline and eventual termination are necessary. While we promote reinforcement-based procedures and a focus on training, in some instances, punishment (e.g., discipline techniques or termination) is necessary, particularly when safety is jeopardized.

Summary of Effective Staff Training Practices

A meta-analysis of the most effective components of staff training across 20 years of research conducted by van Oorsouw et al. (2009) yielded interesting findings and has a number of implications in clinical settings. First, in-service (i.e., classroom or workshop) training in isolation was only effective for staff skills or behaviors that did not address teaching or were unrelated to clients receiving services. When training staff to implement procedures that are directly related to the client, their results suggest that the most effective staff training and management procedures consist of in-service training plus coaching on the job. With respect to the important features of in-service training, their findings reveal that multicomponent procedures produce the greatest effect. However, differences among the unique combinations were not found. That is, role-play, instruction, feedback, and self-management were all equally effective when combined with in-service training. Finally, they found that on-the-job coaching was most effective when combined with verbal feedback consisting of praise and correction.

Weinkauff, Zeug, Anderson, and Ala'i-Rosales (2011) evaluated the effectiveness, desirability, and time to mastery of a comprehensive training program designed to teach staff 125 skills informed by guidelines developed by the Autism Special Interest Group of the Association for Behavior Analysis International and the Behavior

Analyst Certification Board Guidelines for Responsible Conduct. Training consisted of a combination of antecedent and consequent strategies including verbal description, written information, modeling, repeated practice, and feedback (praise and correction). Staff were introduced to skill clusters in a graduated fashion until all of the complex skills were addressed. Results suggest that the program was effective, highly desired by staff, and reasonably efficient (requiring between 20 and 32.5 h to mastery across participants).

The findings of Weinkauff et al. (2011) and van Oorsouw et al. (2009) are consistent with the large body of literature evaluating staff training and support our previous recommendation that trainers should develop training procedures that relate to training goals and consider techniques, such as those described in this chapter, to maximize effectiveness of training. Of course, selecting appropriate staff given the employment setting, client needs, job responsibilities, and supervisory oversight is an important consideration and activity in preparing a well-trained workforce. Even the best training program might be unsuccessful if inappropriate candidates are selected for a job.

Crisis Management Preparation

A well-trained workforce may contribute to *preventing* behavioral crises. For example, staff who implement teaching procedures, behavior intervention plans, and consumer schedules appropriately and consistently may experience less consumer problem behavior (e.g., Dib & Sturmey, 2007; DiGennaro et al., 2005, 2007; Schepis, Ownbey, Parsons, & Reid, 2000; Wilder et al., 2006). Of course, this outcome rests on the premise that the teaching procedures and behavior interventions are linked to adequate assessments and are well designed. Depending on the nature of the consumers receiving services, initial staff training might include formal instruction in appropriate use of therapeutic holds (see Chap. 7 of this handbook for more information). Note that states often have preapproved training programs and require organizations to select

from among these when training and certifying their staff.

Behavioral crises may still arise despite effective training and high levels of treatment integrity. Organizations (i.e., supervisors, managers, behavior analysts) must be prepared to provide additional training to prepare staff for any changes to behavioral procedures as a result of the crisis and be prepared to monitor staff and consumers to ensure appropriate implementation of crisis management techniques. In our experience, on-the-job coaching and feedback in these circumstances can prevent injuries, reduce staff turnover, and minimize further behavioral escalation. Supervisor presence throughout the work day is a critical component of effective staff management procedures (Daniels & Daniels, 2006), especially during a behavioral crisis. As described previously, we encourage a competency-based approach informed by direct observation and performance measures for all training topics (e.g., Reid & Parsons, 2002), particularly for those provided to teach staff how to prevent and respond to behavioral crises.

Conclusion

This chapter provides a summary of relevant research and additional resources regarding personnel recruitment strategies, empirically supported staff training procedures, and research-based staff management techniques. Collectively, these procedures have been shown to be effective across numerous environments and service-delivery settings (e.g., home-based programs, public and private school settings, residential programs, hospitals). Readers are encouraged to adopt multiple techniques when designing training and management systems based on the goals of the program. Moreover, identifying effective monitoring and follow-up strategies that can be feasibly implemented within the present work environment will contribute toward long-term staff development and performance. Despite these wonderful techniques, recruiting and identifying appropriate personnel at the outset is a worthwhile use of resources initially to save time, money, and resources in the long term.

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The Use of Protective Equipment in the Management of Severe Behavior Disorders

6

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What do a roller-coaster harness, boxing gloves, a parachute, and a football helmet all have in common? They are all forms of protective equipment or restraints that allow individuals to safely engage in responses that would otherwise be quite dangerous. For example, a parachute allows a person to jump out of a plane flying 10,000 ft above the earth and, in almost all cases, reach the ground safely. In fact, Captain Joe Kittenger jumped from a gondola that was 102,800 ft (19.5 miles) above the earth and lived to tell about it. This amazing feat illustrates the extent to which protective equipment can reduce the health risks associated with dangerous or risky behavior.

Individuals with autism or other developmental disabilities sometimes display response topographies (e.g., pica, self-injurious behavior [SIB], aggression) that pose a significant danger to self or others. One approach for managing destructive behavior is to apply protective equipment that mitigates or prevents the harm caused by such

behavior. In our field, protective equipment is a term that is generally used to label devices or specialized clothing that is either added to the environment (e.g., padded walls) or worn by an individual (e.g., a padded helmet) in order to lessen the health and safety risks associated with destructive behavior. Common forms of protective equipment include padded helmets worn by individuals who engage in head banging; padded arm guards for therapists, teachers, or parents who are targeted by an aggressive individual; and special locks or alarms used to prevent elopement or wandering.

Often, the first step in determining whether protective equipment is necessary is to conduct a risk assessment to help ascertain the cost-benefit ratio associated with one or more types of protective equipment. A second important consideration for clinicians who prescribe and apply protective equipment is understanding and adhering to the rules and regulations governing such devices. A third important step that clinicians who recommend and manage protective equipment should take is developing a working knowledge of the various types of protective equipment and their potential for mitigating the health risks associated with destructive behavior. In the remainder of this chapter, we will discuss these three important considerations (i.e., risk assessment, rules and regulations, and types of protective equipment). We will also discuss how protective equipment can be used and managed during a functional analysis of destructive behavior in order to strike a reasonable balance between accuracy and safety

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(i.e., obtaining accurate assessment results while minimizing the health risks associated with exposing the client and staff to the antecedents and consequences that are likely to evoke and reinforce potentially destructive behavior). Finally, we will discuss ways in which protective equipment can be used as an active component of a behavioral intervention; that is, we will discuss how various forms of protective equipment can be systematically applied and removed to both reduce destructive behavior and decrease how frequently or for how long the client wears the protective equipment.

Assessing the Potential Risks and Benefits of Protective Equipment

When a client presents with behavior that poses a significant risk to self or others, one potential approach the clinician may consider for decreasing that risk involves applying protective equipment. Before applying one or more forms of protective equipment, the clinician should conduct a risk assessment to determine the cost-benefit ratio associated with one or more types of protective equipment. Although protective equipment often can be financially expensive, generally, the more important costs associated with such devices are the extent to which the equipment interferes with the individual's movement, socialization, and functionality.

It is common for individuals with severe SIB to come to the professional already wearing one or more forms of makeshift protective devices. For example, we once conducted an evaluation of a young girl who entered our clinic with her hands tied behind her back and her legs tied together with ropes, such that she entered the clinic by hopping. Despite wearing these devices, this young girl had multiple skin lesions and open wounds that were produced by her SIB, some of which were infected and required immediate medical attention and intervention. With such severe cases, little clinical experience or judgment is required to ascertain that protective equipment is needed. However, in this case the ropes were markedly interfering with her movement, socialization, and functionality without

providing much protection from the SIB. Thus, although protective equipment was obviously needed in this case, the cost-benefit analysis did not warrant continued use of the ropes as the correct form of protective equipment. Moreover, some forms of restraint may be ethically contraindicated, independent of the devices' effectiveness at reducing the health risks associated with severe destructive behavior.

Most cases are not as clear-cut as the above example, and clinicians often need guidance in determining whether protective equipment is warranted and, if so, what type of equipment would provide the optimal cost-benefit ratio. One tool that can assist clinicians assessing the need for protective equipment for clients who display severe SIB is called the Self-Injury Trauma (SIT) Scale (Iwata, Pace, Kissel, Nau, & Farber, 1990). The SIT Scale is a direct observation measure that quantifies and classifies topographies of SIB (e.g., air swallowing, eye gouging, forceful contact with the head/face) and types (abrasions, lacerations, contusions) and locations (left eye, nose, wrist) of tissue damage produced by the SIB. Each area of the body is scored for the number of wounds at the location and the severity of those wounds, with severity scored on a 3-point scale (e.g., reddened skin = 1, skin break with no damage to the underlying tissue = 2, skin break with damage to the underlying tissue = 3). After the individual locations are scored, these scores are combined to produce summation scores in three areas: (a) number of topographies (on a 5-point scale), (b) severity index (on a 5-point scale), and (c) overall risk estimate (on a 3-point scale).

Strengths or advantages of the SIT Scale are that it has high interobserver agreement and clear face validity. In addition, the results are fairly easy to interpret with respect to the need for protective equipment in that individuals who receive an overall risk estimate of 1 would generally not require protective equipment, those receiving a 3 would probably benefit from some form of protective equipment, and those receiving a 2 may benefit from protective equipment, but other information would need to be taken into consideration (e.g., medical history of repeated injuries). The main limitations of the SIT Scale are

that it is fairly time-consuming, it is not applicable to other destructive behavior (e.g., aggression, elopement), and it is not clear that the risk estimates produced by the SIT Scale are different from what might result from a less time-consuming and less formal evaluation.

Unfortunately, few efficient and valid alternatives to the SIT Scale are available. Most behavior rating scales do not measure severity of health risks to self and others and, therefore, are not very relevant to determining the need for protective equipment. For example, rating scales such as the Aberrant Behavior Checklist (Aman, Singh, Stewart, & Field, 1985), the Behavior Problem Inventory (Rojahn, Matson, Lott, Esbensen, & Smalls, 2001), and the Repetitive Behavior Scale-Revised (Bodfish, Symons, Parker, & Lewis, 2000) are useful for certain purposes (e.g., evaluating pharmacological interventions); however, they are not helpful in determining the need for protective equipment because the severity scales for these instruments typically use relative ratings (e.g., “not a problem” to “severe problem”) that are not tied to actual injuries or health risks. There are other rating scales that were designed to measure SIT in adult psychiatric populations (e.g., borderline personality disorder); however, these rating scales would not be appropriate for individuals with developmental disabilities (for a review of these instruments, see Craigen, Healey, Walley, Byrd, & Schuster, 2010).

We have developed an informal rating scale, similar to the SIT Scale, that is directly tied to health and injury risks. The rating scale also covers dangerous or destructive behavior that poses a risk to self (risky behavior, pica, and self-injury), others (aggression), or the environment (property destruction). Like the SIT Scale, this scale has relatively clear face validity for determining the need for protective equipment; however, its reliability has not been established, and we have not developed an overall risk estimate. Nevertheless, this assessment might be useful for clinician’s who are unable to administer the SIT Scale to their clients with SIB (e.g., due to time constraints) or for use with clients who display other forms of destructive behavior (e.g., aggression). Our Destructive Behavior Severity Scale is not

copyrighted, and thus, other clinicians are free to use it in their practices, as long as they cite this chapter and acknowledge that the scale was developed in our program (see “Appendix”).

Although the SIT Scale and the Destructive Behavior Severity Scale may be useful for assessing the severity of destructive behavior relative to the need for protective equipment, they should not be the sole source of information on which the decision to apply protective equipment is made. In most cases, the behavior analyst should be working in conjunction with a physician, physician’s assistant, or a nurse when assessing, prescribing, and managing protective equipment. In most states, protective equipment that restricts an individual’s movement (e.g., arm splints) requires a prescription from a physician prior to its application (see the section on regulations below).

The role of the medical or nursing staff is typically to identify the medical risks associated with the application of protective equipment. For example, it is common for arm splints to cause minor heat or sweat rashes, especially in the summer. Periodic monitoring by medical and/or nursing staff can provide guidance about whether modifications are needed to the splints (e.g., air holes) or to the schedule of equipment removal (e.g., splints are typically removed for 10 min every 2 h, but more frequent removal may be required if a skin rash is observed).

Other forms of monitoring may be useful when patients with severe SIB have been prescribed protective equipment, but they continue to show new skin wounds or lesions and it is not clear why. In such cases, it is possible that the equipment is not providing enough protection (e.g., the individual finds a way to engage in SIB, perhaps at night or at other times when the individual is not directly monitored). Alternatively, it is possible that the equipment is not being applied as prescribed in certain settings (e.g., a parent or teacher removes the equipment when the individual is displaying infrequent or mild forms of SIB and replaces it only after the SIB has become much more severe). In these cases, we often take photos of the individual’s wounds and lesions at the beginning and at the end of our appointments with the client to ascertain whether the equipment

is providing adequate protection to the individual when they have been applied and used as prescribed. We may also ask the parents and school personnel to similarly document the status of wounds and lesions to help determine when and where the ongoing tissue damage is occurring.

Rules and Regulations Governing the Use of Protective Equipment

Restraint (chemical or mechanical) and/or *seclusion* are typically used as either a preventative measure to avoid harm or injury to self or others or as a consequence for destructive behavior (i.e., punishment). The primary purposes of using restraint or seclusion are to establish and maintain the safety of the individual and others in the vicinity and to affect the future probability of the occurrence of the destructive behavior. Restraint and seclusion are often effective at reducing the probability of injury during the period of time that the individual is restrained or secluded. However, questions remain about the efficacy of restraint or seclusion as a long-term treatment option. Furthermore, federal and state laws limit restraint and seclusion for individuals with developmental disabilities, and several organizations have developed policies that must be considered when using restraint or seclusion.

Federal and State Law

To date, restraint and seclusion in education settings are not specifically addressed in federal law (Government Accountability Office (GAO), Report on Seclusions and Restraints: *Seclusions And Restraints: Selected Cases of Death and Abuse at Public and Private Schools and Treatment Centers*, 2009). Specifically, GAO determined that there were no existing federal laws governing the use of seclusion and restraints in public and private schools, and state laws and policies vary greatly across states. There are several other laws, though, that address restraint and seclusion in particular circumstances. For instance, the Children's Health Act of 2000 specifies conditions for the use

of restraint and seclusion with patients in certain hospitals and health-care facilities that receive federal funds. There are also rules for applying restraint and seclusion with children in certain residential, nonmedical, and community-based facilities that are funded through the Public Health Service Act. Finally, there are additional regulations for restraint and seclusion with patients of hospitals that receive funding from the Medicare and Medicaid programs.

The Individuals with Disabilities Education Act (IDEA) specifically addresses children with disabilities. IDEA requires that eligible students are educated in the least restrictive environment and that special education students have an individualized education program (IEP). The IEP is a written document that includes detailed information about all interventions, including the use of restraint and seclusion. Finally, the *Keeping All Students Safe Act* proposes federal regulations for restraint and seclusion in elementary and secondary schools. Federal oversight of restraint and seclusion would provide a standard policy for all schools and, thus, minimize or eliminate across-state variation.

With lack of specific federal oversight, the United States Department of Education compiled a summary of restraint laws and policies and published the information in one comprehensive file entitled, "Summary of seclusion and restraint statutes, regulation, policies and guidance, by state and territory: Information as reported to the regional comprehensive centers and gathered from other sources" (www.ed.gov/policy/seclusion/seclusion-state-summary.html). Arne Duncan, Secretary of Education, initiated research on each state's laws, regulations, guidance, and policies on the use of restraint and seclusion in schools. In December 2009, each state was asked to review and confirm the accuracy of the summary and the information for their specific state and to edit the information accordingly. The report is updated as states develop new policies and guidelines or change existing policies on the use of restraint and seclusion. Until federal law provides specific guidance on the use of restraint and seclusion, this document provides direction for their use within specific geographic locations.

Professional Practice and Association Policy Statements

The Association for Behavior Analysis International (ABAI) and the Association of Professional Behavior Analysts (APBA) have both adopted policies about the use of restraint and seclusion. There is significant overlap between the policy statements of the organizations. For example, both recognize that violations of legal, ethical, and professional practice guidelines are possible with the use of restraint and seclusion, especially when restraint or seclusion is used with a vulnerable population. Both policy statements acknowledge, though, that there are times when restraint or seclusion is necessary within the context of a carefully constructed treatment package for destructive behavior. Below, we summarize some of the essential guiding principles and concerns of the policy statements.

Conditions Under Which Restraint or Seclusion or Both May Be Acceptable

Despite voluminous evidence of the efficacy of reinforcement-based treatments, destructive behavior may remain resistant to treatment. Resistance to treatment may take several forms. For example, the rates of destructive behavior may be reduced relative to an established baseline, but the reduction may not be enough to be deemed socially acceptable. Alternatively, the topography of a response may be so dangerous (e.g., eye poking, severe aggression) that any occurrence of the behavior may be intolerable. In any case, both ABAI and APBA state that the use of restraint or seclusion may be acceptable and important. Both organizations also state that specific safeguards should be put in place when restraint or seclusion is used as a part of a treatment package.

Restraint may be in the best interest of an individual when it is an essential component of an effective treatment. The APBA policy emphasizes that essential safeguards, consent, professionally developed protocols, the proper oversight by qualified individuals, ongoing staff training, and accountability are all features of the ethical

and responsible use of restraint or seclusion. In fact, the use of restraint or seclusion, when used in this context, may represent best practice, and denying access to an effective treatment may represent violations of the right to a safe and effective treatment and the right to make their own treatment decisions (Van Houten et al., 1988). Finally, the principle of least restrictiveness may actually include the use of restraint or seclusion. Other treatments may be less effective at preventing serious destructive behavior from occurring, which increases the risk of serious injury to the individual or others.

The ABAI policy statement provides professionals with a specific point-by-point guide for determining the appropriateness of the use of restraint or seclusion. The three *guiding principles* provide professionals with the conceptual basis for having restraint or seclusion in a behavior intervention plan. For example, the welfare of the individual is of the highest priority, and restraint or seclusion must be among the options considered to attain that goal. Individuals have a right to choose, and it is possible that individuals, parents, or caregivers may prefer and choose restraint or seclusion over other available treatment options. Finally, as stated above, the principle of least restrictiveness may help guide practitioners' decisions on the relative intrusiveness of available treatment options.

Potential Uses of Restraint or Seclusion

The policies of both ABAI and APBA emphasize that restraint or seclusion may be part of a comprehensive treatment. It is important to note that both policies state that restraint or seclusion should not be used in isolation. There are three general categories of use for restraint or seclusion. First, restraint or seclusion may be part of a comprehensive behavioral treatment. Second, restraint or seclusion may be used as a form of timeout from reinforcement. The purpose of using restraint or seclusion in this manner is to reduce the future probability of responding. Finally, restraint or seclusion may be used as an emergency procedure for ensuring the immediate safety of the individual and others in close proximity. The ABAI policy statement provides very

specific conditions under which each of the above categories should be considered and implemented if a behavior intervention team decides that restraint or seclusion should be a part of treatment.

Accreditation Agencies

Accreditation agencies typically develop standards by which programs must abide to maintain standing within those agencies. Concerning restraint and seclusion, two well-known accreditation agencies relevant to individuals with developmental disabilities regarding restraint and seclusion are *The Joint Commission* (TJC; formerly the *Joint Commission on Accreditation of Healthcare Organizations*, or JCAHO) and the *Commission on Accreditation of Rehabilitation Facilities* (CARF).

The standards developed by TJC and CARF are, in principle, similar to each other, are consistent with federal law on restraint and seclusion, and reflect (to some degree) the guiding principles of ABAI's and APBA's policy statements. That is, the standards reflect the ethical and legal use of restraint or seclusion, the limits that are applied to their use, the conditions under which restraint and seclusion may be used, and the procedures that should be put in place to ensure safety and monitoring. As you will see, the standards developed by TJC and CARF specifically address the use of restraint and seclusion in enough detail to guide their use as a part of an individualized behavior plan. Clinicians may wish to review these standards when developing a behavioral treatment that includes restraint or seclusion.

Side Effects of Protective Equipment

Despite the advantages of protective equipment for maintaining the safety of individuals who engage in serious destructive behavior, wearing protective equipment has several disadvantages. First, protective equipment may be a form of restraint if the protective equipment limits a person's movement. Practitioners may also encounter difficulty removing protective equipment after

it has been used to maintain an individual's safety. Below we discuss some of the potential difficulties with the use of protective equipment.

Jones, Allen, Moore, Phillips, and Lowe (2007) reviewed the types, prevalence, and main and side effects of restraint with individuals who engage in SIB. Jones et al. proposed a continuum of management strategies that they described as least to most restrictive. The three most restrictive types of strategies involved minimizing the capacity of an individual to physically move in such a way that they were less capable of producing harm. Those strategies consisted of physical or personal restraint, protective devices that prevented or reduced injury (but did not produce restraint per se), and appliances whose application mechanically restrained individuals' ability to engage in the harmful behavior. Jones et al. concluded that although protective equipment and restraint may be successful for decreasing injury, there are several side effects that warrant attention when considering their use.

Long-term use of protective equipment, for example, may protect an individual from the effects of the serious destructive behavior, but may also be associated with common medical concerns, including the potential for bone demineralization, shortening of tendons, and hindered motor development due to limited use of limbs (Fisher, Piazza, Bowman, Hanley, & Adelinis, 1997; Lovaas & Simmons, 1969). There are also several studies that provide evidence of the potential problems that may arise, even with the short-term use of protective equipment. First, self-restraint may emerge subsequent to treatment involving the use of protective equipment or restraint (Powers, Roane, & Kelley, 2007). This is a common concern of practitioners when using protective equipment such as helmets. That is, wearing a helmet may decrease the potential for self-infliction of serious harm, but the function of the use of the protective equipment may change over time. Powers et al. used protective equipment in the form of arm splints to reduce severe SIB and self-restraint emerged as rates of SIB decreased. Noncontingent access to preferred stimuli reduced levels of self-restraint while maintaining low levels of SIB.

Second, access to restraint (i.e., using the protective equipment to restrict movement) may function as positive reinforcement for engaging in destructive behavior (e.g., Favell, McGimsey, & Jones, 1978; Smith, Lerman, & Iwata, 1996). That is, caregivers may use protective equipment to establish and maintain the safety of the individual during times when destructive behavior is either occurring or likely to occur. Then, once the caregivers attempt to remove the protective equipment, the individual may display destructive behavior to regain access to the protective equipment. Unfortunately, this outcome may be a difficult cycle to break because withholding the restraint device may result in tissue damage due to SIB, whereas delivering the restraint device may reinforce SIB (e.g., Rooker & Roscoe, 2005; Vollmer & Vorndran, 1998). To illustrate, Vollmer and Vorndran conducted a functional analysis of SIB that suggested that SIB was maintained by access to restraint materials (a leather jacket). In the treatment analysis, the individual was taught a functional communication response that produced access to an alternative preferred item (a cardigan sweater), which reduced SIB to near-zero levels. Vollmer and Vorndran demonstrated that it is possible to find alternative stimuli (rather than restraint materials) that both compete with SIB and minimize the likelihood of restraint.

Types of Protective Equipment for Clients and Clinicians

Equipment for Protecting Clients

During the assessment and treatment of destructive behavior, the use of a variety of equipment with a client may be needed in order to prevent or decrease physical damage produced by destructive behavior. In this section, we describe several types of protective equipment that are organized according to categories of destructive behavior, including elopement, property destruction, and topographies of SIB. The protective equipment described below involve gear commonly used in mixed martial arts (e.g., Macho Martial Arts®, Century Martial Arts®) and in athletics such as

hockey, soccer, football, and lacrosse. In addition, possible protective equipment can be identified by visiting a local department store that sells mixed martial arts and sports gear.

Equipment for Elopement

When a client leaves the proximity of a supervising adult (i.e., beyond arm length) or a designated location (e.g., house, school), life-threatening consequences may occur such as touching, eating, or drinking poisonous or dangerous items and entering dangerous situations (e.g., running into a street). Several antecedent tactics that may be employed include installing locks on the top of exit doors and door alarms as well as embedding location-aware systems on the client's clothing (e.g., global positioning system, radio frequency identification). Consideration of each option should be based on both the frequency of elopement and the level of danger it causes. Using more restrictive protective equipment (e.g., an elastic harness) may be warranted if the behavior poses a clear and serious health risk.

Equipment for Property Destruction

Topographies of property destruction that may warrant protective equipment are banging, kicking, overturning, or defacing objects (e.g., academic materials, tables, walls, and chairs). One relatively common form of property destruction is denting or creating holes in drywall. When this occurs, Acrovyn® wall panels (pictured in Fig. 6.1c) can provide a durable barrier that often prevents wall damage. For destructive behavior directed at windows, Plexiglas decreases the likelihood of glass shattering from a client banging on or throwing objects at windows. Foam mats that are 1–2 in. thick can be placed between the limbs of a client and objects in a room as a barrier to protect both the client and the environment. For organizations that regularly provide assessment and treatment services for clients who engage in destructive behavior, padding the floors and walls of a designated room with covered foam as pictured in Fig. 6.1a should be considered. Installing padding in a commode (Fig. 6.1b) may also prevent damage to the client and property (e.g., from head banging).



Fig. 6.1 Acrovyn® wall panels covering the wall in a hallway are shown in picture (a). A room with a padded floor and walls with a one-way mirror for observation is shown in picture (b). A padded commode is shown in picture (c)

Equipment for SIB

Preventing or minimizing physical damage produced by topographies of SIB is presumably one of the most common reasons for using protective equipment. Below are topographies of SIB that were described in Iwata et al.'s (1990) SIT Scale; corresponding types of protective equipment are depicted in Fig. 6.2.

Head hitting or banging. Forceful contact of a client's hand or arm to his or her head can cause injury. A thick foam helmet with ear protection and a chin strap, as depicted in Fig. 6.2a₁, may protect a client's head from injury. Having a client wear a cloth guard that covers the outside of their forearm and hand with padding may provide additional protection (c₂). When forceful contact is directed toward the face, adding a plastic face shield to the foam helmet described above (a₂ and a₃) may be an option; padded gloves also may be necessary to decrease the likelihood of injury produced by the client's digits contacting the plastic face shield (e₁ and e₂). A foam or hard plastic helmet would also decrease the likelihood of damage

from head banging; when possible, staff should also place a mat between the client's helmet and targeted objects (e.g., wall, furniture, or floor).

Eye gouging. SIB in the form of fingers contacting the skin within the orbit of an eye or inserting fingers into the eye socket can cause irreparable damage. Helmets with only partial face shields are inadequate for protecting a client with this topography. Attaching a fullface shield to a hard plastic hockey helmet (a₄), however, prevents direct finger-to-eye contact.

Biting arm or hand. A helmet with a partial face shield may also prevent mouth-to-skin contact (a₂). The use of arm (c₁ or c₂) and hand (e₁ or e₂) guards also should be considered.

Assessing Whether Selected Equipment Will Sufficiently Protect a Client

Although we suggest forms of equipment that may be effective at protecting a client, it is also typically helpful to empirically assess the effectiveness of the equipment under controlled analogue



Fig. 6.2 Types of protective equipment for the head, chest, arms, hands, knees, and skin are shown in pictures (a) through (g). A person wearing several pieces of protective equipment is shown in picture (h)

conditions. With this type of assessment, the client should wear the selected protective equipment under conditions that have historically evoked SIB (e.g., demands, low attention) for relatively short sessions (e.g., 10 min). Data should be collected on the frequency and severity of SIB and on any injuries produced by SIB or from wearing the protective equipment (e.g., chin strap on helmet inadvertently chafes or scratches throat or chin). For example, adequate protective equipment for hand-to-head SIB may include a helmet and hand guards that cannot be easily removed by the client, protect the head from any

direct contact with a hand, and protect the hand from injury that may result from hitting the hard plastic of the helmet. When this type of assessment is conducted with target responses that may produce irreparable damage (e.g., eye gouging), a therapist should be present and block actual contact with the targeted body part.

Equipment for Protecting Staff

Staff members may be at risk for physical injuries when they work with a client who displays intense

aggressive behavior or when they attempt to block a client's severe SIB (Urban, Luiselli, Child, & Parenteau, 2011). In such cases, it may be prudent to have the staff members wear protective equipment. In Fig. 6.2h, an adult is wearing a foam helmet with a partial face shield (similar to (a₂)), a chest and shoulder pad (b₁), arm and hand foam pads (c₁), knee pads (f₁), and shin guards (g₁) while holding a foam body shield (d₁). With this set of protective equipment (or other types such as (b₂), (c₂), (f₂), (g₂), and (d₂)), a staff member's limbs, joints, and head are covered by foam or hard plastic, which may help prevent physical injuries. However, it is important to understand that staff-worn protective equipment could occasion aggression toward unprotected body parts or more intense aggression toward the actual protective equipment (Urban et al.).

Equipment for Protecting Clients and Staff During Vehicle Transportation

A client engaging in destructive behavior in a moving vehicle could cause serious injury to all passengers by distracting the driver or interrupting the driver's control of the vehicle. Installing a vest with chest, waist, shoulder, and crotch straps that is mounted to the floor, seat, or both may maintain the safety of a client and a driver. A company named E-Z-ON[®] manufactures vests with these features specifically for safely transporting clients who exhibit destructive behavior. Accessories that allow tethering of a client's legs or arms are also available.

Use of Protective Equipment During Functional Analyses

The aim of a functional analysis is to identify variables that maintain destructive behavior. To do so, destructive behavior must be allowed to occur such that levels of responding can be compared across test and control conditions. The risks associated with SIB make the use of protective equipment during a functional analysis appealing. As long as the device does not prevent

the occurrence of the destructive behavior, then its use during a functional analysis may reduce the risk of injury while allowing for an analysis of the operant function of destructive behavior.

Protective Equipment May Mask an Automatic Function

Despite the potential advantages of using protective equipment during functional analyses, several studies have shown that protective equipment may interfere with functional analysis outcomes (e.g., Borrero, Vollmer, Wright, Lerman, & Kelley, 2002; Le & Smith, 2002; Moore, Fisher, & Pennington, 2004). For example, Borrero et al. conducted functional analyses with and without protective equipment with two individuals diagnosed with moderate or profound mental retardation. The protective equipment was a helmet for the participant who engaged in head hitting and head banging and gauze plus a baseball cap for the participant who engaged in trichotillomania (attempts to engage in the target destructive behavior when the protective equipment was on were scored as SIB). When protective equipment was worn throughout session (i.e., noncontingently), zero or near-zero levels of SIB occurred across all conditions of the functional analysis. It was only during the functional analysis without protective equipment that the function of self-injury, automatic reinforcement, was identified. Similar results were obtained by Moore et al. in their comparison of functional analysis outcomes with and without protective equipment for a girl diagnosed with autism who engaged in SIB. Together, these studies suggest that the noncontingent application of protective equipment across all functional analysis conditions may suppress levels of destructive behavior, making it difficult (or impossible) to identify an operant function.

Protective equipment is most likely to obscure functional analysis results when destructive behavior is maintained by automatic reinforcement. That is, protective equipment may function as extinction if it eliminates or attenuates the automatic reinforcement produced by engaging in the destructive behavior (Iwata, Pace, Cowdery,

& Miltenberger, 1994). For example, if hand mouthing is maintained by the soothing feeling it produces, then gloves may reduce the quality of reinforcement such that mouthing one's hand is no longer reinforcing. If gloves are worn across all conditions of a functional analysis, then the likelihood of observing hand mouthing, and thereby identifying the function of this behavior, is greatly reduced.

Because the function of behavior is unknown until a functional analysis can be conducted, a discussion of the factors that should influence the decision to use protective equipment in a functional analysis is warranted. Prior to beginning a functional analysis, it is important to assess the immediate and prolonged risks associated with destructive behavior. If the risks of physical injury are no greater than that which occurs in their natural environment (e.g., minor reddening of the skin or swelling that resolves overnight), are not permanent, and require only routine care (e.g., applying an ice pack), then one should consider conducting a functional analysis without protective equipment, provided that proper oversight and precautionary measures are in place. For example, in their seminal study on the functional analysis of self-injury, Iwata, Dorsey, Slifer, Bauman, and Richman (1994) described a set of precautionary measures consisting of routine checks and individualized criteria for terminating session contingent on the degree of injury or level of responding.

If there are irreversible effects that can occur from one instance of destructive behavior (e.g., permanent blindness from one intense blow to the eye), then protective equipment during a functional analysis is likely to be essential to maintaining the safety of the individual. In such cases, protective equipment may be applied only to those parts of the body that are at risk of permanent damage. Doing so allows for a functional analysis of other topographies of destructive behavior. Moore et al. (2004) conducted a component analysis in which foam padding or boxing gloves were systematically applied to and removed from various parts of the body during an alone condition in order to conduct a more fine-grained analysis of multiple topographies of SIB. SIB

was grouped into four categories based on the part of the body affected by self-injury: head, shoulder, hand, and leg. Due to the risk of blindness associated with head SIB, a helmet with a plastic face shield and rigid arm sleeves (used to prevent hand-to-head SIB) were worn throughout all sessions. An increase in SIB occurred only in those conditions in which padding was not worn and only for those topographies that were not padded (e.g., hand SIB increased only in the condition in which the boxing gloves were *not* worn). These results suggest that shoulder, hand, and leg SIB were maintained by automatic reinforcement. Further, because head SIB did not occur in the conditions of the functional analysis that test for maintenance by social reinforcement in the second phase of their study, it is likely that head SIB was also maintained by automatic reinforcement, particularly if this behavior tended to occur in close temporal proximity to the other topographies of SIB. Nevertheless, conclusions regarding the function of head SIB must remain tentative because a proper functional analysis of this topography could not safely be conducted.

Protective Equipment May Reveal a Social Function

Although protective equipment often attenuates the consequences of destructive behavior maintained by automatic reinforcement, protective equipment should have little or no effect on destructive behavior maintained by social consequences. Iwata, Pace, et al. (1994) conducted an evaluation of three variations of extinction, each targeting a different function (attention, escape, and automatic) and each involving different procedures (ignoring [extinction-attention], follow through with instructions [extinction-escape], and noncontingent helmet [extinction-automatic]). For all three participants, destructive behavior decreased only when access to the functional reinforcer was discontinued. For the participant who engaged in head banging maintained by automatic reinforcement, low levels of head

banging occurred in the condition during which a helmet was worn continuously, even when head banging continued to result in access to adult attention or escape. By contrast, a helmet had no effect on levels of destructive behavior for the two participants whose SIB was maintained by social contingencies.

In other examples, Contrucci Kuhn and Triggs (2009) and Kuhn, DeLeon, Fisher, and Wilke (1999) used protective equipment during a functional analysis to identify whether SIB was sensitive to social reinforcement. In Contrucci-Kuhn and Triggs's study, undifferentiated levels of head and face hitting and head banging occurred across all conditions of an initial functional analysis. A subsequent analysis was then conducted during which the participant wore a helmet with a face shield throughout all sessions but continued to gain contingent access to attention and escape in the attention and escape conditions, respectively. Elevated rates of responding occurred in the attention condition, suggesting that head and face hitting and head banging were maintained by both automatic reinforcement and attention. In Kuhn et al.'s study, results from the initial functional analysis suggested that face hitting and head banging were maintained by automatic reinforcement, escape, or both. SIB decreased to zero or near-zero levels in the condition during which the helmet was worn throughout session. By contrast, levels of SIB remained elevated in the escape extinction condition, during which a helmet was not worn (i.e., escape extinction alone had no effect on levels of responding), suggesting that SIB was maintained by automatic reinforcement alone.

These studies highlight how protective equipment can be used to validate initial functional analysis results as well as identify whether destructive behavior is multiply controlled. Such information can be essential to identifying an effective treatment. Thus, if destructive behavior occurs across both nonsocial and social test conditions of a functional analysis, one should consider conducting a second functional analysis with protective equipment to determine whether destructive behavior is also sensitive to social consequences.

Summary Recommendations for Protective Equipment During Functional Analysis

Before conducting a functional analysis, we recommend that clinicians and practitioners consider the following guidelines:

1. Evaluate the risks associated with destructive behavior to determine whether protective equipment is necessary to prevent permanent physical damage.
2. If there is not an imminent risk of permanent physical damage, develop criteria for session termination that is intended to prevent sustained injury that may occur from repeated occurrences of the destructive behavior. For example, criteria may be based on the level of injury or frequency or duration of destructive behavior. In our program, we typically use protective equipment or response blocking for topographies of SIB directed at the eyes. For SIB topographies that produce mild reddening, swelling, or bleeding, we either wait for the skin to heal or apply protective equipment if it is not likely to interfere with the results (e.g., socially reinforced SIB that occurs at similar rates with and without protective equipment).
3. If there is a risk of permanent physical damage, take all necessary precautions, including using protective equipment. Conduct a functional analysis with protective equipment to determine if the destructive behavior is sensitive to social contingencies. Note that the protective equipment may not attenuate the automatic reinforcer (e.g., if hand mouthing is maintained by the pressure it produces on the hand, thin gloves may not prevent access to this reinforcer); thus, there is still a chance that an automatic function may be revealed in the functional analysis.
4. If protective equipment is needed to prevent permanent damage, consider the potential benefits of conducting a functional analysis of other responses that tend to occur in close temporal proximity to the behavior of interest (e.g., precursor behavior or other destructive behavior that occurs in clusters with the behavior

of interest, e.g., Borrero & Borrero, 2008; Moore et al., 2004).

5. Consider whether modifications can be made to the environment to reduce the risk of injury (e.g., padded session room, padded table or chair) and the potential benefits that doing so may have over applying protective equipment. For example, if the risk of physical injury is significantly greater for head banging than it is for hand-to-head SIB, then environmental arrangements may adequately address these risks without affecting the consequences of hand-to-head SIB.
6. Consider that protective equipment can be used as an instrument of aggression and select protective equipment accordingly (e.g., soft-padded helmet versus a hard plastic helmet; Dorsey, Iwata, Reid, & Davis, 1982).

During functional analysis:

1. Conduct ongoing assessments of physical injury.
2. Ensure proper oversight by qualified individuals (e.g., medical doctor, nurse, and certified behavior analyst).

Following functional analysis:

1. If destructive behavior occurred across both nonsocial and social test conditions, consider conducting a second functional analysis with protective equipment to determine whether destructive behavior is also maintained by social contingencies.

The Use of Protective Equipment as Treatment

Noncontingent Application

Because protective equipment may attenuate the sensory consequences produced by destructive behavior (i.e., function as extinction), there are implications for the treatment of behavior maintained by automatic reinforcement. Indeed, several studies have demonstrated decreases in SIB under conditions during which protective equipment is worn continuously (e.g., Deaver, Miltenberger, & Stricker, 2001; Dorsey et al., 1982; Mazaleski,

Iwata, Rodgers, Vollmer, & Zarcone, 1994; Parrish, Iwata, Dorsey, Bunck, & Slifer, 1985; Roscoe, Iwata, & Goh, 1998). For example, Deaver et al. conducted a functional analysis of hair twirling, a behavior that was reported to frequently occur immediately prior to hair pulling. Differentially high levels of hair twirling occurred in the alone condition, suggesting that this behavior was maintained by automatic reinforcement. The effects of the noncontingent application of mittens were then assessed within a reversal design. When thin cotton mittens were worn continuously throughout session, the percentage of session time during which hair twirling occurred decreased to zero or near-zero levels. The authors suggested that these effects could have been due to sensory extinction or increased response effort.

Contingent Application

One advantage of the noncontingent application of protective equipment is that it does not require constant monitoring by a caregiver. However, noncontingent protective equipment may limit opportunities to engage in appropriate behavior such as interacting with leisure items or other individuals or participating in daily living or educational activities (Jones et al., 2007; Lindberg, Iwata, & Kahng, 1999; Wallace, Iwata, Zhou, & Goff, 1999). For example, boxing gloves make it difficult to manipulate an object such as a toy, toothbrush, or pencil. In addition, extended use of protective equipment (particularly mechanical restraints that limit muscle use) can result in muscular atrophy, demineralization of bones, shortening of tendons, and arrested motor development.

Contingent application of protective equipment may minimize the adverse effects of prolonged use of such devices. For example, Dorsey et al. (1982) demonstrated that, following exposure to a noncontingent protective equipment condition, SIB (e.g., head hitting, hand biting, and eye gouging) maintained at low levels during a condition in which protective equipment (i.e., foam-padded gloves and a foam-padded football helmet) was

applied contingent on SIB (also see Parrish et al., 1985). The equipment remained in place in the contingent protective equipment condition for 2 min and was not removed until 30 s had elapsed from the last instance of SIB. However, because access to leisure items was also removed while the protective equipment was in place, and leisure items were not available in the noncontingent protective equipment condition, it is unknown whether the maintenance of low levels of SIB was due to the contingent application of equipment, the contingent removal of leisure items, or both.

Mazaleski et al. (1994) assessed whether prior exposure to noncontingent equipment was necessary to establish low levels of responding when protective equipment was applied contingent on destructive behavior. Participants included two women with profound mental retardation who had been referred for the assessment and treatment of chronic hand mouthing (and tongue pulling, for one participant) that resulted in mild tissue damage. Functional analyses suggested that hand mouthing was maintained by automatic reinforcement. The effects of the contingent application of oven mitts were then assessed within a reversal design. In the contingent-mitts condition, oven mitts were placed on the participants' hands for 30 s following an instance of hand mouthing or tongue pulling. Occurrences of hand mouthing or tongue pulling while the mitts were in place prolonged the removal of the mitts. Low levels of hand mouthing and tongue pulling occurred in the contingent-mitts condition for both participants, regardless of whether the participant had a prior history with the noncontingent-mitts condition. Further, because hand mouthing during the contingent-mitts condition occasionally resulted in direct contact with the skin (i.e., the mitts were applied after an occurrence of hand mouthing, amounting to intermittent reinforcement), it is unlikely that sensory extinction accounted for the low levels of destructive behavior observed during this condition. Instead, contingent mitts may have functioned as punishment or time out by limiting access to alternative sources of reinforcement (see also Luiselli, 1986, 1989).

Response Prevention and Response Effort

Certain types of protective equipment prevent destructive behavior by making it physically impossible to perform. For example, when prompts plus edible reinforcement for item engagement were not effective in decreasing the head and face picking of a 46-year-old man diagnosed with profound mental retardation, Lindberg et al. (1999) added arm splints to the treatment package to eliminate this destructive behavior. The arm splints restricted elbow flexion but did not prevent manipulation of leisure materials. Indeed, the percentage of intervals with item engagement increased from a mean of 37.4–78.6 % when arm splints were added to the treatment package.

Because prolonged restriction of movement can be associated with negative side effects, restraints should be faded or modified in order to increase range of motion (e.g., Fisher et al., 1997; Irvin, Thompson, Turner, & Williams, 1998; Wallace et al., 1999). Wallace et al. described a method for empirically determining optimal levels of restraint. The use of arm sleeves that contained five pockets that could accommodate five thin metal stays or one thick metal stay allowed for the manipulation of response effort. Each participant was exposed to eight conditions that varied in terms of arm-splint rigidity. The optimal level of restraint was determined by comparing levels of SIB and adaptive behavior (drinking) across conditions. Drinking was selected as the adaptive response because it required a similar type of arm movement as the participants' SIB (head and face hitting and hand mouthing) and because highly preferred liquids could be used to assure that participants were motivated to engage in the adaptive response. Practitioners may consider other treatment components that may be combined with restraint use, such as decreasing response effort (e.g., decrease the number of stays or remove restraints), increasing motivation (e.g., by providing reinforcement for adaptive responding), or combining treatment components (e.g., adding response blocking) during certain activities to increase the probability that individuals will engage in a variety of adaptive responses (e.g., self-care, educational, or vocational tasks).

Fading Restraints and Protective Equipment

Fisher et al. (1997) demonstrated that the effects of arm restraints could be maintained even when the device had been modified to no longer provide protection from SIB. A pre- and post-fading comparison of bare-arms and flexible-sleeves conditions suggested that stimulus control over low levels of hand-to-head SIB was transferred from rigid sleeves to flexible sleeves. The fading process involved gradually reducing the rigidity (i.e., the number of stays) of arms sleeves until there was full range of motion (i.e., flexible sleeves). Comparable levels of hand-to-head SIB were observed in the bare-arms condition prior to and following fading; by contrast, a large reduction in the level of hand-to-head SIB was observed in the post-fading, flexible-sleeves condition (levels of SIB during this condition were similar to levels of SIB when rigid sleeves were worn). During restraint fading, the number of stays was reduced contingent on 2 consecutive days in which levels of SIB remained below 5 % of baseline levels. For one of three participants, a water mist procedure was added to maintain low levels of SIB during fading process. SIB maintained at low levels in the flexible-sleeves condition following fading for this participant without the continued use of the water mist procedure. Interestingly, a second participant developed a new topography of SIB during the fading procedure (arm-to-head SIB). Thus, although hand-to-head SIB remained low when flexible sleeves were worn, the addition of a padded cap was necessary to reduce arm-to-head SIB to near-zero levels.

In addition to reducing the physical risk associated with prolonged use of restraints and immobility, restraint fading may result in more socially acceptable forms of protective devices (e.g., cloth arm sleeves versus arm splints). Presumably, similar procedures could be used to transfer stimulus control from other types of protective equipment (e.g., a helmet) to more socially acceptable devices (e.g., a baseball cap). However, it may be difficult to gradually modify the physical properties that offer protection from SIB (e.g., the thickness of padding) for other types of protective equipment unless the equipment is specifically designed for this purpose.

Summary Recommendations for Protective Equipment During Treatment

1. If SIB is maintained by automatic reinforcement, incorporating protective equipment into a treatment package may reduce SIB as well as the risk of physical injury as a result of this behavior.
2. When selecting protective equipment, consider whether the equipment (a) is likely to reduce the risk of injury and attenuate putative automatic reinforcers based on the topography of the SIB, (b) can withstand potential extinction bursts, and (c) is amenable to fading procedures. The social acceptability of protective equipment and its effects on adaptive behavior should also be taken into consideration.
3. Identify a plan for minimizing the deleterious effects of the prolonged use of protective equipment. For example, consider whether the amount of time protective equipment is worn can be reduced by applying protective equipment contingently (e.g., Dorsey et al., 1982; Mazaleski et al., 1994; Parrish et al., 1985), introducing competing items (e.g., Roscoe et al., 1998), or by alternating the noncontingent application of protective equipment with periods of time during which other procedures such as response blocking or competing items are in place. Alternatively, consider whether restraint fading can be used to transfer stimulus control to equipment that allows for a greater range of motion (Fisher et al., 1997; Pace, Iwata, Edwards, & McCosh, 1986).
4. Conduct daily skin checks for physical injury.
5. When restraints will be used, conduct an analysis similar to Wallace et al. (1999) to identify the optimal level of restraint.
6. Monitor the effects of protective equipment on both destructive behavior and adaptive behavior (e.g., Lindberg et al., 1999).
7. Monitor the emergence of other topographies of destructive behavior (e.g., Fisher et al., 1997; Silverman, Watanabe, Marshall, & Baer, 1984).
8. Note that protective equipment does not address the motivating operation for SIB. Efforts should be made to provide the individual with an alternative means of accessing the putative automatic reinforcer (e.g., by

providing access to matched stimuli; Piazza, Adelinis, Hanley, Goh, & Delia, 2000).

(i.e., whether the potential benefits outweigh the risks) and also to empirically test the effectiveness of protective devices. We also discussed the rules and regulations that govern use of such devices so that client’s rights are protected. We described and provided pictures of devices that may be used to mitigate the potential dangers associated with various topographies of destructive behavior. Finally, we discussed ways in which protective equipment may be employed in the functional analysis and treatment of severe destructive behavior.

Summary

Individuals with severe behavior disorders may display destructive behavior that poses a serious health risk to themselves, others, or to the environment. In this chapter, we described assessment methods that a clinician might use to determine whether protective equipment is warranted

Appendix

UNMC-MMI’s Center for Autism Spectrum Disorders
Destructive Behavior Severity Scale

Patient’s Name: _____ UNH#: _____
DOB: ____/____/____ DOB: ____/____/____

INJURY RISK BEHAVIOR involves frequently engaging in destructive behavior without recognizing the potential hazards, such as: (a) climbing on objects where falling is probable; (b) running into a street without watching for cars; (c) pulling down objects onto oneself; (d) touching electrical wires, stoves or other dangerous items; (e) drinking or eating dangerous fluids or items (e.g., cleaners, medicines, fertilizer); (f) placing a bag over one’s head; or (g) getting ropes or cords tangled around one’s neck.

For each of the four levels of injury risk behavior listed below, circle how often this type of behavior occurs, ranging from never (N) to over 10 times per hour (+10).

N = Never M = Monthly W = Weekly H = Hourly +5 = Over 5 per hour +10 = Over 10 per hour

FREQUENCY

N M W H +5 +10	Level 1 = INJURY RISK BEHAVIOR resulting in: (a) <u>no</u> marks on body, (b) <u>no</u> burns, (c) <u>no</u> gagging, (d) <u>no</u> vomiting, or (e) <u>no</u> choking.
N M W H +5 +10	Level 2 = INJURY RISK BEHAVIOR resulting in: (a) reddening of skin or mild swelling; (b) a 1st degree burn; and/or (c) mild gagging.
N M W H +5 +10	Level 3 = INJURY RISK BEHAVIOR resulting in: (a) light scratches, small or shallow breaks in skin, moderate to severe swelling; (b) a 2nd degree burn; (c) vomiting or significant choking.
N M W H +5 +10	Level 4 = INJURY RISK BEHAVIOR resulting in: (a) scars, lasting tissue damage, disfigurement; (b) a 3rd degree burn; (c) poisoning; or (d) loss of consciousness.

AGGRESSION involves forceful pushing or striking others with body parts (e.g., pushing, hitting, kicking, head-butting); hitting others with objects; or scratching, pinching or biting others.

For each of the four levels of aggression listed below, circle how often this type of behavior occurs, ranging from never (N) to over 10 times per hour (+10).

N = Never M = Monthly W = Weekly H = Hourly +5 = Over 5 per hour +10 = Over 10 per hour

FREQUENCY

N M W H +5 +10	Level 1 = AGGRESSION resulting in (a) <u>no</u> marks on body and (b) <u>no</u> blows close to or contacting the eyes.
N M W H +5 +10	Level 2 = AGGRESSION resulting in (a) reddening of skin, and/or (b) mild swelling.
N M W H +5 +10	Level 3 = AGGRESSION resulting in (a) light scratches, (b) small or shallow breaks in skin, and/or (c) moderate to severe swelling.
N M W H +5 +10	Level 4 = AGGRESSION involving blows close to or contacting the eyes or resulting in (a) scratches that leave scars, (b) breaks in skin that leave scars, and/or (c) trauma resulting in broken bones or lasting tissue damage or disfigurement.

PICA involves the repetitive and persistent ingestion of inedible items (i.e., items that should not be eaten) such as bark, bugs, cigarette butts, clothing, coins, dirt, food dropped on the floor or ground, grass, leaves, paint chips, pet hair, etc.

For each of the four levels of pica listed below, circle how often this type of behavior occurs, ranging from never (N) to over 10 times per hour (+10).

N = Never M = Monthly W = Weekly H = Hourly +5 = Over 5 per hour +10 = Over 10 per hour

FREQUENCY

N M W H +5 +10	Level 1 = PICA involving: (a) <u>no</u> solid items larger than 1/2 inch in diameter (e.g., coins, large buttons), (b) <u>no</u> sharp items (e.g., pins, staples), (c) <u>no</u> contaminated items (e.g., items from garbage can or ash tray, paint chips), and (d) <u>no</u> toxic or poisonous items (e.g., medicines, glue).
N M W H +5 +10	Level 2 = PICA involving (a) solid items larger than 1/2 inch in diameter (e.g., coins, large buttons), but <u>not</u> sharp, contaminated, or toxic or poisonous items.
N M W H +5 +10	Level 3 = PICA involving sharp, contaminated, or toxic or poisonous items, but <u>not</u> requiring emergency medical attention (e.g., called physician for advice).
N M W H +5 +10	Level 4 = PICA involving sharp, contaminated, or toxic or poisonous items and requiring emergency medical attention.

PROPERTY DESTRUCTION involves banging, kicking, throwing, overturning, tearing, cutting, defacing, burning or stomping on objects not made for that purpose.

For each of the four levels of property destruction listed below, circle how often this type of behavior occurs, ranging from never (N) to over 10 times per hour (+10).

N = Never M = Monthly W = Weekly H = Hourly +5 = Over 5 per hour +10 = Over 10 per hour

FREQUENCY

N M W H +5 +10	Level 1 = PROPERTY DESTRUCTION resulting in disruption of property but <u>no</u> permanent damage to paper items, toys, teaching materials, furniture, vehicles or buildings.

N M W H +5 +10	Level 2 = PROPERTY DESTRUCTION resulting in damage to paper items or other light objects.
N M W H +5 +10	Level 3 = PROPERTY DESTRUCTION resulting in (a) breakage of pencils, plastic toys, glassware, or other breakable items, and/or (b) scratches or permanent marks on furniture, walls, cars, etc.
N M W H +5 +10	Level 4 = PROPERTY DESTRUCTION resulting in structural damage to furniture, cars, walls, etc.

SELF INJURIOUS BEHAVIOR (SIB)—forceful striking, scratching, rubbing, poking or biting own body parts such that repetition of the behavior over time has or will cause bodily injury (e.g., hitting, kicking, pinching, scratching or biting self; eye-poking); banging body parts against objects (e.g., head-banging).

For each of the four levels of SIB listed below, circle how often this type of behavior occurs, ranging from never (N) to over 10 times per hour (+10).

N = Never M = Monthly W = Weekly H = Hourly +5 = Over 5 per hour +10 = Over 10 per hour

FREQUENCY

N M W H +5 +10	Level 1 = SIB resulting in (a) <u>no</u> visible marks on body and (b) <u>no</u> blows close to or contacting the eyes.
N M W H +5 +10	Level 2 = SIB resulting in (a) reddening of skin, and/or (b) mild swelling.
N M W H +5 +10	Level 3 = SIB resulting in (a) light scratches, (b) small or shallow breaks in skin, and/or (c) moderate to severe swelling.
N M W H +5 +10	Level 4 = SIB involving blows close to or contacting the eyes or resulting in (a) scratches that leave scars, (b) breaks in skin that leave scars, and/or (c) trauma involving broken bones or lasting tissue damage or disfigurement.

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Therapeutic Restraint and Protective Holding

7

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Introduction

Individuals with intellectual disabilities (IDD) are at risk for developing severe problem behaviors such as aggression or self-injury (SIB; Schroeder, Rojahn, & Oldenquist, 1991). While conclusive epidemiological studies are lacking in this area, the consensus is that such severe problem behaviors are found in many disability types and across numerous settings (see Rojahn & Ebensen, 2002). Recent research focusing on individuals with autism suggests that as many as 94 % of this population engages in some form of problem behavior (Matson, Wilkins, & Macken, 2009). Other studies suggest indicate prevalence rates for aggression in approximately 7 % of the population with intellectual disabilities (Emerson et al., 2001), while 15 % of IDD engage in some form of self-injurious behavior (SIB; Wicks-Nelson & Israel, 1999). The unfortunate reality

behind these numbers is that such behaviors are related to increased risk for extreme negative outcomes such as tissue damage, retinal detachment, and death (e.g., Berzlanovich, Schöpfer, & Wolfgang, 2012) to the individual or to the caregivers charged with serving the individual. To protect the individual and others from harm, strategic application of therapeutic restraint (TR) and protective holding is sometimes necessary (Matson & Boisjoli, 2009) but only as a last resort and for emergency situations.

This chapter aims to provide families, caregivers, and clinicians with information on what constitutes therapeutic restraint. This discussion will be supplemented with a review of policy statements on its use from professional organizations. We will then provide recommendations for clinical decision making regarding therapeutic restraint along with empirical evidence for supporting its use. In addition, we will discuss the dangers and limitations associated with programmatic use of therapeutic restraint for individuals with developmental disabilities and offer clinical strategies to reduce the necessity and use.

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What Therapeutic Restraint Is and Is Not

Throughout the literature, researchers and clinicians frequently use many different terms to describe TR. For example, Luiselli, Dunn, and Pace (2005) used the term “protective holding” to

describe the therapeutic holding of individuals' arms and legs contingent upon aggression, destruction, or self-injury until the individuals were calm and safe. Alternatively, others have used the terms "physical restraint" (e.g., Foxx & Meindl, 2007) and "immobilization" (e.g., Bitgood, Crowe, Suarez, & Peters, 1980) to describe the contingent use of physical means to address problem behaviors. For the remainder of this chapter, we will use the term TR to describe any restraint procedure specifically aimed at protecting the safety of clients, caregivers, and environment.

The term "therapeutic restraint" refers to the strategic application of safety procedures consisting of some form of immobilization contingent upon clearly defined crisis behaviors putting the individual, his/her caregivers, or his/her immediate surroundings in imminent danger. As described by Luiselli (2011), TR typically consists of one or more caregivers using physical means to limit mobilization by holding the individual's arms, legs, torso, or body. These procedures may be used in standing positions while seated or in supine positions on the ground (see Luiselli, 2011). At first glance, these procedures appear to serve as aversive consequences meant to punish the individual's behavior—this, however, is *not* the intention of TR. As defined in this manner, TR should be *therapeutic*, not necessarily a programmed behavior reduction procedure. It may very well be the case that TR does indeed serve as an effective punisher to the target crisis behavior, as reviews have found that it successfully decelerates problem behaviors (Matson & Farrar-Schneider, 1993). As we will discuss later in this chapter, however, TR may actually reinforce or accelerate severe problem behavior in some individuals. Clinicians and caregivers should never view TR as a way to simply modify behavior, despite the possible suppressive effects of the procedure. TR controls safety associated with dangerous behavior. Understanding the difference in goals between (a) restraint (physical, mechanical [i.e., using equipment or devices to limit individuals' mobility], or chemical [i.e., sedation]) to punish behavior and (b) TR is

paramount in understanding the caregivers' role in protecting the safety of everyone involved in crisis management. The use of restraint to intentionally reduce target behavior is beyond the scope of this chapter. We encourage the reader to consult other sources (e.g., Harris, 1996; Jones, Allen, Moore, Phillips, & Lowe, 2007; Luiselli, 2011; Matson & Farrar-Schneider, 1993) when considering the ethics and value of these kinds of aversive procedures. Note that institutional, organizational, credentialing boards/agencies and/or state policies may prohibit certain forms of restraint and caregivers wishing to proceed with such intervention should do so with caution and discretion (see Ryan, Robbins, Peterson, & Rozalski, 2009, for a review of state policies on restraint in schools). In the next section, we articulate several important policy statements on the use of TR.

Policy Statements on the Use of Therapeutic Restraint Procedures

In 1982, an important Supreme Court case was held involving Nicholas Romeo, an individual with intellectual disability, and the Pennsylvania state hospital in which he was a resident. In this landmark court case, the issue in dispute was of the standard of care and if the Pennsylvania state hospital had violated that standard of care. Further, and seemingly more significant, was the issue of whether intellectually disabled individuals have the constitutional right to safe conditions of confinement and freedom from bodily restraint. After the initial trial and several appeals, the Supreme Court ruled, in accordance with the 14th amendment, that Nicholas Romeo had the right to "safe conditions of confinement and freedom from unreasonable bodily restraints" (<http://case-law.lp.findlaw.com/scripts/getcase.pl?court=US&vol=457&invol=307>). This was a landmark court case because, up until that point, the standard of care had not been well established for intellectually disabled populations. Additionally, the result of this court case has influenced how organizations, who primarily deal with individuals

with disabilities, view the role of TR as well as under what conditions TR should be used.

As noted in the preceding section, there are many different forms of TR that may be used. Likewise, there are a number of organizations and entities that differ on their views and policies toward the use of TR. All of the entities discussed below advocate the use of TR but do not all agree upon under what conditions TR should be used. It may be easiest to think of a continuum, ranging from the most positive or liberal to the least positive or conservative use of restraint, on which these organizations may be placed.

On the farthest end toward the most positive use of TR lie the Association for Behavior Analysis International (ABAI) and the Association for Professional Behavior Analysts (APBA). According to ABAI's position statement, the welfare of the individual is the highest priority (Association for Behavior Analysis International, 2010) and that the research and intervention literature should guide therapies that aim to serve the individual's best interest. Furthermore, in agreement with the US Supreme Court ruling discussed above, individuals as well as parents and guardians have the right to choose treatments. The APBA holds a similar stance in that they are firmly against the illegal or improper use of restraints but recognize restraints may be a necessary part of a behavioral intervention plan. Moreover, they understand that when used in conjunction with a proper behavioral plan, the use of restraint may serve a "protective and therapeutic role" (Association for Professional Behavior Analysts, 2007). Additionally, the APBA is strongly opposed to categorically prohibiting or severely restricting the use of restraint. The organization, however, does outline under what conditions and what form of TR should be used. Some of the conditions under which TR may be used include when there is a clear possibility of immediate harm inflicted either on the individual or others, when less restrictive alternatives are not feasible, when a functional behavioral assessment has been conducted, and when a specific comprehensive intervention plan has been developed for that individual. It is, therefore, in

accordance with both ABAI and APBA's position statement that the least-restrictive treatment should be used and only under very specific circumstances.

Toward the middle of the spectrum lies the American Psychological Association. The APA is in complete accordance with the above-mentioned Supreme Court ruling that individuals with intellectual disability have the right to choose treatments and safe standard of care as this institution testified in support of Romeo during the 1982 court case.

At the far end of the spectrum in which there is a more conservative view of restraint lie the Arc, the American Association of Intellectual and Developmental Disabilities (AAIDD), the Bureau of Developmental Disabilities Services (BDDS), the Bureau of Quality Improvement Services (BQIS), and the Council for Exceptional Children (CEC). The Arc, AAIDD, BDDS, and BQIS all hold the position that those interventions in which TR is used are the least desirable. Further, these organizations believe restraint should be used as the last resort when all other attempts have failed. The Arc and AAIDD are strongly against the use of any and all aversive procedures such as, but not limited to, electric shock, deprivation, and isolation and seclusion. The CEC, on the other hand, believes the use of restraint should only be restricted to educational settings in which there is immediate harm to the individual or others specifying that if restraint is to be used in a classroom, it should be part of a positive behavior support plan. In the case that restraint is used in the classroom, the CEC requires a comprehensive debriefing and completion of an incident report. Any use of restraint to force compliance is also strictly prohibited. On a more extreme end, the CEC believes any use of restraint to force compliance is strictly prohibited as well as the case that it should only be used in emergency situations and should not be considered as a treatment.

For a more comprehensive description or clarification of the aforementioned organizations' policies, readers are encouraged to contact the organizations directly (Table 7.1).

Table 7.1 Organizations (and URLs) with TR policy statements referenced in text

Organization	URL
The American Association of Intellectual and Developmental Disabilities (AAIDD)	http://aaidd.org/
The American Psychological Association (APA)	http://www.apa.org
The Arc	http://aaidd.org/
The Association for Behavior Analysis International (ABAI)	http://www.abainternational.org/
The Association for Professional Behavior Analysts (APBA)	http://www.apbahome.net/
The Bureau of Developmental Disabilities Services (BDDS)	http://www.in.gov/fssa/files/Use_of_Restrictive_Interventions.pdf
The Bureau of Quality Improvement Services (BQIS)	http://www.in.gov/fssa/files/Use_of_Restrictive_Interventions.pdf
The Council for Exceptional Children (CEC)	http://www.cec.sped.org/

Clinical Decision Making Regarding TR

Deciding When TR Is Necessary

As discussed throughout this volume, behavioral crises emerge when an individual's topography or rate of destructive behavior suddenly reaches dangerous levels that can no longer be managed using the current behavioral support plan in place. Such crisis situations may feature episodes of severely destructive behavior that places the individual, the caregivers, or the surrounding environment in danger of harm. In such situations, the caregivers should be knowledgeable on emergency unplanned restraint techniques. Many forms of physical restraint systems exist, and many organizations train their staff on such procedures for both emergency and planned procedures during new-hire orientation. Examples of organizations that provide training on TR procedures are summarized in Table 7.2. Note that this list is not exhaustive and many other options exist.

Table 7.2 Examples of organizations that provide TR training

Organization	URL
Crisis Prevention Institute, Inc. (CPI)	http://www.crisisprevention.com
The Mandt System, Inc.	http://www.mandtsystem.com
PMT Associates, Inc.	http://www.pmtassociates.net
Professional Crisis Management Association (PCMA)	http://www.pcma.org
Quality Behavioral Solutions, Inc.	http://www.qbscompanies.com
Therapeutic Crisis Intervention	http://rccp.cornell.edu/TCIpage1.htm

Documenting Unplanned Emergency TR

Emergency TR occurs when staff intervenes during an unanticipated and potentially dangerous behavioral crisis. Conversely, staff implements planned restraint as one component of a written behavior support protocol. Although emergency TR appears to be necessary in most treatment settings, many professionals recommend planned restraint as a better and more therapeutically effective strategy (Luiselli, 2011; Matson & Boisjoli, 2009; Williams, 2009a, 2009b). While unplanned emergency TR procedures are appropriate to maintain safety, these should not be used on a continued basis. Rather, staff and caregivers should carefully monitor both the frequency and duration of these emergency procedures to examine whether either metrics begin to increase over time. Regardless of whether the organization requires TR reporting, we encourage staff/caregivers to document the duration of each TR procedure, the kind of TR procedure utilized, the individuals involved, the setting, the context warranting the use of the TR procedure, and whether any individuals were harmed as a result. The context of the TR procedure should document precursor/antecedent events that occurred before the destructive behavior. Analysis of these antecedent conditions will ultimately aid in identifying variables predictive of the destructive behavior. For an example of the successful use of such antecedent reviews, the reader is encouraged to consult Luiselli, Pace, and Dunn (2003).

Moving from Unplanned to Planned TR

Increases in the frequency or duration of emergency TR is an indicator that planned TR should be incorporated into the individual's behavior support plan. Decisions regarding the criteria to move from emergency to planned TR should be made with an interdisciplinary team of staff and with parental guidance/approval. These criteria should factor into account the topography of the destructive behavior, as well as the severity/risk associated with the behavior. Moreover, the specific form of the TR procedure should be carefully selected based on the idiosyncratic features of the destructive behavior, as well as the context in which the behavior has been occurring (e.g., different forms of TR may be selected if the behavior occurs in close proximity to other individuals vs. more secluded environments).

Once decisions are made regarding the form of TR to be used, the next step in decision making concerns the scheduling/timing of the TR. Using the antecedent analysis described above, the team should identify the most reliable predictors of the emergency situation. Such predictors could be proximity based (e.g., the individual moves to the corner of the room), rate based (e.g., at least two instances of hand-to-head self-injury within 30 s), or topographically based (e.g., the individual places his/her wrist in his/her mouth). It may also be the case that the most reliable predictor of destructive behavior is an interaction of several contextual variables. Identifying the requisite contextual events to contingently apply TR leads to decisions regarding the duration of the TR application. We describe examples of these decisions in detail below.

Ultimately, the decision to move to planned TR is not easy. These decisions are based off careful observations and data collection. As we have repeatedly emphasized throughout the chapter, TR is an intervention of last resort. Caregivers should always attempt to manage behavior using less intrusive means, such as antecedent interventions and environmental enrichment (see Luiselli, 2006) or function-based treatments (see Chap. 8 of this handbook) before moving to TR. Nevertheless, careful and strategic use of TR in

crisis intervention is an efficacious approach to enhancing safety and reducing levels of destructive behaviors.

Forms of Therapeutic Restraint

Regardless of the context in which restraint is used, it is useful to group restraint procedures into some general categories based on form of the procedures to help delineate whether they are considered TR and when they should be used. Some general categories include brief response prevention, extended response prevention, and assisted movement. In this section, we provide some details about each type of procedure.

Brief response prevention, or response blocking, is when the problematic behavior of an individual is temporarily disrupted by an intervener through physical contact that lasts only a few seconds. This can include moving one's hand between the body part of an individual and the surface (e.g., another body part of the individual, another person, or property) that the behavior would contact if uninterrupted. For example, if a child were to engage in SIB in the form of eye poking, a caregiver could prevent the child's finger from reaching the eye simply by placing their hand in the way and guiding the child's hand to their lap, immediately releasing the hand. Response blocking is often taught within programs of restraint focusing on TR as a means to protect the individuals engaging in problem behavior and their caregivers; however, it is often used for less intense behaviors such as stereotypy, pica, and some forms of SIB (e.g., Lancioni, Singh, O'Reilly, & Sigafos, 2009). When used properly, empirical research has shown that response blocking can be used effectively to accomplish therapeutic changes (e.g., Reid, Parsons, Phillips, & Green, 1993).

Although using any intervention that prevents or limits movement can be considered a step toward more restrictive procedures, response blocking is not typically considered a form of TR. The essential characteristic that separates response blocking from TR is the brevity of the procedure. It is important to note this difference

because even though response blocking typically lasts only a few seconds, some procedural variations involve more extended movement suppression, at which point they would be considered forms of TR. For instance, in the previous example of the child eye poking, if the caregiver were to block and then hold the child's hands down for 30 s, it would be considered restraint. Knowing the threshold of when a procedure becomes TR may help to avoid unintentional application of restraint without the appropriate therapeutic safeguards for the individual and to adhere to least-restrictive practices. Because response blocking is not technically a form of TR, it is not within the scope of this chapter to cover it in any further detail.

Extended response prevention in the form of physical holds are those usually implemented as TR. Within the broader category of physical holds, there are several subgroups based on the number of caregivers required to implement the hold. These include single-person holds, two-person holds, three-person holds, and four-person holds. Typically, the more people that are required to perform the hold, the greater the restrictiveness (as when nearly all movement by the individual engaging in the problem behavior is prevented in a four-person hold), and therefore, the type of hold used should match the severity of the behavior.

Single-person holds can vary in form and typically involve restriction of one or both arms. Holds involving control of a single arm are often done to keep the caregiver in a safer position (e.g., slightly behind and to the side) during the problematic episode. A commonly used hold controlling both arms and the torso of the individual engaging in problem behavior is the basket hold. This tends to put the caregiver in a safer position (e.g., behind the individual) while also preventing the individual from using either arm to engage in problem behavior. It can be performed in either a standing or seated position. This form of TR is necessarily more restrictive than a single-arm hold and, as with any escalation of restrictive practice, should be used with increasing levels of safeguards for both the individual receiving TR and the caregiver implementing it.

Two-person holds can also occur in a variety of forms. The less restrictive holds can simply be

two caregivers each controlling one arm (similar to the single-person one-arm hold). Some two-person holds are intended to keep the individual receiving TR off balance as a means of preventing problem behavior, while others are intended to prevent problem behavior through physical restriction of the body and legs (as with one person implementing a basket hold and the other restricting movement of the legs).

Three-person and four-person holds should be reserved for instances of extreme problem behavior in which the individual is at a high risk of causing severe harm to themselves or others. These involve a great deal of training and coordination to implement effectively and safely. They tend to have fewer variations, as the positions from which control of an individual's body can be effectively produced are limited. Three-person holds are typically implemented with two caregivers controlling the arms and one controlling the legs and can be done in a standing position or a supine position. This results in a high degree of movement restriction. Four-person holds are typically conducted in the supine position, similar to the three-person hold, with the fourth caregiver restricting movement of the head. The result of a four-person hold is the complete immobilization of the individual receiving TR. With this level of restrictiveness, it is absolutely essential that there be systems of professional oversight and monitoring of implementation of the TR to ensure the safety and rights of the individual.

Another category of TR involves assisted movement, as when a situation requires an individual to be lifted or transported to another area during an episode of problem behavior. Transports can involve minimal restriction of body parts, as with guidance, while a caregiver controls a single arm, or maximal restriction of body parts, as when an individual is completely lifted from the ground and moved. As with physical holds, assisted movement can involve one to several caregivers to perform. Anytime that TR involves moving an individual, as opposed to restricting movement, there is added potential for injury to either the individual receiving TR or the caregiver. Oftentimes transports and lifts are reserved for emergency situations in which it is necessary to

relocate the individual to avoid imminent danger (e.g., if property destruction results in broken glass, moving the individual away from the glass) but sometimes can be used to help caregivers relocate the individual so that physical holds can be more safely and effectively implemented. Some programs of TR also incorporate minimally restrictive assisted movement (e.g., walking with single-arm control) as a means to help calm the individual during episodes of problem behavior. Regardless of the context in which these types of TR are used, it is important that caregivers are adequately trained to implement these procedures properly.

Programs of Therapeutic Restraint

As mentioned in Section “Clinical Decision Making Regarding TR,” there are numerous programs of TR (see Table 7.2 for some examples). For professional caregivers working in clinical settings, there are benefits to using a specific program of TR. These programs have been developed specifically to provide caregivers with safe and effective procedures for managing severe behaviors. As a result, there is the potential for decreased injury during episodes of problem behavior for both those implementing and receiving TR. Additionally, some programs of TR may provide aid in the event of litigation resulting from injuries incurred during their use. The extent to which specific programs of TR are safe and effective has not been well researched. Few studies have sought to empirically validate the efficacy of programs of TR, and even fewer have directly compared programs to determine if one program is relatively more effective than another. Those studies that do exist have examined these programs with individuals with psychiatric disorders rather than with individuals with developmental disabilities (e.g., Henderson, Siddons, Wasser, Gunn, & Spisszak, 2005), despite the fact that the programs of TR are used with both populations.

Limitations of Therapeutic Restraint

As indicated earlier in the chapter, TR is a controversial procedure that many professionals do not endorse, notwithstanding that it may be necessary

and clinically justified on a case-by-case basis. In this section, we review limitations to TR and suggest ways to resolve them.

Injury from TR

A notable limitation of TR is the potential for injury to the people receiving and implementing it. Most concerning are restraint-related deaths which have been reported among individuals in institutions, prisons, and similar settings (Weiss, 1998). Medical reports reveal that fatalities can be caused by the method of restraint (e.g., prone floor control) and associated positional asphyxia (Mohr & Mohr, 2000; O'Halloran & Frank, 2000). Nonlethal but serious restraint-related injuries to clients and staff are also prevalent in treatment settings for children and adults with IDD (Hill & Spreat, 1987; Luiselli, 2011; Sanders, 2009; Spreat, Lipinski, Hill, & Halpin, 1986; Tilli & Spreat, 2009; Williams, 2009a, 2009b).

Staff Training

One factor that accounts for injury during restraint is procedural misapplication by staff. Convention demands that human services and behavioral health-care organizations for people with IDD train direct-care staff in approved methods of physical management including TR (Lennox, Geren, & Rourke, 2011). However, there is no uniformly accepted restraint training curriculum, and indeed, the quality of training varies from one organization to another. Poorly trained staff is at high risk for misapplying restraint. Accordingly, organizations must continuously monitor their restraint training program to ensure that the content and method are consistent with best practices, meet regulatory guidelines, and accommodate internal policies and procedures.

Supervision

Even properly trained staff can apply TR improperly if they are not adequately supervised. One objective of supervision is verifying that what staff was trained to do, in fact, is demonstrated under actual conditions and interactions with clients.

A common problem, termed *procedural drift*, refers to staff departing from a criterion implementation standard. For example, when working with a child or adult who displays low-frequency but high-intensity challenging behaviors, procedural drift could develop because some staff may never have had to apply TR or done so infrequently. Consequently, intervention implementation may deviate from the protocol that was originally trained.

Another influence on procedural misapplication is a person resisting and struggling against restraint. Many times staff responds to restraint-provoked challenging behaviors with forceful counterreaction (e.g., intensifying pressure against the person's body) that includes improvised positioning and contact points. By altering approved techniques and safe-restraint practices, staffs themselves are susceptible to injury and more likely to harm the person they restrain.

Routine supervision is critical for preventing improperly applied restraint and resulting injuries. Clinical supervisors should observe staff applying restraint and provide performance feedback that reinforces skilled implementation and corrects procedural errors (DiGennaro, Martens, & Kleinmann, 2007). In effect, supervision functions both as intervention integrity assessment (DiGennaro Reed & Coddington, 2011) and, in vivo, competency-based training (Ricciardi, 2005).

Emergency Versus Planned Restraint

Concerning injuries, there is research showing that they are more likely to be sustained with emergency restraint than planned restraint (Spreat et al., 1986; Tilli & Spreat, 2009; Williams, 2009a, 2009b). This outcome should not be surprising given the preceding discussion. That is, emergency restraint, it would seem, allows staff too much discretion about when to implement restraint, perhaps more often than required, and in consequence increasing the probability of injury. It also is possible that because emergency restraint is typically applied at last resort, the person being restrained is in a state of high arousal and therefore prone to injury.

Reinforcing Effects of TR

It may appear paradoxical, but TR sometimes can function as reinforcement (Favell, McGimsey, & Jones, 1978; MaGee & Ellis, 1988). If so, the clinical scenario is bleak: contingently applied restraint will increase the behaviors targeted for reduction (Kahng, Leak, Vu, & Mishler, 2008). Although more research about the reinforcing effects of TR is needed, at this time several plausible explanations, presented below, can be considered.

Social Positive Reinforcement

Functional behavioral assessment and functional analysis reveal that many challenging behaviors of children and adults with IDD are maintained by social positive reinforcement (Hanley, Iwata, & McCord, 2003). In lay terms, social reinforcement operates when someone "attends" to a person as a consequence of behavior that subsequently increases. The social consequences can be verbal, such as a comment about behavior, or non-verbal, such as a facial expression. For some people, being restrained may provide social attention, albeit unintended but sufficiently reinforcing. It is also worth noting that the source of social attention could be the responses of peers and not staff implementing restraint. For example, some children and adults receiving restraint may "enjoy" seeing and hearing their peers react emotionally.

Social Negative Reinforcement

Children and adults with IDD also display challenging behaviors that are escape motivated (Miltenberger, 2006). An escape-motivated function is seen in persons whose challenging behaviors have been negatively reinforced through contingent removal or termination of non-preferred conditions and interactions. Certainly, the process of applying TR temporarily removes a person from situation she or he dislikes. If the reinforcing consequence of escape is more potent than the aversive features of restraint, the restraint-provoking behaviors will be maintained and not reduced. Escape, therefore, makes TR a reinforcing event.

Automatic Reinforcement

The physical contact, holding, and positioning that characterizes TR could function as sensory pleasurable stimulation that is automatically reinforcing. To illustrate, we have witnessed children and adults with IDD that seemed to enjoy the tactile sensations, pressure, and body immobilization associated with restraint. Also, people that were exposed to physical and sexual maltreatment may have heightened sensitivity to potential automatic reinforcement that is contacted during TR. Whereas it may be possible to eliminate or greatly attenuate the social reinforcement occurring contemporaneously with restraint, automatic reinforcement is not as easy to identify and manipulate. Should automatic reinforcement be a concern, restraint may not be a therapeutic option.

Adventitious Reinforcement

Social positive, social negative, and automatic reinforcement may not operate initially but be acquired after a person experiences restraint. Consider the case of an adolescent boy, whom staff restrains several times per guidelines in his behavior support plan. Unexpectedly, the boy spits at staff during restraint, staff reacts with surprise and disgust, and restraint episodes with spitting increase week to week. This scenario illustrates what could happen when a previously non-encountered behavior, spitting at staff, contacts social consequences during restraint, which then function as reinforcement.

Interventions to Reduce and Eliminate TR

The need to reduce and eliminate TR is widely recognized and reflected in the clinical research and systems-level analyses described in this section (Harris, 1996; Luiselli, 2009, 2011; Williams, 2009a, 2009b). We emphasize that more studies must be conducted to further validate and replicate findings reported in the extant literature as well as extend applications to larger populations of people with IDD and service settings.

Preventive Intervention

To reiterate, with planned TR, staff implements restraint when a child or adult demonstrates specific challenging behaviors such as aggression or self-injury. A logical approach toward restraint reduction and elimination is, first, assessing conditions that reliably set the occasion for the behaviors (Luiselli et al., 2005; Luiselli et al., 2003) and, second, manipulating these conditions so that the behavior and subsequent restraint are prevented.

Luiselli, Kane, Trembl, and Young (2000) described a preventive intervention approach with two boys (14 and 16 years old) who had IDD and frequent aggressive behaviors toward peers and staff at a residential school. Following a baseline phase, restraint reduction was not achieved through a program of differential positive reinforcement and behavior-specific restraint criteria. The next phase of intervention included antecedent control procedures that were intended to remove situations that consistently predicted aggression. The procedure were (a) having staff cue the boys to “take time” when they appeared agitated, (b) teaching them to request a “break” from demanding activities, (c) scheduling more high-preference activities during the day, and (d) strategically positioning the boys so that they were less proximate to peers within groups. Luiselli et al. (2000) found that these antecedent modifications essentially eliminated aggressive behaviors and use of restraint with both boys.

Another example of preventive intervention is Luiselli et al. (2005) in the case of a 15-year-old girl who had IDD and aggressed toward staff by biting them, often causing skin bruises and lacerations. Intervention was implemented with the girl at a residential school and included aggression-contingent TR. Through antecedent assessment, it was determined that her actual and attempted biting was more likely to occur in certain instructional contexts and when she was presented with particular tasks. Luiselli et al. (2005) were able to drastically reduce TR to near-zero frequency by preventing aggression through (a) scheduling instructional activities outside of the

classroom, (b) implementing a curriculum that emphasized functional life skills instead of sedentary desk work, and (c) allowing her to choose the type and sequence of tasks.

The preceding studies support antecedent intervention as effective in reducing and possibly eliminating TR. As Luiselli (2009) advised, “A long-term objective of such intervention is to minimize restraint while gradually re-introducing conditions that previously set the occasion for restraint-provoking behaviors” (p. 130).

Fixed-Time Release

When staffs implement TR, they typically maintain physical contact until the child or adult achieves a behavior-contingent release (BCR) criterion. For example, a BCR criterion might specify that staff does not terminate restraint until the person demonstrates 60 consecutive seconds of “calm” behavior (e.g., absence of screaming, struggling, resisting). A BCR criterion is intended to avoid negatively reinforcing disruptive behaviors that occur immediately preceding staff terminating restraint. Unfortunately, most clinicians are familiar with children and adults who experience prolonged restraint because they do not easily achieve the BCR criterion. Furthermore, having to maintain lengthy episodes of restraint burdens staff physically and may increase probability of injury to everyone involved.

Several years ago, Luiselli et al. initiated research that questioned whether a person’s total exposure to TR could be reduced by releasing restraint after a preset duration of time had elapsed independent of the challenging behavior during restraint (Luiselli, Treml, Kane, & Young, 2004; Luiselli, Pace, & Dunn, 2006). The impetus of our research into *fixed-time release* (FTR) was studies suggesting that relatively low-duration physical restraint was as effective as longer-duration physical restraint (Singh, Dawson, & Manning, 1981; Winton & Singh, 1983) and one study which found that time-based release from time-out was as effective as BCR (Mace, Page, Ivancic, & O’Brien, 1986). In Luiselli et al. (2004), we were able to reduce the average duration of TR

applications with a 12-year-old girl from 5.6 min under BCR to 3.1 min under FTR. The study by Luiselli et al. (2006) targeted three youths (11–14 years old) and revealed decreased time in TR from averages of 14.2, 5.1, and 11.2 min under BCR to 3.8, 1.4, and 3.0 min under FTR, respectively. Notably, when compared to BCR, the *frequency* of TR in these studies either remained the same or decreased with the change to FTR. This effect, the reduced total exposure to restraint and the possibility of better intervention integrity, suggests that FTR is a promising approach toward restraint reduction.

Restraint Fading

Several studies have evaluated fading methods for gradually limiting frequency of TR. Lerman, Iwata, Shore, and DeLeon (1997) addressed restraint fading with four adults (25–35 years old) who had IDD and self-injurious behavior. An initial intervention evaluation revealed that in all cases, restraint applied on a continuous (FR-1) schedule reduced self-injury. Fading was implemented by thinning the schedule from FR-1 to fixed-interval 120 s (FI-120 s) with two of the adults and from FR-1 to fixed-interval 300 s (FI-300 s) with the other two adults). The intervals were lengthened by a prespecified duration based on the rate or percentage of recording intervals with self-injury. Fading was successful with two of the adults but ineffective with two others—these adults required that restraint be applied continuously to maintain minimal self-injury.

Grace, Kahng, and Fisher (1994) attempted to minimize TR of an 11-year-old boy with IDD by implementing it with different topographies of challenging behavior. “Less severe” topographies included the boy making mild physical contact with other people, banging objects, and pushing materials off tables. “More severe” topographies were the boy forcefully hitting other people, overturning furniture, and destroying objects. Relative to baseline (no restraint) conditions, both behavior topographies decreased substantially with TR. During phases when restraint was applied to the “more severe” topographies but not

the “less severe” topographies, the former behaviors occurred infrequently, but the latter behaviors persisted at baseline levels. Thus, the results of Grace et al. (1994) suggest that partial TR, or intervening with some but not all challenging behaviors, may not be an effective restraint-fading strategy.

One additional method, reported by Luiselli (2008), is FTR fading. The participant was a 13-year-old boy with autistic disorder and PDD-NOS diagnoses. He slapped, pinched, bit, and pulled the hair of classroom staff, resulting in a behavior support plan that had aggression-contingent TR. In an initial (prefading) intervention phase, staff released the boy from restraint after 60 s. During subsequent phases, the FTR criterion was decreased from 60 to 30, 15, and 7 s, based on a decreasing frequency of restraint and, by default, reduced duration. Upon reaching the FTR-7 s criterion, TR was successfully eliminated by having staff move behind the boy as if to implement restraint, touch him gently on the shoulder, and instruct him to “sit down.” When he complied, staff stepped back, waited a few seconds, and then had the boy stand up.

Staff Training

All of the restraint reduction clinical procedures we have described demand comprehensive staff training and supervision. Singh et al. (2009) proposed and evaluated an innovative approach toward reducing physical restraint that relied on mindfulness-based staff training. The setting was four group homes serving 20 people with IDD (20–25 years old) and staffed by 23 direct-care providers. The staff was separated into morning and afternoon shifts, each shift receiving 12 2-h mindfulness training sessions that taught meditation and exercises to enhance mindfulness throughout the day. In a subsequent phase that immediately followed mindfulness training, staffs were instructed to apply their mindfulness skills when interacting with clients but otherwise did not receive further support. As evaluated in a multiple baseline design across staff shifts, mindfulness training and practice was associated with

decreased restraint to almost zero frequency among all of the group home residents. These results are promising but certainly mindfulness-based staff training and intervention is a relatively novel approach within IDD (Singh et al., 2006), and its principles and mechanisms of change must be researched in greater detail. On this matter, Singh et al. (2009) posited that mindfulness “enables staff to disengage themselves from a premature cognitive commitment to pre-empt or control the behavior of the individuals, based on history. Staff can observe without judgment or an expectation of specific resultant behaviors, whether social or aggressive” (p. 198).

Organizational (Systems-Level) Intervention

Within child and adult psychiatric hospitals, use of restraint has been reduced through large-scale organizational intervention such as a mandatory behavioral consultation (Donat, 1998), administrative policy change (Singh, Singh, Davis, Latham, & Ayers, 1999), and systems-level modifications (Donat, 2002). Similarly, Sanders (2009) described an organization initiative and intervention plan that reduced physical restraint of children and adults with IDD at a regional facility over a 4-year period. Among several directives aimed at minimizing restraint and supporting clinical safety, the intervention emphasized (a) intensified staff training, (b) alternatives to restraint, (c) increased supervision by senior management personnel, and (d) systematic review of restraint utilization. In addition to less-frequent restraint, corollary benefits from intervention were fewer staff injuries and related salary costs to the facility.

In a project concerned about mechanical and not physical restraint, Williams and Grossett (2011) incorporated principles of organizational behavior management (OBM) at a large residential facility for people with IDD (13–65 years old). The project formed residential treatment teams that were responsible for identifying youth and adults with restraint histories, received consultation from a senior-level psychologist, and

participated in peer review with behavioral and medical specialists. Other components of the OBM intervention were instituting a restraint monitoring and feedback system, submitting incident reports to a management coordination team, and standardizing acceptable and non-approved conditions for applying mechanical restraint. Over 17 months of intervention evaluation, mechanical restraint decreased by 80 %, and there was a corresponding increase in written behavior support plans. Although Williams and Grossett (2011) had to do with mechanical restraint, the methods and policies they implemented are applicable to organizational change projects for reducing physical restraint as well (see Luiselli & Russo, 2005, and Luiselli, 2011, for further discussion about organizational tactics).

Summary

This chapter highlighted (a) what constitutes TR, (b) clinical decision-making strategies when considering use of TR, (c) policy statements on TR by relevant professional organization, (d) forms of TR, (e) limitations of TR, and (f) ways to reduce the necessity and need for TR for IDD in crisis. The use of TR should be avoided whenever possible. Behavioral crises may necessitate the use of TR for safety reasons but should never be considered a long-term solution for behavior problems. Should TR be required/necessitated, the clinical team should immediately begin strategies to fade this procedure. TR should only be used in conjunction with thorough behavioral treatment strategies that incorporate the technologies and procedures outlined throughout this volume.

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Part II

Crisis Identification and Acknowledgement

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Abbreviations

ABC	Aberrant Behavior Checklist	BPI-01	Behavior Problems Inventory
A-B-C	Antecedent-Behavior-Consequence	C-SHARP	Children's Scale of Hostility and Aggression: Reactive/Proactive
ADHD	Attention-deficit/hyperactivity disorder	DAS-B	Disability Assessment Schedule for Problem Behaviors
ADI-R	Autism Diagnostic Interview-Revised	DBC	Developmental Behavior Checklist
ASD-BPA	Autism Spectrum Disorders-Behavior Problems for Adults	DDs	Developmental disabilities
ASD-CA	ASD-Comorbidity for Adults	EFA	Experimental functional analysis
ASD-DA	ASD-Diagnosis for Adults	FAC	Functional Analysis Checklist
ASD-PBC	Autism Spectrum Disorders-Problem Behavior for Children	FACT	Functional Assessment for multiple CausaliTy
ASDs	Autism spectrum disorders	FAIF	Functional Analysis Interview Form
BISCUIT-Part 3	Baby and Infant Screen for Children with aUtism Traits-Part 3	FAOF	Functional Assessment Observation Form
		ID	Intellectual disability
		MARS	Motivation Analysis Rating Scale
		MAS	Motivation Assessment Scale
		MTS	Momentary time sampling
		NCBRF	Nisonger Child Behavior Rating Form
		PDDBI	Pervasive Developmental Disorder Behavior Inventory
		PTS	Partial-interval time sampling
		QABF	Questions About Behavioral Function
		RBS-R	Repetitive Behavior Scale-Revised
		RSMB	Reiss Screen for Maladaptive Behavior

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SBS	Stereotyped Behavior Scale
SIB	Self-injurious behavior
WTS	Whole-interval time sampling

Introduction

The overarching goal of all who care for individuals with developmental disabilities (DDs) is to improve their quality of life and structure an environment to offer the best supports possible. Many of these disabilities, however, such as autism spectrum disorders (ASDs) and intellectual disability (ID), serve as risk factors for the development of challenging behaviors (Farmer & Aman, 2011; Matson & Shoemaker, 2009; Murphy, Healy, & Leader, 2009). The terms “challenging behavior,” “problem behavior,” and “maladaptive behavior” will be used interchangeably throughout this chapter. These behaviors have been described as ones that “present a significant challenge to carers and support agencies” (Emerson et al., 2008, p. 197); place the individual in serious jeopardy due to their intensity, frequency, or duration; are generally socially unacceptable (Emerson, 2001); and seriously limit or deny access to and use of ordinary community facilities (Emerson, 1995).

When the individual presents with behaviors which upset their daily functioning (i.e., social, occupational, or academic), it is necessary to intervene with appropriate supports. Horner, Carr, Strain, Todd, and Reed (2002) demonstrated that early behavioral interventions can lead to reductions in challenging behaviors by 80–90 %. This is important as it has been widely demonstrated that problem behaviors can lead to numerous negative consequences (Matson, Kozlowski, et al., 2011). Detrimental consequences to the individual may include tissue damage, interference with learning novel skills, prevention of the acquisition of adaptive behavior, competition with socially acceptable behaviors, negatively impacted social relationships, poorer academic performance, and an overall lower quality of life (Herzinger & Campbell, 2007). Their challenging behaviors can also lead to a greater likelihood

that guardians will decide to place them in a residential care facility (Mansell, Ashman, Macdonald, & Beadle-Brown, 2002). In addition, physicians are also more likely to prescribe psychotropic medications for behavior management (Holden & Gitlesen, 2004). Caregivers have also been shown to be directly impacted by the behavioral presentation of these individuals, as research has indicated that the presence of challenging behaviors can lead to increased caregiver stress and staff turnover (Felce, Lowe, & Beswick, 1993; Hartley & MacLean, 2007; Quine & Pahl, 1989; Qureshi, 1995; Rose & Rose, 2005). This multitude of negative consequences ultimately leads to these individuals requiring a disproportionate number of supports warranting the implementation of effective behavioral treatment.

However, prior to working collaboratively to implement a successful treatment plan, an accurate portrayal of the problem must be obtained through data collection (Hartmann, Barrios, & Wood, 2004). The use of a functional behavior assessment to inform treatment of challenging behaviors is currently mandated under certain circumstances by federal law in the United States as stated by the Individuals with Disabilities Education Act Amendments of 1997 and 2004 (Individuals with Disabilities Education Act Amendments of 1997, 20 U.S.C. Section 1400 et seq, 1997; Individuals with Disabilities Education Act Amendments of 2004, 11 Stat. 37 U.S.C. Section 1401, 2004). In addition to being mandated by law, a functional behavior assessment should be conducted in order to identify the purpose and function of the behavior and to guide the clinician in selecting appropriate treatment procedures.

Data can be gathered in a number of ways. In recent years, a wide range of assessment instruments have been developed to assess challenging behaviors in individuals with DDs. In addition to standardized assessment, data can also be gathered through descriptive assessments or behavioral observations. There are multiple advantages to both methods; therefore, this chapter will discuss several instruments and techniques used to conduct a comprehensive problem behavior assessment.

Problem Behavior Overview

Prevalence of Challenging Behaviors

The first step in behavior assessment is to become familiar with the prevalence of maladaptive behaviors, specifically within this population. While it is known that challenging behaviors, as a whole, are common in the DD population, it is useful to obtain information regarding the commonality of specific behaviors. Examples of problem behaviors that are typically seen include aggression, tantrums, hand mouthing, property destruction, stereotypes, and self-injurious behavior (SIB; Harris & Glasberg, 2007; Herzinger & Campbell, 2007; Matson, Kozlowski, et al., 2011; Mudford et al., 2008).

For individuals with ID, some have found aggression to be the most common problem behavior (Tenneij, Didden, Stolker, & Koot, 2009). Emerson et al. (2001) found there to be a 7 % prevalence rate for aggressive behavior, 4–5 % for destructive behavior, and 4 % prevalence rate for SIB among individuals with ID. This study is particularly useful as it includes individuals from a number of different settings. Other researchers have found that approximately 15 % of those with a DD engage in SIB (Wicks-Nelson & Israel, 1999). Elsewhere, high prevalence rates among the DD population have also been reported for elopement (e.g., leaving an area without supervision or permission; Jacobson, 1982; Lowe et al., 2007).

More specifically, Horner et al. (2002) found 13–30 % of a sample of children with autism presented with challenging behaviors. Matson, Wilkins, and Macken (2009), however, found 94.3 % of children with an ASD presented with some type of problem behavior. With this in mind, some have shown autism to serve as a risk marker for many challenging behaviors for those with an ID (McClintock, Hall, & Oliver, 2003). While studies about prevalence rates provide useful information for clinicians, one must exercise caution when interpreting findings from such studies as some articles

may include a sample of participants from a restricted setting, while others include those living in the community. Additionally, the way challenging behaviors are defined often varies across studies (Darrow, Follette, Maragakis, & Dykstra, 2011).

Maintaining Variables

A better understanding of the ways in which problem behaviors are reinforced and, thus, maintained are valuable for conducting a functional behavior assessment. One learning theory, called operant conditioning, formulated by B.F. Skinner, is often used to explain the occurrence of many problem behaviors (Matson, Shoemaker, et al., 2011). One's behavior can be shaped (i.e., strengthened or weakened) by providing the individual with either reinforcement or punishment for that behavior. For example, when a behavior is reinforced, the frequency of that behavior tends to increase (Feldman, 2006). A number of maintaining variables have been identified as being reinforcing, such as attention, escape, tangible, nonsocial, and physical (Joyce, 2006; Matson, Kozlowski, et al., 2011; Mudford et al., 2008; Tarbox et al., 2009; Vollmer & Matson, 1995).

A 2011 study (Matson, Kozlowski, et al., 2011) found that out of 173 papers which studied functions of challenging behavior for those with ID and ASDs, less than 5 % of assessments determined the behavior in question to be maintained by a physical function (i.e., pain or discomfort). This same study found attention and escape to be the two most common functions of challenging behaviors in this population. Additionally, individuals with DDs (e.g., ID) often have limited communication abilities; thus, socially inappropriate or maladaptive behaviors (e.g., aggression, SIB, elopement) are often used to express one's needs and wants (Dura, 1997; Durand & Carr, 1991). It is important to recognize the basics of operant conditioning in addition to various potential functions of behavior in order to provide adequate supports for the individual.

Functional Behavioral Assessment

Functional behavioral assessment refers to both experimental and nonexperimental methods of assessing the maintaining variables of the challenging behavior. This includes three main types of assessment: standardized assessment, descriptive assessment, and functional analysis (Herzinger & Campbell, 2007). As many of these terms are used differently and can be confused, it is common to find in the literature others referring to functional assessment as solely the nonexperimental methods of data collection to identify maintaining variables of the behaviors in question (Sturme, 1994). Various methods of functional assessment include standardized assessments (e.g., interviews, questionnaires, checklists, rating scales) and descriptive assessments (e.g., direct observation). A functional analysis involves the *experimental* manipulation of environmental variables and is not considered a method of functional assessment defined in the manner above. This control over the individual's environment informs the observer of factors responsible for either the presence or absence of the target behavior (Sturme). For the purposes of this chapter, the focus will remain on functional assessment (see Chap. 9 for further description of functional analysis).

The term "problem behavior assessment" will be used to include functional assessment measures as well as nonexperimental methods of data collection which do not address function (i.e., structural or topographical assessment). Prior to conducting any type of treatment, it is crucial to identify exactly which behaviors are being targeted and develop clear, operational definitions for all behaviors in question. Many researchers will agree that functional assessment holds the key to establishing an effective treatment program, particularly for those with DDs (Huete & Kurtz, 2009; Matson, Horovitz, et al., 2011; Matson, Mayville, & Laud, 2003). Although the importance of functional assessment was discovered early on (Bijou, Peterson, & Ault, 1968), many researchers began conducting interventions without the consultation of a proper functional

behavior assessment (Arndorfer & Miltenberger, 1993). Today, researchers once again emphasize the importance of functional, assessment-driven interventions (Matson, Bamberg, Cherry, & Paclawskyj, 1999; Matson, Kozlowski, et al., 2011; Tarbox et al., 2009). The remainder of this chapter will discuss measures and procedures which are designed to assess the topography and function of problem behaviors.

Information obtained from problem behavior assessments can be utilized by clinicians in a number of ways. First, this data can help develop a baseline for an individual prior to the implementation of a treatment program, as it is widely established that effective treatment relies upon accurate assessment (Matson & Nebel-Schwalm, 2007). Once this baseline is established, gathered data can assist in actually formulating the behavior plan. For example, different maintaining variables will call for different interventions (Arndorfer & Miltenberger, 1993; Tarbox et al., 2009), and data can also be used to monitor progress of interventions (Hartmann et al., 2004). Furthermore, problem behavior assessments often determine placement and the level of supports needed. Psychological evaluations often require the inclusion of a comprehensive assessment of one's challenging behaviors as well. Proper assessment and treatment can aid in thwarting any imminent risk, such as risk of death from SIB or causing harm to others. Additionally, adequate supports can help prevent social stigma created by these socially unacceptable behaviors and address some limitations that these behaviors place on one's independence (Harris & Glasberg, 2007).

While problem behavior assessment is quite informative to those caring for and treating the individual, there are a number of problems associated with these assessments. Many procedures such as contingency event recording can be quite time consuming, particularly if they require a narrative account (Arndorfer & Miltenberger, 1993). Informant-based assessment may be vulnerable to bias, incorrect reporting, and the informant having little experience with the target behavior (Lennox & Miltenberger, 1989). Additionally, if the target behavior is of low frequency, then the behavior may not occur during times of

observation (Tarbox et al., 2009). This chapter will provide an overview of a number of different measures beginning with standardized assessments and followed by descriptive assessments.

Standardized Assessment

The first type of assessment that will be discussed is standardized assessment, also known as informant-based assessment. Informants for such assessments are typically a parent, teacher, direct care staff, or other caregiver whom is familiar with the individual in question and their specific problem behaviors. Harris and Glasberg (2007) advise those conducting the behavioral assessment to begin with multiple forms of standardized assessment prior to conducting any direct observation of the behavior. One may formulate hypotheses regarding the target behavior during the standardized assessment and simply support or refute these hypotheses during the descriptive assessment (O'Neill et al., 1997), another method of assessment which will be explained later in this chapter.

Standardized Assessments for Gathering Topography, Frequency, Duration and Severity of Behavior

To truly understand and implement successful interventions for one's problem behavior, many researchers argue that knowing the function of the behavior is vital. Prior to gathering this information, however, more general information (e.g., topography, frequency, duration, and severity) must be collected. A number of measures have been designed to solely assess descriptive qualities of one's behavior, which will be discussed below. In addition to the descriptive textual information provided below, Table 8.1 also provides an easy reference to each measure discussed including information about the measure's purpose, target population, item content, and length.

Behavior Problems Inventory (BPI-01). The *BPI-01* is one of the most extensively studied measures

to assess problem behaviors in adults and teenagers with ID and other DDs (Edlinger, 1983; Rojahn, 1984). Originally, the *BPI-01* was only offered in German and assessed SIB. However, over time this measure has grown to include various challenging behaviors such as SIB (e.g., self-biting, hair pulling, and pica), stereotypic behavior (e.g., rocking, spinning, and finger movements), and aggressive/destructive behavior (e.g., hitting, biting, pinching; Rojahn, Matson, Lott, Esbensen, & Smalls, 2001). The most recent version of the *BPI-01* consists of 52 items measuring the frequency of each behavior on a five-point Likert scale and severity on a four-point scale (Rojahn et al.). Psychometrically, the *BPI-01* has been found to have excellent interrater reliability, good internal consistency, and good criterion-related validity (Rojahn et al.). While this scale was developed to address problem behaviors of those with intellectual and developmental disabilities as a whole, this advantage can also serve as a shortcoming for those with more specific disabilities (e.g., ASD; Kozlowski, 2010).

Developmental Behavior Checklist (DBC). The *DBC* (Einfeld & Tonge, 1995) is a collection of instruments that can be used to assess the frequency of behavioral and emotional problems in children, adolescents, and adults with developmental and intellectual disabilities. Items on the measure are to be completed based on the behavior of the past 6 months of the individual and are formatted in a Likert scale with "0" corresponding to "not true as far as you know," "1" corresponding to "somewhat or sometimes true," and "2" corresponding to "very true or often true." Two versions of the *DBC*, a primary caregiver version (*DBC-P*) and a teacher version (*DBC-T*), are used to assess problems in children ages 4–18 years old with developmental and intellectual disabilities (Hastings, Brown, Mount, & Cormack, 2001). For each version of the *DBC*, six subscales and a total score are used. The six subscales derived from factor analysis are Disruptive Behavior, Self-Absorbed Behavior, Communication Disturbance, Anxiety, Autistic-Relating Behavior, and Antisocial Behavior (Hastings et al.). Internal

Table 8.1 Standardized assessment measures used for problem behavior

Measure	Target population	Item content	Number of items
Behavior Problems Inventory (BPI-01)	Adolescents and adults with DDs	SIB, stereotypic, and aggressive/destructive behaviors	52
Developmental Behavior Checklist (DBC)	Children, adolescents, and adults with IDs and DDs	Varies according to measure	107
Aberrant Behavior Checklist (ABC)	Children and adults with IDs	Irritability, lethargy, stereotypy, hyperactivity, and inappropriate speech	58
Nisonger Child Behavior Rating Form (NCBRF)	Children with DDs	Conduct problems, insecure anxious, hyperactive, SIB self-isolated, ritualistic, and overly sensitive	62
Disability Assessment Schedule for Problem Behaviors (DAS-B)	Adults with IDs	Aggression, SIB, hyperactivity, among others	14
Pervasive Developmental Disorder Behavior Inventory (PDDBI)	Children with PDDs	Adaptive (e.g., joint attention skills) and maladaptive (e.g., aggressive) behaviors	124/180–188
Reiss Screen for Maladaptive Behavior (RSMB)	Adolescents and adults with ID	Aggressive behavior, psychosis, depression, paranoia	38
Children's Scale of Hostility and Aggression: Reactive/Proactive (C-SHARP)	Aggressive children with IDs or DDs	Verbal aggression, bullying, covert aggression, hostility, physical aggression	52
Stereotyped Behavior Scale (SBS)	Adolescents and adults with ID who engage in stereotyped behaviors	Stereotyped behaviors	24
Repetitive Behavior Scale-Revised (RBS-R)	Individuals with repetitive and restricted behaviors	Stereotyped, self-injurious, compulsive, ritualistic, sameness, and restricted behavior	43
Autism Spectrum Disorders-Behavior Problems for Adults (ASD-BPA)	Adults with ASDs and challenging behaviors	Aggression, destructive behavior, disruptive behavior, SIB	19
Autism Spectrum Disorders-Problem Behavior for Children (ASD-PBC)	Children with ASDs and challenging behaviors	Aggression, property destruction, stereotypy, inappropriate sexual behaviors, odd behaviors	18
Baby and Infant Screen for Children with Autism Traits-Part 3 (BISCUIT-Part 3)	Infants aged 17–37 months with challenging behaviors	Aggressive/destructive behavior, stereotypies, SIB	15

consistency data for the *DBC-P* and *DBC-T* has yielded Cronbach's alpha values ranging from 0.67 to 0.91 for the six subscales (Hastings et al.). Additionally, validity has been established for the *DBC-P* and *DBC-T* with high correlations between these measures and two other measures of behavior disturbance in children with intellectual and developmental disabilities: the *Scales of Independent Behaviour* (Bruininks, Woodcock, Weatherman, & Hill, 1984) and the *American Association on Mental Deficiency Adaptive Behavior Scales* (Lambert & Windmiller, 1981). In addition to the *DBC-P* and the *DBC-T*, which

are measures used for children, the *DBC-A* is a format offered to assess behavioral and emotional problems of adults with developmental and intellectual disabilities. This 107-item checklist focuses on behavior of the person over the past 6 months and is typically completed by family members or caregivers familiar with the individual. Excellent internal consistency has been established for the total scale of the *DBC-A*, $\alpha=0.95$, and adequate, $\alpha=0.60-0.88$, for the subscales (Einfeld & Tonge, 1995). Additionally, concurrent validity has been established between the *DBC-A* and the *Aberrant Behavior Checklist*

(*ABC*; Aman & Singh, 1986) and the *Psychiatric Assessment Schedule for Adults with Developmental Disability Checklist (PAS-ADD Checklist*; Moss et al., 1998). In addition to the *DBC-P*, *DBC-T*, and *DBC-A*, the *DBC* is also offered in a format which allows for early screening of autism in children ages 18–48 months (*DBC-ES*), a screening tool used to identify children ages 4–18 who are at risk for autism, a short form of the *DBC-P* with only 24 items (*DBC-P24*), and a measure used for daily monitoring of specific behaviors (*DBC-M*). Overall, the *DBC* provides many reliable and valid measures for assessing behavioral and emotional problems in children, adolescents, and adults with developmental and intellectual disabilities.

Aberrant Behavior Checklist (ABC). The *ABC* (Aman & Singh, 1986) is a generalized behavior rating scale used to assess problem behaviors in children and adults with ID. The *ABC* consists of 58 items divided into five subscales (i.e., Irritability, Lethargy, Stereotypy, Hyperactivity, and Inappropriate Speech), which were developed by a factor analysis (Aman & Singh; Hill, Powlitch, & Furniss, 2008). Each subscale item is rated using a three-point Likert scale with 0 corresponding to “not at all a problem” to 3 corresponding to “the problem is severe in degree.” Sample items include “hyperactive at home, school, and/or work”; “will not sit still for any length of time”; and “unresponsive to structured activities (does not react)” (Aman & Singh, 1986). Results from a number of studies have yielded criterion validity ranging from adequate to very good (Aman, Singh, Stewart, & Field, 1985; Rojahn & Helsel, 1991). Concerning reliability, Aman et al. (1985) found the *ABC* to have good internal consistency, acceptable inter-rater reliability, and very good test-retest reliability. Additionally, Aman, Singh, and Turbott (1987) investigated the reliability of this measure and found generally comparable levels of inter-rater reliability to previous studies and slightly lower, yet still acceptable, levels of test-retest reliability. In sum, this measure is most useful for situations in which an assessor needs to gather information about the severity of a child or adult’s challenging behaviors.

Nisonger Child Behavior Rating Form (NCBRF). The *NCBRF* (Aman, Tasse, Rojahn, & Hammer, 1996; Tasse, Aman, Hammer, & Rojahn, 1996) is an informant-based behavior rating scale for children ages 3–16 years of age with a DD. Conveniently, this scale has versions designed for both parents and teachers. The scale consists of two subsections (i.e., Social Competence and Problem Behavior) and is a modified version of the *Child Behavior Rating Form* (Edelbrock, 1985). For the Problem Behavior subsection, 62 items comprise six subscales: Conduct Problems, Insecure/Anxious, Hyperactive, Self-Injury/Stereotypic, Self-Isolated/Ritualistic, and Overly Sensitive (Rojahn et al., 2010). The following are sample items of the measure: “fails to finish things he/she starts”; “engages in meaningless, repetitive body movements”; “feeling easily hurt”; and “gouges self, puts things in ears, nose, etc., or eats inedible things.” Items on the Problem Behavior subsection are rated on a four-point scale which accounts for both frequency and severity of the behavior. Tasse et al. (1996) found age and gender norms for the *NCBRF* with a sample of 369 children and adolescents between the ages of 3–16 years. Additionally, several studies have been conducted on the reliability (Lecavalier, Leone, & Wiltz, 2006; Tasse et al., 1996; Tasse & Lecavalier, 2000) and validity (Lecavalier, Aman, Hammer, Stoica, & Mathews, 2004; Tasse & Lecavalier, 2000) of the *NCBRF* with mixed results.

Disability Assessment Schedule for Problem Behaviors (DAS-B). The *DAS-B* (Holmes, Shah, & Wing, 1982) is a measure used to assess the frequency and severity of problem behaviors such as aggression, SIB, and hyperactivity in adults with an ID. The 14-item measure includes items such as “physically aggressive to others”; “self-injury, head banging, picking sores, etc.”; and “over-active, paces up and down, does not sit still” (Tsakanikos, Underwood, Sturmey, Bouras, & McCarthy, 2011). Many researchers have examined the reliability of the *DAS-B* using test-retest and inter-rater reliability and have found acceptable to high reliability (Holmes et al., 1982; Shah & Holmes, 1987; Shah, Holmes, &

Wing, 1982). A recent study by Tsakanikos et al. (2011) found items in the *DAS-B* to be internally consistent with a Cronbach's alpha of 0.87. An independent investigation of the validity of the *DAS-B* is needed; however, the *DAS-B* is time efficient due to the fact that it contains only 14 items (Tsakanikos et al.); however, with its brevity the *DAS-B* does not incorporate an extensive range of challenging behaviors as other measures.

Pervasive Developmental Disorder Behavior Inventory (PDDBI). The *PDDBI* (Cohen, Schmidt-Lackner, Romanczyk, & Sudhalter, 2003) is an informant-based rating scale used to measure maladaptive as well as adaptive behaviors in children ages 2–12 with an ASD. The *PDDBI* can provide age-standardization scores for both parent and teacher versions of this scale. Additionally, these two forms are available in standard (124 items) and extended (180–188 items) formats. The adaptive behaviors assessed by the *PDDBI* include core features of ASDs (e.g., joint attention skills, pretend play, and referential gesture), while some of the maladaptive behaviors include stereotyped behaviors, fears, aggression, social interaction deficits, and aberrant language (Cohen et al.). In 2005, an updated and expanded version of the *PDDBI* was published and included computer scoring software (Cohen & Sudhalter, 2005). Cohen et al. (2003) found the *PDDBI* to have a high degree of internal consistency ranging from 0.80 to 0.98, and inter-rater reliability was better for the adaptive behaviors subscale than the maladaptive behaviors subscale. Cohen et al. (2003) also conducted a factor analysis on the *PDDBI* which confirmed the structure of the measure; good construct validity for the measure was also found. In addition to being a strong tool for measurement of behaviors, the *PDDBI* also is a robust instrument for assessing responsiveness to intervention (Cohen et al.).

Reiss Screen for Maladaptive Behavior (RSMB). The *RSMB* (Reiss, 1988) is a screening instrument for psychopathology (e.g., aggressive behavior, psychosis, depression, and paranoia) in adolescents and adults with ID. The *RSMB*

contains 38 items yielding eight scales and a 26-item total score (Sturmey, Jamieson, Burcham, Shaw, & Bertman, 1996). Normative data are available for individuals from 12 to 70 years of age and for all levels of severity of ID (Havercamp & Reiss, 1997). Sturmey and Bertman (1994) investigated the validity of the *RSMB* by correlating 81 subjects' scores on the *RSMB* with their scores on the *Psychopathology Inventory (PPI)* and *ABC*. The researchers found that the *RSMB* showed modest to good concurrent validity with the *PPI* and *ABC* (Sturmey & Bertman). The *RSMB* has also been shown to have modest to good inter-rater and test-retest reliability (Sturmey et al., 1996). The *RSMB* has an advantage over some of the other measures mentioned in this chapter in that it assesses not only problem behaviors but also psychopathology.

Children's Scale of Hostility and Aggression: Reactive/Proactive (C-SHARP). The *C-SHARP* (Farmer & Aman, 2009) is a tool used to gain an in-depth analysis of aggression in children with intellectual or developmental disabilities. The *C-SHARP* contains five empirically derived subscales: Verbal Aggression (12 items), Bullying (12 items), Covert Aggression (11 items), Hostility (nine items), and Physical Aggression (eight items; Farmer & Aman, 2011). Sample items from the measure include "breaks others' things," "intimidates others," "is overly argumentative," and "encourages others to gang up on someone." Each of the 52 items is rated on two different Likert scales. One scale (the Problem Scale) pertains to the severity of aggressive and hostile behaviors and the other scale (the reactive scale) examines proactive or reactive qualities of the aggression (Farmer & Aman, 2009). Proactive aggression is typically predatory and calculated, such as what you see in some types of bullying behaviors, whereas reactive aggression is usually fear-based and a reaction to a threat or anxiety. Reliability studies of the *C-SHARP* yield that inter-rater reliability of the Problem Scale is very high and that inter-rater reliability of the Provocation Scale is slightly lower however still acceptable (Farmer & Aman, 2010). Additionally, validity was shown in the

Problem Scale by expected differences in children with autism, Down syndrome, comorbid disruptive behavior disorders, and attention-deficit/hyperactivity disorder (ADHD). Validity was also shown in the Provocation Scale with differences in children with disruptive behavior disorders, however, was less effective in those with ADHD (Farmer & Aman).

Stereotyped Behavior Scale (SBS). The *SBS* (Rojahn, Tasse, & Sturmey, 1997) is an empirically developed 24-item behavior rating scale for adolescents and adults with intellectual disabilities exhibiting stereotyped behaviors. Sample items on the *SBS* include “rocks back and forth” and “has repetitive hand movements” (Rojahn et al.). Each item is rated on two scales: a six-point frequency-of-occurrence scale and a four-point severity scale (Rojahn et al.). Reliability studies of the *SBS* have been conducted by Rojahn, Matlock, and Tasse (2000) yielding test-retest coefficients of 0.93 and 0.71 for the frequency and severity scales, respectively; inter-rater reliability of 0.76 and 0.75 for the frequency and severity scales, respectively; and internal consistency alphas of 0.91 for each (Rojahn et al.). For criterion validity, the *SBS* frequency and severity scores correlated with the *Aberrant Behavior Checklist-Residential (ABC-R)* “Stereotypy” score at 0.80 and 0.84 (Pearson r) and with the a priori classification at 0.50 and 0.65 (Spearman p ; Rojahn et al.). In sum, the *SBS* is an excellent scale for gathering frequency and severity information about stereotyped behaviors in adolescents and adults.

Repetitive Behavior Scale-Revised (RBS-R). The *RBS-R* (Bodfish, Symons, Parker, & Lewis, 2000) is a 43-item measure designed to measure restricted and repetitive behaviors observed in individuals with an ASD. On the *RBS-R*, Bodfish et al. (2000) included items pertaining to stereotypic behavior, SIB, compulsions, ritualized behaviors, insistence on sameness, and restricted interests. These items were adapted from the *Autism Diagnostic Interview-Revised (ADI-R*; Lord, Rutter, & Le Couteur, 1994), the *Childhood Routines Inventory* (Evans et al., 1997), the

Sameness Questionnaire (Prior & MacMillan, 1973), and the *Abnormal Focused Affections Checklist* (Schultz & Berkson, 1995). Family members or caregivers rate each item based on a four-point Likert scale with 0 representing “behavior does not occur” to three representing “behavior occurs and is a severe problem.” Raters are asked to answer the questionnaire based on the past month of the client’s behavior. The items are grouped into six subscales that were conceptually grouped: Stereotyped Behavior, SIB, Compulsive Behavior, Ritualistic Behavior, Sameness Behavior, and Restricted Behavior (Lam & Aman, 2007). Subscale inter-rater reliability ranged from 0.55 for the Sameness Behavior subscale to 0.78 for the SIB subscale, and test-retest reliability ranged from 0.52 for the Ritualistic Behavior subscale to 0.96 for the Restricted Interests subscale (Bodfish & Lewis, 2002). Lam and Aman (2007) also found high internal consistency and inter-rater reliability for the measure. The *RBS-R* and *SBS* are similar in their item content. The advantage the *RBS-R* has over the *SBS* is that it covers a broad range of stereotyped behaviors; however, the *RBS-R*’s disadvantage is that it does not measure the severity of the behaviors like the *SBS*.

Autism Spectrum Disorders-Behavior Problems for Adults (ASD-BPA). The *ASD-BPA* is a 19-item measure developed to measure challenging behaviors (e.g., aggression, SIB, disruptive behavior) in adults with an ASD and comorbid ID. The *ASD-BPA* is part of a comprehensive assessment for adults with autistic disorder and Pervasive Developmental Disorder-Not Otherwise Specified along with the *ASD-Diagnosis for Adults (ASD-DA)* and *ASD-Comorbidity for Adults (ASD-CA)*. The *ASD-BPA* is intended to be used as a screener to determine if a further investigation for the frequency, intensity, and duration of their challenging behaviors is needed (Matson & Rivet, 2007). The 19 items of the *ASD-BPA* are rated either as 0=“not a problem” or 1=“problem, impairment.” Sample items from the *ASD-BPA* include “harming self by hitting, pinching, scratching, etc.”; “repeated and unusual body movements (e.g., hand flapping, waving arms)”;

and “property destruction (e.g., ripping, breaking, tearing, crushing)” (Matson & Rivet). The three subscales derived from a factor analysis include the following: Aggression/Destruction, Disruptive Behavior, and SIB. A total score is also computed for further interpretation. Matson and Rivet (2007) investigated the validity of the *ASD-BPA* by correlating it to the already established *BPI-01* (Rojahn et al., 2001) and found there to be good validity. In sum, the *ASD-BPA* is a good quick screener for examining the prevalence of challenging behaviors and can be used in conjunction with the *ASD-DA* and *ASD-CA* to obtain information about autistic symptoms and other psychopathology of the individual.

Autism Spectrum Disorders-Problem Behavior for Children (ASD-PBC). In addition to the *ASD-BPA*, the *ASD-PBC* is an 18-item informant-based measure used for children with an ASD and comorbid challenging behaviors (Matson, Mahan, Hess, Fodstad, & Neal, 2010). The measure is part of a comprehensive battery of measures for children to assess problem behaviors, comorbid psychopathology, and ASD symptoms among children with ASDs. Each item on the scale is based on a two-point Likert scale with 0 equivalent to “not a problem or impairment,” 1 equivalent to “mild problem or impairment,” and 2 equivalent to “severe problem or impairment.” Caregivers rate items according to recent severity exhibited by the child. The 18 items yield an externalizing composite, internalizing composite, and total score (Matson et al.). Items on the externalizing scale assess aggression toward self and others and property destruction; whereas, items on the internalizing scale focus on stereotypy, inappropriate sexual behaviors, and odd behaviors. With regard to reliability of the *ASD-PBC*, past studies have found the internal consistency to be 0.90, test-retest reliability to be 0.64, and a mean inter-rater reliability of 0.49 (Matson, Gonzalez, & Rivet, 2008). Mahan and Matson (2011) demonstrated the convergent and discriminant validity of the *ASD-PBC* against the *Behavioral Assessment System for Children, Second Edition* (Reynolds & Kamphaus, 2004).

Baby and Infant Screen for Children with aUtism Traits-Part 3 (BISCUIT-Part 3). The *BISCUIT-Part 3* is a 15-item informant-based measure designed to measure challenging behaviors such as aggression, stereotypies, and SIB in infants aged 17–37 months with autistic traits (Rojahn et al., 2009). The *BISCUIT-Part 3* is part of a larger battery of assessments which also includes a section designed to assess symptoms of ASDs (*BISCUIT-Part 1*) and a section designed to assess symptoms of comorbid psychopathology (*BISCUIT-Part 2*). The 15 items on the *BISCUIT-Part 3* are scored on a three-point Likert scale with 0=“not a problem or impairment, not at all”; 1=“mild problem or impairment”; and 2=“severe problem or impairment” (Rojahn et al.). Sample items on the measure include “poking him/herself in the eye,” “unusual play with objects (e.g., twirling string, staring at a toy),” and “pulling others’ hair.” A factor analysis conducted by Matson, Boisjoli, Rojahn, and Hess (2009) yielded three factors for the *BISCUIT-Part 3* which include aggressive/destructive behavior, stereotypies, and SIB. Additionally, Matson, Wilkins, et al. (2009) investigated the reliability for the *BISCUIT-Part 3* and found excellent internal consistency, $\alpha=0.91$. No validity information is currently available on the *BISCUIT-Part 3*.

Standardized Assessments for Pretreatment Functional Assessment

Following the acquisition of general data, commonly accepted practice is to conduct a pretreatment functional assessment. This will identify any maintaining variables that reinforce the problem behavior (Carr et al., 2000). Standardized assessment is one method used to do so. Below are some common informant-based assessments used for pretreatment functional assessment. See Table 8.2 for a reference to these measures, their target audiences, potential functions assessed, and length.

Questions About Behavioral Function (QABF). In 1995, Matson and Vollmer developed the

Table 8.2 Standardized assessments for pretreatment functional assessment in individuals with DDs

Measure	Target population	Potential functions measured	Items
Motivation Assessment Scale (MAS)	Individuals with challenging behaviors	Attention, escape, tangibles, and sensory consequences	16
Questions About Behavioral Function	Individuals with DDs and challenging behaviors	Attention, escape, tangible, nonsocial, physical	25
Functional Analysis Checklist (FAC)	Individuals with challenging behaviors	Biological factors, physical environment, communication, escape/demand factors, elicited or adjunctive behavior, activity transitions, and positive reinforcement	41
Functional Analysis Interview Form (FAIF)	Individuals with challenging behaviors	Various potential functions (structured interview)	32
Functional Assessment for multiple Causality (FACT)	Individuals with challenging behaviors with multiple functions	Attention, escape, tangible, nonsocial, and physical	35
Motivation Analysis Rating Scale (MARS)	Individuals engaging in SIB and stereotypy	Positive environmental consequences, task escape/avoidance, and self-stimulation	

QABF in order to help determine the function of challenging behaviors in individuals. This 25-item measure was specifically designed for use with persons with a DD. During an interview with an informant, all items are scored along a four-point scale, which produces summary statistics for five different functions on a score sheet. Based upon one's scores, behavior can be found to be maintained by any of the following functions: attention, escape, physical, nonsocial, and tangible (Matson & Vollmer, 1995). Sample items on the scale include "engages in the behavior to get attention," "engages in the behavior when there is something bothering him/her physically," and "engages in the behavior in a highly repetitive manner, ignoring his/her surroundings." As this instrument has good test-retest reliability, inter-rater reliability, stability, and convergent validity (Matson et al., 1999; Paclawskyj, Matson, Rush, Smalls, & Vollmer, 2000, 2001; Singh et al., 2006), the *QABF* is a sound measure to assess the function of behavior among the DD population (Sturmey, 1996).

Motivation Assessment Scale (MAS). Another example of a questionnaire which assesses behavioral functions is the *MAS* (Durand & Crimmins, 1992), which consists of 16 items scored along a seven-point Likert scale from *never* to *always*. Subscales include attention, escape, tangibles, and sensory consequences. Sample items found

on the *MAS* include "does the behavior seem to occur in response to your talking to other persons in the room?"; "does the behavior stop occurring shortly after you give this person the toy, food, or activity he or she has requested?"; and "does it appear to you that this person enjoys performing the behavior?" A sample of 50 children with developmental delays and SIB was assessed using the *MAS* to develop psychometric properties for this scale (Durand & Crimmins, 1988). Inter-rater and test-retest reliabilities were both found to be high. Iwata, Dorsey, Slifer, Bauman, and Richman (1982) and Durand, Crimmins, Caulfield, and Taylor (1989) found the *MAS* to have excellent validity as well. While initial studies found the *MAS* to be psychometrically sound, other researchers were unable to replicate such findings. For example, a 1991 study found the *MAS* to have an inter-rater reliability ranging from 0.20 to 0.70 and poor internal consistency (Newton & Sturmey, 1991). Two other studies have found similarly disappointing results (Goza & Ricketts, 1993; Zarcone, Rodgers, Iwata, Rourke, & Dorsey, 1991). While the *MAS* may be considered by some to be a hallmark in this area of study as it is the first of its kind, other instruments have proven to be strong contenders as they have surpassed the *MAS* psychometrically.

Functional Analysis Checklist (FAC). The *FAC* (Van Houten, Rolider, & Ickowitz, 1989) is

another functional assessment measure that has been created to examine variables which control challenging behaviors in individuals. The *FAC* is a 41-item questionnaire administered to caregivers and family members. For each problem behavior item, the caregiver or family member will respond “yes” or “no” in regard to if this behavior is exhibited by the individual in question. If the informant answers “yes,” then they are required to provide further details concerning whether that behavior is associated with biological factors, physical environment, communication, escape/demand factors, elicited or adjunctive behavior, activity transitions, and/or positive reinforcement (Sturmey, 2001). One should use caution when administering and interpreting the *FAC*, as it has been found to have poor to mediocre reliability and especially poor inter-rater reliability (Sturmey).

Functional Analysis Interview Form (FAIF). Another interview/checklist used to obtain information about the functions of behavior is the *FAIF* (O’Neill, Horner, Albin, Storey, & Sprague, 1990). This 45–90-min structured interview consists of nine sections: (1) the behaviors; (2) potential ecological events; (3) events and situations that predict occurrences of the behavior, (4) identifying the functions of the undesirable behaviors; (5) the efficiency of the undesirable behaviors; (6) the person’s primary methods of communication; (7) events, actions, and objects that the person perceives as positive; (8) functional alternative behaviors; and (9) history of the behaviors including previous programs (Paclawskyj, Kurtz, & O’Connor, 2004). Each section consists of several open-ended questions related to the challenging behavior (Sturmey, 1994). These measures yield detailed information concerning the client’s problem behaviors, potential maintaining variables, functional alternative responses, and previous treatment attempts. A major problem with the *FAIF* is that there is no current psychometric data available on this instrument (Sturmey). Unlike the *MAS* and *Motivation Analysis Rating Scale (MARS)*, the *FAIF* not only addresses the potential motivation for challenging behavior, it also explicitly collects data on antecedents, settings, response

classes, and alternative functional behaviors. Also, as many of the standardized measures discussed in this chapter are rating scales, the *FAIF* is a useful tool as it allows caregivers to offer their point of view in a structured format.

Motivation Analysis Rating Scale (MARS). The *MARS* (Weiseler, Hanson, Chamberlain, & Thompson, 1985) was developed in order to determine the functions specifically for SIB and stereotypy (Sturmey, 1994). The *MARS* consists of six items based on a four-point Likert scale (“almost never,” “less than 50 % of the time,” “more than 50 % of the time,” and “almost always”). The six items are grouped into three pairs, and each pair of items summed together yields one of the three scaled scores: positive environmental consequences, task escape/avoidance, and self-stimulation (Sturmey). Weiseler et al. (1985) conducted studies examining the reliability and validity of the *MARS*. Inter-rater agreement on the primary motivating consequence was found to be at 73 %. Additionally, validity data was collected by comparing *MARS* data with naturalistic observations of the antecedents and consequences of the target behavior (Weiseler et al.). For the individuals for whom both raters were able to agree on the primary motivating consequence, 95 % agreement was found between the two methods for detecting the primary motivating consequence. Nevertheless, there are many problems with the *MARS*. For example, no other studies besides the original Weiseler et al. (1985) have been published on this scale. Additionally, while the brevity of this measure may be appealing to some, one cannot dismiss the fact that the total score is calculated from only six items.

Functional Assessment for multiple CausaliTy (FACT). While the above pretreatment functional assessment measures (i.e., *QABF*, *MAS*, *FAC*, *FAIF*, and *MARS*) identify the maintaining variables of the individual’s behavior, the *FACT* allows the clinician to determine which is the primary function. The *FACT* is a measure constructed to identify a hierarchy of behavioral functions for individuals with ID who present

with maladaptive behaviors with multiple functions. This informant-based, forced-choice measure consists of 35 items to identify the most prominent function associated with the occurrence of the challenging behaviors. The forced-choice procedure pairs each item on the *QABF* with each other, asking which is more fitting for the individual. A sample item of the *FACT* is “engages in the behavior more (A) because he/she likes to be reprimanded, or more (P) when he/she is ill, or (N) neither.” The *FACT* is a useful second tier instrument to identify behavior function if the *QABF* or other similar measures yield multiple functions of the challenging behavior (Matson, Kuhn, et al., 2003). Results from this measure inform clinicians to the primary function of a challenging behavior as expressed through higher elevations on the subscales. The five potential functions used in the measure include the same functions seen with the *QABF* (i.e., tangible, physical, attention, escape, and nonsocial functions). The *FACT* was normed on 197 individuals residing in a large southeastern developmental center. Zaja, Moore, van Ingen, and Rojahn (2010) found this measure to have good reliability. Mean inter-rater reliability across two administrations ranged from 0.65 to 0.78, and mean test-retest reliability ranged from 0.86 to 0.87. All subscales proved to have excellent internal consistency with coefficients ranging from 0.92 to 0.96. While this scale may not be best for initially identifying behavioral functions, the *FACT* is useful in guiding which maintaining variable to target during treatment interventions should there be multiple functions of the behavior.

Descriptive Assessment

Although many of the informant-based measures mentioned thus far are reliable, Thomas points out in her 1929 paper the need for behavioral assessment techniques which unite the richness of the descriptive reports and the standardization of the informant-based assessment. Today, best practice expects clinicians to incorporate data from a number of different methods and sources to inform their diagnostic and/or treatment

decisions. Therefore, in addition to a standardized assessment, it is important to directly observe the behavior as well. Observation methods supplement the informant-based material to allow for a more comprehensive functional behavior assessment.

As much research blurs the line between observational methods of assessment and experimental functional analysis (EFA), it is essential to distinguish the two. Unlike EFA, descriptive assessment or naturalistic observation methods do not manipulate the individual’s environment to inspect variables which may be influencing or maintaining the challenging behavior. Instead, the clinician assesses circumstances in which the behavior occurs by simply observing the individual in their natural setting (Gardner, 2000). This method allows for greater understanding of how the behavior presents itself in the individual’s typical setting; whereas, if the individual was observed in a clinic or laboratory setting, the frequency, intensity, and duration may change for a number of reasons (e.g., the unfamiliarity of the setting; Gardner). Nevertheless, the observer-reaction paradigm states that the act of observing someone regardless of the setting will likely change their behavior (Kazdin, 1982; Lipinski & Nelson, 1974; Nelson, Lipinski, & Black, 1976). Additionally, descriptive assessments are not only more commonly used in clinical practice than EFAs (Tarbox et al., 2009), but one study found that descriptive assessments were also thought to be more useful than EFAs by members of the Psychology Division of the American Association on Mental Retardation (Desrochers, Hile, & Williams-Mosely, 1997).

Another advantage of descriptive assessments is that they call for direct observation and description of the behavior in real time, thereby providing the opportunity for observers to take note of several variables which may be related to the presence of the behavior (Tarbox et al., 2009). Also, as mentioned earlier, informant-based assessments have many confounding variables (e.g., personal biases and faulty recollection; Eddy, Dishion, & Stoolmiller, 1998; Fergusson, Lynskey, & Horwood, 1993). These methods do not rely upon retrospective report as many

standardized assessments do, thus avoiding these shortcomings. Others have indicated, however, that direct observation is also subject to similar biases. For example, Harris and Lahey (1982) outlined several potential sources of bias during behavioral observations: *expectation bias* (e.g., reporting fewer occurrences of the behavior when the observer expects there to be a decrease possibly due to treatment), *observer drift* (i.e., observers stray from the original definition of the behavior over time), *consensual observer drift* (i.e., observers modifying their recordings to better agree with the other observer with whom they have previously compared their recordings), *coding complexity* (e.g., the greater the complexity of the recording sheet, the less accurate the recordings of the observer becomes), and *predictability of behavior* (e.g., observers who are collecting data on an individual's behavior which is known to be very predictable are more likely to make commission errors—reporting that the behavior occurred when it actually did not). The plethora of potential biases that could occur during direct observation support the need for highly trained and educated observers when conducting this type of assessment.

Another disadvantage of direct observation is that it is usually quite time consuming, especially if a narrative account is required (Arndorfer & Miltenberger, 1993; Gardner, 2000). Secondly, if the behavior is of low frequency, then it may not even occur during the period of observation (Tarbox et al., 2009); thus, this type of assessment is best for high-frequency, low-intensity behaviors (Matson & Nebel-Schwalm, 2007). Additionally, while the correlational quality of the gathered information can be informative, it does not imply that the target behavior occurs as a function of the antecedents and consequences (Lennox & Miltenberger, 1989; Tarbox et al., 2009). For example, since most challenging behaviors are generally followed by some sort of reprimand, an inexperienced observer may infer that the function of the target behavior is attention, whereby attention may, in fact, be unrelated to the behavior's occurrence.

Other problems with direct observation methods involve limited reliability. In 1970, Reid

conducted a study in which one experimental group consisted of observers who were informed that their observations would be compared to another assessor's observations for reliability and the other experimental group consisted of observers who were not aware that their observations would be compared to another assessor's observations. Those who were informed of this reliability check had greater reliability than those who were not informed. This shows how invariable one's data collection can be. Others have replicated these findings as well (e.g., Harris & Lahey, 1982; Romanczyk, Kent, Diamant, & O'Leary, 1973). Additionally, if the operational definition of the target behavior is not explicitly stated to all observers, then it is likely that there will be great disparity among observers (Romanczyk et al.). One observer, for example, may consider raising a fist at another as aggression, while another observer may only consider acts which actually make physical contact as forms of aggression. Another common problem with direct observation techniques is determining when to discontinue data collection (Lipinski & Nelson, 1974).

The multiple forms of descriptive assessment, along with the advantages and disadvantages of each method, will be discussed here further. In general, there are two types of direct observation methods, which include event recording and time sampling (Bijou et al., 1968; Mace, Lalli, & Lalli, 1991; Touchette, MacDonald, & Langer, 1985).

Event Recording

Two common types of event recording are contingency event recording and continuous event recording. The similarities and differences between these two methods will be discussed.

Contingency Event Recording

Being the most prevalent method of descriptive assessment, contingency event recording, otherwise known as Antecedent-Behavior-Consequence (A-B-C) assessment, was one of the first functional behavioral assessment methods utilized in applied settings. This method was developed by Bijou

et al. (1968). Real-time data are gathered on any environmental events which immediately precede the behavior (i.e., antecedents), the challenging behavior itself (i.e., behavior), and any environmental events which follow the problem behavior's occurrence (i.e., consequences). The information collected is typically recorded in a descriptive or narrative manner on a recording sheet with separate columns for antecedents, behaviors, and consequences (Arndorfer & Miltenberger, 1993; Rojahn, Schroeder, & Hoch, 2008; Rojahn, Whittaker, Hoch, & Gonzalez, 2007). The ultimate goal of completing several A-B-C sheets is to over time gain knowledge of the frequency of the behavior, when it is most likely to occur, and possibly the duration of the behavior (Rojahn et al., 2007). Based upon this information, hypotheses are developed regarding the function of the behavior (Arndorfer & Miltenberger, 1993). Although this method gives much freedom to the observer in regard to what data is actually recorded, there are a number of drawbacks to this style of data collection. First, this narrative style recording requires great attention from the observer to actually transcribe their descriptive account, thereby limiting their available attention to allot to the behavior itself (Lipinski & Nelson, 1974). Also, the descriptive nature of these sheets causes the task to be quite time consuming (Arndorfer & Miltenberger, 1993). Please see Appendix for an example of a blank A-B-C sheet.

Other forms of data collection are A-B-C checklists, which are easy to complete and often less time consuming. This is best for situations in which the observer is also interacting with or caring for the person being observed during the time of data collection. While this is not an ideal situation, parents or teachers are often the ones given the task to collect data. A-B-C checklists, thus, do not require narrative accounts on each occurrence of the behavior and allow the observer to minimize distraction from caring for the individual. One study comparing the more descriptive A-B-C sheets with A-B-C checklists found that teachers and paraprofessionals preferred the structured checklists, which also proved to be slightly more accurate than the descriptive recording

sheets (Lerman, Hovanetz, Strobel, & Tetreault, 2009). Although descriptive A-B-C sheets allow the observer freedom to take note of anything they feel may be relevant, A-B-C checklists also have the advantage of cuing the observer on certain antecedents or consequences that they may not have even considered prior to reading the checklist.

One example of this form of A-B-C data collection is the *Functional Assessment Observation Form (FAOF)* developed by O'Neill et al. in 1997. Each sheet is headed with the individual's name and date of observation. One form can be used across multiple days. Observation time intervals are also noted on the form (e.g., 1 h, 30 min). The observer notes the times of each observation interval and during which settings or activities the observation is happening. For example, if the individual is in school, then the class times and subjects are listed. The observer can also opt to use time intervals of differing lengths at different times of the day or during different activities depending upon their behavioral pattern. The behaviors, antecedents, functions, and consequences are offered in checklist format. The checklist of behaviors can be very flexible. For instance, one can decide to list positive behaviors if these need to be tracked as well. Behaviors that occur at both high and low intensity can also be listed as separate behaviors entirely. Or, behaviors that occur together can be grouped together as one behavior on the form. Blanks are also provided to include any other antecedents or consequences which are not provided on the form. Antecedents that are provided include demand/request, difficult task, transitions, interruption, and alone (no attention). Listed consequences include attention, desired item/activity, self-stimulation, demand/request, activity, person, and other/don't know.

Murdock, O'Neill, and Cunningham (2005) inspected the reliability and validity of a number of different data collection methods, one of which was the *FAOF*. Participants of this study included eight boys ranging in age from 12 to 15 years each with a behavior disorder. Interobserver agreement for the *FAOF* was estimated to be 80 % with much of the disparity occurring in the perceived function category of the form.

Research conducted since the founding of A-B-C assessment has been promising. Repp, Felce, and Barton (1988) found that interventions based upon functions gathered by direct observations were more effective than ones that were not informed. Other researchers have reported similar experiences (e.g., Smith, 1985). Furthermore, the increasing technological advancements of today's world have allowed data collection techniques to progress as well, as personal data assistants are sometimes utilized to gather data electronically (Tarbox et al., 2009). While more research in this area is needed, this advancement is promising as it offers several benefits including simplicity and computerized programs for data storage and analysis (Tarbox, Wilke, Findel-Pyles, Bergstrom, & Granpeesheh, 2010). Tarbox et al. (2010) compared electronic to traditional pen-and-paper data collection during discrete trial training for four children with autism. The authors concluded that while both formats are of approximately equal accuracy, traditional data collection is quicker during observation periods. The amount of time saved, however, was not vast.

Continuous Event Recording

A 1991 paper by Mace et al. describes continuous event recording. This form of data collection differs from the aforementioned contingency event recording in that all antecedents are recorded by the observer even if they are not followed by the targeted behavior. First, the observer conducts unstructured observations of the individual and creates lists of all possible antecedents, behaviors, and consequences based upon their findings. The authors have found that there are usually three to five identified possibilities for each factor (i.e., antecedents, behaviors, consequences) and that each one can range from broad to narrow depending on what is deemed appropriate for the individual. It is encouraged that two observers conduct the observation to establish interobserver agreement. Mace et al. (1991) also advise on predetermining time intervals for data collection. The authors state that the observation sessions can range from 15- to 60-min sessions and suggest that each session be divided evenly into 10-s time intervals. All antecedents and

behaviors are recorded, and any consequences occurring within 30 s of the targeted behavior are also noted. It should be noted that these time frames are simply suggestions put in place by Mace et al. (1991) and can be altered for the needs of each individual. This form of descriptive assessment offers unique advantages because it allows the observer to calculate how often the targeted behavior actually followed an antecedent and how often a certain consequence followed a certain challenging behavior.

Time Sampling

There are three primary forms of time sampling: whole-interval time sampling (WTS), partial-interval time sampling (PTS), and momentary time sampling (MTS). Time sampling does not require the observer to observe the behavior continuously during data collection. Rather, the observer will divide the observation session into time intervals (e.g., 15 s) and record behavior that occurs during that interval. WTS, however, requires that the behavior occurs throughout the entire time interval; therefore, if the behavior does not occur for the full 15 s, then it would not be recorded. In contrast, PTS only requires the behavior to occur at some point during the interval. Finally, MTS only records a behavior if it occurs precisely at a predetermined moment, typically at the end of a time interval (Gardenier, MacDonald, & Green, 2004). For example, the observer may observe behavior for 1–2 s at the end of each time interval and record any behavior which happens at that moment. When utilizing time-sampling techniques, the level of reliability varies as the number of behaviors which are being targeted changes (Lipinski & Nelson, 1974). For example, reliability is generally higher when only two behaviors are being tracked rather than when there are six targeted behaviors.

These methods of data collection are best for observers who are expected to collect data while teaching, caring for, or interacting with the individual as you do not have to continuously record data. Nonetheless, there are a number of disadvantages with time-sampling methods as well.

First, these methods do not record any antecedents or consequences of the behaviors. This information, as previously mentioned, is vital to determining hypotheses of maintaining variables/functions which are necessary to inform effective treatments. Second, these forms of data collection are not ideal for behaviors which occur at low frequencies. If the behavior does not occur at high rates, it is unlikely that it will occur once every 15 min or so; therefore, information from the time sampling will likely be either uninformative or contraindicated. Those with mental illness often exhibit low-frequency, high-intensity challenging behaviors, making time sampling, along with many other direct behavioral observations, ineffective (Singh et al., 2006).

Repp, Roberts, Slack, Repp, and Berkler (1976) compared MTS and PTS in assessing rate of responding. The authors concluded MTS to be very inaccurate, and PTS accurately recorded low and medium rates of responding but underestimated high-rate responding. This suggests that PTS is a superior method of descriptive assessment. It should be noted that the definition of MTS slightly differed in this study than what is commonly accepted—the definition previously mentioned. Furthermore, some contradicting results were found in 1975 when Powell, Martindale, and Kulp compared WTS, PTS, and MTS in assessing the duration of in-seat behavior of a participant in 20-min videotaped sessions. PTS overestimated duration of the behavior, and WTS underestimated this behavioral construct. MTS was found to overestimate behavior duration in some instances and underestimate it in others; nevertheless, MTS produced less error than the other two forms of time sampling. Powell, Martindale, Kulp, Martindale, and Bauman (1977) replicated these findings in a follow-up study. PTS once again overestimated the duration of the behavior being targeted, WTS underestimated the duration, and MTS over- and underestimated behavior. To shed more light onto these issues, Harrop and Daniels (1986) compared MTS to PTS once again. In regard to measuring duration of the behavior, MTS was found to be superior. However, PTS better detected changes in rates of the behavior than MTS did. It

should be noted that all of these studies utilized a computer simulation program, limiting the influence of natural behavior.

More recently, PTS and MTS were compared in assessing durations of stereotypic behavior in children with an ASD (Gardenier et al., 2004). Unlike the studies that were previously described, the authors utilized real behavior rather than a computer simulation program. Nevertheless, the findings were similar. PTS overestimated the duration by approximately 164 %, and MTS both over- and underestimated the duration of stereotypy by an average of 12–28 %. More research is needed to clearly distinguish which time-sampling methods surpass others for various challenging behaviors, frequencies, and durations.

Scoring and Interpretation

While there is no agreed-upon gold standard for analyzing A-B-C data, a number of methods have been researched and developed. One such method is calculating conditional probabilities to interpret descriptive functional assessment data (Iwata, Kahng, Wallace, & Lindberg, 2000; Lerman & Iwata, 1993). When calculating conditional probabilities, investigators are looking for a relationship between the behavior and either its antecedents, consequences, or concurrent events. Contingency event-recording data may be analyzed by calculating conditional probabilities (Lerman & Iwata). First, the proportion of times the target behavior followed each antecedent out of all of the times the target behavior occurred is calculated. In addition, the percentage of times each consequence followed the target behavior is also calculated. Conditional probabilities may also be calculated for continuous event recording with additional calculations possible. For example, intervals during which a specific antecedent preceded the target behavior divided by the number of intervals containing that specific antecedent can also be calculated since all antecedents are documented regardless of whether or not they are followed by the target behavior. Therefore, this data allows the clinician to determine how often the target behavior actually followed the

antecedent—perhaps the antecedent occurred frequently without a subsequent occurrence of the target behavior. While calculating conditional probabilities can provide useful information in interpreting descriptive functional assessments, it also generally requires specialized equipment such as electronic data collection which is not realistic for many real-life settings.

A second method for interpreting descriptive functional assessment data is to do a simple visual inspection of recorded frequencies of antecedents, behaviors, and consequences. This method is straightforward and low tech, as compared to the more complicated conditional probabilities method. If the most repeatedly recorded antecedents and consequences both suggest the same function, then it is realistic to theorize that the suggested function may be correct. However, if the functions of the antecedent and consequence do not align, then this interpretation becomes less clear.

Scatter-Plot Assessment

The scatter-plot assessment is the simplest method of descriptive analysis which reveals temporal distributions of behavior (Touchette et al., 1985). Observers of the scatter-plot technique record the frequency of certain challenging behaviors within a specified predetermined block of time throughout the day. This helps to determine whether there is any reliable distribution of the behavior across the day. Although these time intervals can be hour or half hour blocks of time throughout the day, it is strongly suggested that the time periods represent different activities occurring during the day or even other changes in the environment, such as staff shift changes. Recording data according to differing environmental aspects will allow for easier interpretation of the data. Scatter-plot data is simpler to collect in comparison to contingency or continuous event-recording data because its collection only requires that an individual denotes whether or not the target behavior occurred during the specified time interval rather than supplies a descriptive narrative account or determines the antecedents

or consequences of the behavior. Data collection can be implemented in two ways—either frequency data can be collected with a tally mark being placed in the time period during which the target behavior occurred or data can be plotted on a grid during the observation period. If a pattern is found, then the individual's schedule is modified in an attempt to reduce the frequency of the challenging behavior. Although the scatter-plot method produces measurable data, there is no way to obtain information about the antecedents and consequences of the behavior, and the method will only detect those environmental conditions that are related to the behavior on a consistent basis (Axelrod, 1987).

Conclusion

Problem behaviors are a common occurrence in individuals with DDs and present many challenges for both the individual and caregivers assisting the individual (Farmer & Aman, 2011; Matson & Shoemaker, 2009). In dealing with challenging behaviors, it is essential to utilize structural and functional behavioral assessments to determine topographical information and the maintaining variables of the problem behavior. EFA, which is often deemed the gold standard of functional behavioral assessment methods, is not always practical, safe, or even possible. Therefore, alternative functional behavioral assessment techniques are often deemed necessary (e.g., standardized and descriptive assessments).

Within the current chapter, various standardized and direct observation methods commonly used to aid in functional behavioral assessment have been reviewed. All of these assessments have their own strengths and weaknesses, which have been addressed accordingly. Based on the information presented, while many problem behavior assessment techniques exist, none are without flaws. Despite the fact that standardized and descriptive assessments have different advantages and disadvantages to consider prior to beginning any behavioral assessment, the key to a comprehensive problem behavior assessment does not rely on only one method but rather a

collaboration of different methodologies to assist in the treatment planning process. Furthermore, problem behavior assessments should be individualized so that one set protocol is unlikely to be appropriate for all cases.

Didden (2007) proposes a seven-step blueprint for conducting a comprehensive functional behavioral assessment: (1) identify and operationally define the targeted challenging behaviors; (2) utilize direct observation methods such as contingency event recordings and scatter plots; (3) administer interviews and scales to those familiar with the individual; (4) complete an EFA; (5) integrate results from functional behavioral assessment to formulate hypotheses regarding the function(s) of targeted challenging behaviors; (6) develop a treatment plan based on the derived function maintaining the targeted

challenging behavior(s); and (7) monitor effectiveness of treatment interventions. Although this seven-step plan appears to be without question the ideal assessment, in most cases it is not practical. Therefore, in cases in which a comprehensive functional behavioral assessment involving an EFA is not feasible, it is proposed that alternative, brief functional behavioral assessment strategies be used initially with a progression to more time-consuming and labor-intensive methods as deemed necessary (Vollmer, Marcus, Ringdahl, & Roane, 1995). While many time-saving techniques have been devised within functional behavior assessment, it is imperative that future research continues to compare the various types of behavioral assessment as they are likely to differentially impact treatment effectiveness (Herzinger & Campbell, 2007).

Appendix

ABC Analysis

Date ___/___/___ Name of Person Observed: _____ Observer: _____
Behaviors(s): _____

Date	Time	Antecedent	Behavior	Consequence	Possible Function

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Functional Analysis of Problem Behavior

9

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The estimated prevalence of severe problem behavior among individuals with intellectual and developmental disabilities (IDD) is reported to be between 5 and 10 %, while prevalence estimates increase to as high as 50 % when less-severe problem behavior is included (Condillac, 2007; Lowe et al., 2007). Commonly reported topographies of problem behavior include self-injurious behavior (SIB), aggression, property destruction, sexual misconduct, running away (elopement), tantrums, stereotypy, and noncompliance (Hanley, Iwata, & McCord, 2003). However, any behavior may be considered a problem if it occurs at excessively high levels (e.g., SIB, aggression, stereotypy), excessively low levels (e.g., compliance, sleep, eating), or in inappropriate contexts (e.g., urination, sexual behavior, disrobing). Thus, problem behavior exhibited by individuals with IDD is of significant concern because it may jeopardize the health and safety of the individual or others and

also because such behavior poses challenges to clinical treatment and habilitation programs for these individuals. Such degrees of problem behavior ultimately result in many individuals with IDD requiring intensive (sometimes intrusive) intervention, becoming socially isolated from community activities (Harris & Glasberg, 2007; Maes, Brokeman, Dosen, & Nauts, 2003), and requiring care placements outside of the home environment (Larson, Lakin, Salmik, Scott, & Webster, 2010; Sherman, 1988).

Functional behavior assessment (FBA) has become the dominant approach to assessment because it identifies environmental events that influence problem behavior. The information obtained via FBA subsequently informs treatments that alter the contingencies directly responsible for behavioral maintenance, rather than relying on treatments involving powerful, but arbitrary, contingencies of reinforcement or punishment (Kahng, Iwata, & Lewin, 2002). Although several formal methods of FBA exist, this chapter focuses on the experimental¹ method, or functional analysis (FA). The purpose of this chapter is to explain the FA approach to assessment, describe the essential features of conducting a “typical” FA, and offer suggestions for procedural modifications to typical FA methodology that may be required under certain circumstances.

¹ Here, “experimental” does not refer to the level of empirical support for these procedures; rather, that behavior is directly manipulated in a scientific manner.

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Functional Analysis Approach

Goals

Functional analyses involve the direct observation and measurement of problem behavior during systematic manipulation of environmental events (both antecedents and consequents). Functional analysis methodology has allowed for researchers and practitioners to understand the factors responsible for a wide range of problem behaviors exhibited by individuals with IDD (Hanley et al., 2003) and has increased the precision and effectiveness of reinforcement-based treatment programs (Didden, Duker, & Korzilius, 1997; Pelios, Morren, Tesch, & Axelrod, 1999; Scotti, Evans, Meyer, & Walker, 1991). In addition to an increased understanding of problem behavior at the individual level, FA methodology also serves as a means for conducting epidemiological studies of behavioral function, which contributes to a greater understanding of the conditions related to problem behavior in general, (Vollmer & Smith, 1996). For example, several large-scale studies have been conducted to identify the most common functions for SIB in the IDD population (Iwata, Pace, et al., 1994; Kahng et al., 2002). Information provided by decades of FA research has provided a wealth of information about the conditions under which problem behavior occurs. Not only is this information beneficial for developing individual treatment plans, it is useful for designing educational environments to prevent the occurrence of problem behavior (Hanley, 2010a, 2010b).

Assumptions

Generally, there is no correlation between the development of any particular problem behavior and a specific IDD condition, except in rare cases (see Chap. 11). Decades of research have shown that problem behavior is, in most cases, learned behavior that is influenced by the same processes that establish and maintain adaptive behavior (Iwata, Kahng, Wallace, & Lindberg, 2000).

These learning processes include social positive reinforcement (e.g., gaining access to attention or preferred items), social negative reinforcement (e.g., avoiding or escaping aversive situations), automatic positive reinforcement (e.g., producing sensory stimulation), and automatic negative reinforcement (e.g., terminating aversive sensory stimulation). Contingencies of reinforcement consist of (a) reinforcing consequences that maintain problem behavior, (b) discriminative stimuli that signal the availability of reinforcement, and (c) establishing operations that establish the value of the reinforcing consequence (Hanley, 2010a, 2010b). Thus, FAs are designed to experimentally identify the antecedent and consequent conditions under which problem behavior does and does not occur. That is, an FA determines which source(s) of reinforcement contingencies maintains a given individual's problem behavior.

Essential Features

FBA refers to any formal method of identifying reinforcers for problem behavior. The FBA literature has identified three common approaches to assessment: indirect (anecdotal) assessment, descriptive (naturalistic) assessment, and experimental (functional) analysis (Iwata & Dozier, 2008). Although all three methods are commonly used in clinical practice, research suggests that indirect and descriptive assessments may be insufficient for use as the sole means of identifying behavioral function. For example, indirect assessments, such as caregiver interviews or questionnaires, are often unreliable (Sigafos, Kerr, Roberts, & Couzens, 1993; Zarcone, Rodgers, Iwata, Rourke, & Dorsey, 1991). Descriptive assessments that involve direct observation and measurement of problem behavior and its surrounding environmental events provide only correlational information and often provide erroneous information (Camp, Iwata, Hammond, & Bloom, 2009; St. Peter et al., 2005; Thompson & Iwata, 2007). Because of the limitations associated with FBA, conducting an FA is often necessary, as FA is the only method that identifies a functional cause-effect relation between

environmental events and problem behavior. Although insufficient as the *sole* means for determining the function of problem behavior, indirect and descriptive analyses can be invaluable sources of information for the design of an FA.

The essential features of FA are (a) direct observation and measurement of the problem behavior (b) under at least two conditions—test and control—in which suspected reinforcement contingencies are directly manipulated. The test condition involves arranging a reinforcement contingency for problem behavior, while the control condition involves elimination of the reinforcement contingency. Iwata, Dorsey, Slifer, Bauman, and Richman (1982/1994) described the first standardized model for conducting an FA that included a comprehensive set of test conditions containing environmental contingencies shown to maintain SIB: social positive reinforcement, social negative reinforcement, and automatic (nonsocial) reinforcement. Specifically, the percentage of intervals with SIB was measured during 15-min sessions across four conditions (three tests and one control) that were arranged in a multielement design (Ulman & Sulzer-Azaroff, 1975) such that all conditions were presented in a rapidly alternating sequence. In the *social disapproval* condition (test for social positive reinforcement), the client was provided a variety of toys and prompted to play independently. SIB resulted in the delivery of social attention (brief statements of concern); all other behavior was ignored. In the *academic demand* condition (test for social negative reinforcement), tasks were presented to the client. Compliance with the task resulted in praise; SIB resulted in a 30-s escape from the task. In the *alone* condition (test for automatic reinforcement), the client was alone in a barren room. In the *unstructured play* condition (control), no tasks were presented, a variety of toys were provided, and the therapist delivered social praise contingent upon the absence of SIB at least every 30 s. This condition served as a control procedure for the antecedent and consequent events arranged in the three test conditions. Results indicated higher levels of SIB in at least one test condition relative to the control condition for six of nine subjects. Over the past 30 years, FA methodology has been replicated

and extended from its initial focus on SIB to other populations, settings, and forms of problem behavior including aggression (Baker, Hanley, & Mathews, 2006; Northup et al., 1991), property destruction (Fisher, Lindauer, Alterson, & Thompson, 1998), pica (Piazza, Hanley, & Fisher, 1996), elopement (Lang et al., 2010), disruption (Broussard & Northup, 1995), tantrums (Vollmer, Northup, Ringdahl, LeBlanc, & Chauvin, 1996), stereotypy (Ahearn, Clark, & MacDonald, 2007), noncompliance (Reimers et al., 1993), compulsive-like behavior (Rodriguez, Thompson, Sclichenmeyer, & Stocco, 2012), and rumination (e.g., Wilder, Register, Register, Bajagic, & Neidert, 2009).²

Functional Analysis Methodology

Although there is no established set of absolute rules for methodology, decades of FA research have yielded information sufficient for recommendations regarding best practices (Hanley et al., 2003). The information contained in this section describes the general steps involved and important considerations necessary prior to, during, and following a typical FA of problem behavior. Additionally, a flowchart summarizing the information is provided in the Appendix.

Preparation

Problem behavior determination. Severe problem behavior exhibited by individuals with IDD typically includes SIB (head hitting, head banging, self biting, eye poking), aggression, disruption, and tantrums. However, any behavior might be considered a problem if it occurs too often, too infrequently, or in inappropriate contexts. Stereotypy (repetitive behavior that is similar in form such as hand flapping, rocking, repeating words or phrases) is an example of behavioral excess that can serve to significantly interfere

²A detailed review of the results of the past three decades of FA research is beyond the scope of this chapter; for a more comprehensive review, see Hanley et al. (2003).

with an individual's adaptive functioning. Therefore, clinicians should consider the extent to which a given behavior (a) places the individual (or others) at risk for injury or other health concerns and (b) limits educational opportunities for the individual and others in the individual's environment (e.g., disrupts routines, prevents instruction, limits opportunities for social interaction) as the criteria by which to determine whether a problem exists.

Risk assessment. Prior to exposing an individual to the conditions of an FA, a risk assessment should be conducted by reviewing documentation of past or potential risks of the problem behavior, obtaining informed consent, and including procedural safeguards during the FA, if necessary. It is important to conduct a risk assessment and determine whether procedural safeguards are warranted, in light of the fact that problem behavior must occur with some regularity during the FA to determine function (Betz & Fisher, 2011). To date, few experimenters have included information about procedural safeguards in their published work. In the Iwata et al. (1982/1994) study, a number of procedural safeguards were arranged to ensure the health and safety of the clients. First, all procedures were reviewed and approved by a human subjects committee. Second, medical professionals (physicians, nurses) conducted a complete medical examination to rule out the possibility that problem behavior was related to a medical condition (e.g., chronic ear infections). Third, medical professionals recommended a termination criterion—a defined point at which a session would terminate if the behavior placed the individual at risk for severe injury—and those medical professionals routinely observed and assessed the individuals during the course of the FA. Other considerations to minimize risk during the FA include (a) the use of protective equipment (for the individual and/or for the therapist), (b) arranging the delivery of suspected reinforcers on a continuous (fixed-ratio 1 [FR 1]) schedule of reinforcement so that lower rates/intensities of responding are more likely to occur, and (c) using alternative methods of measurement (latency recording, decreased session duration, analysis of

less-severe precursor behaviors) to decrease the overall amount of problem behavior during the FA (for more detail, see section “High-Risk, Dangerous Behavior”). Finally, direct supervision by—or at least close consultation with—a certified behavior analyst is recommended. A database searchable by name and location of Board Certified Behavior Analysts (BCBAs) can be found on the Behavior Analyst Certification Board website (<http://www.bacb.com>).

Information gathering. Designing appropriate FA conditions requires detailed information about the conditions under which problem behavior is more and less likely to occur. Here, indirect and descriptive assessment can be invaluable for providing information about specific environmental events correlated with an individual's problem behavior. This information (e.g., the presence of certain people, the delivery of particular demands, the removal of specific items) can then be used to create more effective test and control conditions (Mace & Lalli, 1991). Indirect assessments involve obtaining information regarding problem behavior from sources other than direct observation (e.g., caregivers familiar with the individual's history of problem behavior). Commonly used indirect assessments include Problem Behavior Questionnaire (PBQ; Lewis, Scott, & Sugai, 1994), Motivation Assessment Scale (MAS; Durand & Crimmins, 1988), Behavioral Diagnosis and Treatment Information Form (BDTIF; Bailey & Pyles, 1989), Questions About Behavioral Function (QABF; Matson & Vollmer, 1995), Functional Analysis Interview Form (FAIF; O'Neill, Horner, Albin, Storey, & Sprague, 1990), and Functional Analysis Screening Tool (FAST; Iwata & DeLeon, 1996). These assessments are relatively easy to implement, do not require a great deal of expertise, and pose no risk to the individual. Open-ended and structured indirect assessments may be particularly useful because they may allow identification of unique variables that influence problem behavior. For a detailed discussion on the assessment of problem behavior, please see Chap. 8.

Descriptive assessments involve obtaining information about problem behavior and relevant

environmental events by way of direct observation and measurement in the settings in which the behavior typically occurs. Descriptive assessment techniques typically involve (a) recording the antecedent and consequent events surrounding occurrences of problem behavior (ABC analysis; Sulzer-Azaroff & Mayer, 1977), (b) recording the temporal occurrence of problem behavior (scatterplot analysis; Touchette, MacDonald, & Langer, 1985), or (c) recording occurrences of prespecified events and behaviors using frequency or interval recording procedures (Bijou, Peterson, & Ault, 1968). Although descriptive assessments can be time consuming, the obtained information may be particularly useful for operationally defining problem behavior and environmental events to be included in the FA. Additionally, descriptive assessments offer the advantage (relative to indirect assessments) of providing a baseline level of the problem behavior in the individual's relevant environment(s) against which to determine if intervention is necessary and to compare the effects of subsequent treatments prescribed by the results of the FA.

Team composition. Conducting the conditions of an FA requires at least one person to conduct the session and one person to collect observational data (or perhaps video record sessions). Research studies have shown that undergraduate students (Iwata, Wallace, et al., 2000), direct-care staff (Page, Iwata, & Reid, 1982), teachers (Moore et al., 2002), parents (Neef, 1995), and family members (Kuhn, Lerman, & Vorndran, 2003) can be trained to conduct FA conditions. However, the entire FA process extends beyond conducting FA conditions and will likely require professional judgments by an experienced behavior analyst on issues related to data collection, interpretation of results, and modification of conditions to identify idiosyncratic variables.

Implementation

Target behavior. To this point it has been presumed that the FA will target only one problem behavior; however, it is common for individuals

with IDD who display problem behavior to engage in more than one type (topography) of problem behavior. Typically, it is best to assess one problem behavior at a time (Beavers & Iwata, 2011; Hanley et al., 2003). If an individual engages in multiple topographies of problematic behavior, both behaviors can be included in the FA, but this should be done after careful consideration. One critical factor is whether both behaviors are likely to be functionally related. For example, if an indirect assessment and/or a descriptive assessment indicates that two behaviors often occur close in time or in a reliable sequence (e.g., the individual usually throws items immediately before hitting others), there is a greater chance that both topographies of problem behavior are maintained by the same consequence because they occur under the same environmental conditions (i.e., members of the same response class). However, in the event that the two behaviors are maintained by different sources of reinforcement, the FA may appear inconclusive or contraindicated treatments may be prescribed for the behaviors. For example, if SIB is maintained by attention and aggression is maintained by escape, a function-based treatment (e.g., discontinuing attention) applied to both behaviors could be beneficial for one behavior (SIB) but serve to worsen the other (aggression). In order to mitigate this problem, it is recommended that each topography be measured separately during the FA (Derby et al., 1994). Another potential limitation of including multiple topographies in an FA is that the function of one topography may be obscured when the behaviors are maintained by different reinforcers. As an example, this may be the case if SIB is maintained by automatic reinforcement (occurring across all conditions) and property destruction is maintained by escape. Although SIB would occur regardless of the escape contingency due to the automatic reinforcement it produces, the provision of escape for SIB would eliminate the motivation to engage in property destruction to access escape, in which case the escape function for property destruction would not be detected (see Asmus, Franzese, Conroy, & Dozier, 2003 for an example of this effect). Therefore, although it

may seem appealing to include multiple behaviors in a single assessment due to the fact that FAs are resource intensive, it is recommended that this be done only when there is good indication that this is appropriate for the problem behaviors being assessed.

Once the target behavior has been identified and defined (as indicated by an IA or DA), the next task is to generate an appropriate measurement system, such that the assessment and treatment data can be objectively evaluated for its effects on the problem behavior. Ongoing measurement of the problem behavior allows for the objective evaluation of the effects of a programmed intervention and is a useful practice regardless of whether an intervention is directly informed by the results of an FA. The specific measurement system selected should be determined by the characteristics of the target behavior. For problem behaviors that are short in duration and have a clear onset and offset, levels are often best captured using frequency counts. For problem behaviors that are more continuous in duration and have a clear onset and offset (e.g., tantrums), levels are often best captured using duration measurement. Alternatively, sampling methods such as partial-interval recording and momentary time sampling may be better measurement systems for problem behaviors that are of longer duration or do not have clear onsets and offsets. See Cooper, Heron, and Heward (2007) for a more detailed description of behavior measurement systems.

Condition types. The test conditions of an FA involve the arrangement of suspected reinforcement contingencies, all of which require the inclusion of three operant mechanisms: (a) discriminative stimuli (S^D s) that signal the consequences to be provided in each condition; (b) establishing operations (EOs) that momentarily increase the value of an event as a reinforcer; and (c) consequent events (CE) suspected to maintain the behavior (Betz & Fisher, 2011). The most commonly used test conditions include the attention, tangible, escape, and alone/no-interaction conditions. In the *attention* condition (test for social positive reinforcement), a therapist

is present (S^D) but does not interact with the client (EO); the therapist provides attention such as reprimands, statements of concern, and physical interaction contingent upon problem behavior (CE). In the *tangible* condition (test for social positive reinforcement), preferred items are present (S^D) but access to the items is restricted (EO); the items (e.g., preferred foods, toys, leisure items) are provided contingent upon problem behavior (CE). In the *escape* condition (test for social negative reinforcement), the therapist presents task materials (S^D) and instructs the client to complete vocational, hygiene, and/or academic tasks (EO); a break from the demand is provided contingent upon problem behavior (CE). The *alone* condition tests for automatic reinforcement, in that problem behavior that is occasioned (EO) by, and persists in, the absence of social events must be maintained by the consequences of the behavior itself (CE).³ A variation of this condition is the *no-interaction* condition, in which a therapist is present but provides no consequences for problem behavior. The no-interaction condition is appropriate for individuals who cannot be left alone due to safety or practical concerns or when the problem behavior cannot occur unless another person is present (e.g., aggression). The alone/no-interaction condition does not determine whether the problem behavior is maintained by automatic positive (e.g., self-stimulation) or automatic negative (e.g., pain reduction) reinforcement. Rather, the alone/no-interaction provides evidence as to whether problem behavior persists in the absence of social contingencies. Levels of problem behavior in the test conditions are compared to the *play* condition that serves as the control condition because all potential sources of reinforcement are freely provided. Although these FA conditions are the most common, the key element of FA conditions is that they isolate specific sources of putative reinforcement and (a) provide them contingently on problem behavior

³Although the mechanism of maintenance for behavior that occurs in the alone condition may be debated (e.g., Lewis, Baumeister, & Mailman, 1987), this definition of automatic reinforcement has been generally accepted for practical assessment and treatment reasons.

in a test condition and (b) provide them noncontingently (or withhold them following problem behavior) in a control condition.

Condition presentation. Once the conditions have been selected, the next step is to determine the length of sessions and experimental design. Functional analysis sessions typically range from 5 to 15 min (Wallace & Iwata, 1999). The FA procedure described by Iwata et al. (1982/1994) used a multielement design in which the FA conditions rapidly alternated (changed from session to session) as an efficient way to evaluate levels of problem behavior across each condition. Sessions typically continue until differentiation occurs between at least one of the test conditions and the control condition. Although the multielement design is an efficient way to expose the individual to different FA conditions, it has the potential to produce unclear results in some cases due to various reasons (e.g., lack of discrimination between conditions, carryover from one session to the next). Alternate design options that may minimize the limitations of the multielement design include conducting (a) a phase of consecutive alone/no-interaction sessions to determine behavioral sensitivity to automatic reinforcement; (b) a reversal design, in which sessions of one type of condition are conducted consecutively until stable levels of problem behavior are seen; and (c) a pairwise design, in which test conditions are presented sequentially across phases as in a reversal design but alternated with the control condition within each phase in a multielement design. Vollmer, Marcus, Ringdahl, and Roane (1995) proposed a strategy of progressing from one design to the next as a means to clarify FA results. They began with a multielement design, followed by a phase of consecutive alone/no-interaction sessions (to determine automatic reinforcement). If problem behavior persisted in the consecutive no-interaction phase, the assessment was complete. If problem behavior extinguished, a reversal design was used to evaluate each test of social reinforcement in isolation. The progressive analysis sequence was utilized with 20 individuals. Although only 50 % of assessments identified behavioral function following

the multielement phase, 85 % of assessments did so after completing the entire sequence.

In further support of a progressive sequence of analysis, Hagopian, Rooker, Deleon, and Jessel (in press) examined the necessary manipulations to obtain a clear FA outcome for 94 of the most difficult clinical cases (patients of an inpatient hospital unit focused on the reduction of severe problem behavior). The authors found that although an initial FA was successful in less than half of the cases, the use of secondary or tertiary modifications to the FA was an effective means to determine the function(s) of problem behavior for nearly all of the subjects. These results indicate that even when an FA does not produce a clear result initially, use of a progressive model will eventually identify a function.

Setting (location). One consideration of the FA is where to conduct the sessions. The FA methodology was developed in a hospital environment in which observation rooms were available. Such resources may not be available to those conducting FAs. However, the assessment has also been effectively conducted in the individual's typical environment, such as classrooms, homes, and others. Assessments have been effective across settings, with each presenting its own challenges and advantages. It is assumed that a higher level of control over extraneous variables can be achieved when using session rooms; however, it has been suggested that this (occasionally) may be at the expense of including the relevant stimuli in the sessions (as noted earlier, use of indirect and descriptive assessments should mitigate this problem). When conducting sessions in the typical environment, a great deal of control is relinquished, such that it potentially becomes more difficult to isolate the maintaining variable and thereby determine the function.

Interpretation of Results

As with most single-subject research, FAs are typically depicted using graphical displays and are analyzed using visual inspection of the data. Some researchers have suggested structural or

statistical criterion for interpreting the results of FAs (Brossart, Parker, Olson, & Mahadevan, 2006; Hagopian et al., 1997; Ma, 2006), but these methods have not been widely accepted as standard practice by researchers or practitioners. In general, a function is determined by comparing the overall level and trend of problem behavior in each test condition to that of the control condition. If the level of problem behavior is consistently higher in the test as compared to the control condition, the data indicate that consequence is a functional reinforcer for that problem behavior. Levels of problem behavior in one test condition should not be directly compared to levels in another test condition. Each test should be separately compared to the control condition, and as a result, multiple functions may be identified for a single form of problem behavior. For example, aggression may be maintained by escape from demands as well as access to tangible items because a child has learned that aggression is an effective means of escaping from seatwork, as well as keeping their favorite toy when others try to take it. In this case the FA may show higher levels of aggression in the tangible condition than in the demand condition, but both are higher than levels in the control condition. It is possible that a problem behavior can be maintained by all social functions tested.

Procedural Modifications to Address Challenges to FA Methodology

The methodology described thus far has been extremely effective in identifying the environmental conditions that maintain problem behavior across a wide range of behaviors and contexts. However, as FAs have been conducted in contexts of increasing variety, researchers and clinicians have encountered situations that required procedural adjustments in order to effectively identify the function of these behaviors. Situational constraints such as limited time for assessment, dangerous or unsafe behaviors (both to the clients themselves and those immediately around the clients), excessively high-rate behaviors, and idiosyncratic antecedent or consequent events

can lead to difficulties in identifying behavioral functions. This section describes adaptations to the FA methodology that have been shown to facilitate assessment.

Setting and Time Constraints

Functional analyses reported in the research literature have been conducted primarily in controlled settings (e.g., analog settings) to mitigate the influence of uncontrolled extraneous variables present in an individual's typical environment (e.g., attention from peers in a preschool classroom). Practitioners may feel constrained because they do not have access to such controlled settings. However, a number of studies have described the successful use of FA under less controlled conditions. Wacker, Berg, Derby, Asmus, and Healey (1998) trained parents to conduct FAs and subsequent treatment sessions for 28 young children with IDD, and all procedures were conducted in the children's homes (see Chap. 23). Impressively, results showed that a function was identified for 86% of the children, demonstrating that these procedures can be implemented by the child's parents in the child's home. Mueller, Nkosi, and Hine (2011) summarized 90 FAs conducted in public school settings. Sixty-one percent of the FAs were conducted in the student's classroom; all others were conducted in a separate room in the school (therapy room, conference room, school office, utility room, library, etc.). Overall, results showed that the function of problem behavior was identified in 90% of the analyses. Perhaps the most efficient school-based FA procedure is the trial-based FA. This is because session lengths are significantly shorter and sessions can be embedded into the child's routine. In a trial-based FA, a test and its control condition are presented in a probe trial (3–7 min) embedded in the individual's typical environment when naturally occurring events resemble those targeted by the test conditions (e.g., conduct a demand trial during the morning self-care routine; Bloom, Iwata, Fritz, Roscoe, & Carreau, 2008; Sigafos & Sagers, 1995). Although trial-based FAs have received minimal attention in the research

literature and the clinical utility of this approach remains to be demonstrated on a large scale, the success described by studies to date is promising for clinicians and practitioners who do not have access to special settings that maximize control. It appears that setting variables may not be such a limiting factor if one is able to minimize confounding influences for brief periods of time (Iwata & Dozier, 2008).

Limited assessment time is a frequently cited practical constraint faced by clinicians (Gresham, Quinn, & Restori, 1998; Hayes & Follette, 1993; LaRue, Weiss, & Ferraioli, 2007; Mueller et al., 2011). That is, limited contact with clients may prevent the possibility of obtaining repeated measures across an extended analysis. However, Mueller et al. (2011) reported that no more than 3 h was required to complete FAs in 80 % of the 90 FAs they reviewed. The authors commented that the FA itself was the least time-consuming aspect of the FA process, as compared to the time required conducting both an indirect assessment and a descriptive assessment to generate hypotheses about behavioral function for inclusion in the FA. Northup et al. (1991) described an abbreviated version of the typical FA procedure designed for use in a 90-min outpatient appointment. This “brief FA” consisted of condition “probes” such that the individual only experienced one or two sessions of a condition. Derby et al. (1992) summarized the results of 79 brief FA cases and found that problem behavior occurred in 63 % of cases, a function was identified in 73 % of cases, and that this function was verified by effective treatment in 54 % of cases (however, as demonstrated by Vollmer et al., 1995, this percentage can be boosted by using a progressive model).

Another suggestion to potentially avoid extended time in assessment is to conduct a single-function test, in which only the reinforcement contingency strongly hypothesized to maintain the problem behavior is tested in the FA (Iwata & Dozier, 2008). The potential advantage to single-function testing is that the assessment process may be expedited (if the presumed function is confirmed). Additionally, the chance that new functions of problem behavior would be learned

during a multiple-function FA through the exposure of problem behavior to novel reinforcement contingencies is minimized (Rooker, Iwata, Harper, Fahmie, & Camp, 2011; Shirley, Iwata, & Kahng, 1999). However, the disadvantage to conducting a single-function test is that by including fewer test conditions, there is increased risk that a maintaining function could be missed because it was not tested (Type II error). This is particularly true when problem behavior is maintained by more than one function (multiply controlled), as identification of one function does not rule out other functions. In addition, there is always the possibility that the indirect assessment and/or the descriptive assessment may not have correctly identified the presumed functional reinforcer, in which case the assessment would need to be prolonged to include additional test conditions. In the event that the functional reinforcers currently maintaining problem behavior are not identified, there is a high likelihood that the effectiveness of reinforcement-based treatment procedures would be compromised (Carr, Robinson, & Palumbo, 1990). Additionally, it may be valuable to know what consequences are likely to function as reinforcers in order to be proactive in preventing those consequences from being delivered contingent on problem behavior in the individual's typical environment.

High-Risk, Dangerous Behavior

Assessing the function of problem behavior that causes (or could potentially cause) severe physical injury to the individual (SIB) or to others (aggression) is particularly challenging. However, there are several modifications that may be made to FA methodology to allow safe and effective assessment. Several researchers have suggested the use of response blocking (Le & Smith, 2002) or protective equipment (Borrero, Vollmer, Wright, Lerman, & Kelley, 2002; Moore, Fisher & Pennington, 2004; see Chap. 6) during FAs. Results may be confounded by the possibility of punishment or sensory extinction effects across sessions resulting in a low-rate, undifferentiated FA outcome. However, the use of blocking and

protective equipment has allowed some researchers to identify a previously masked social function (Contrucci-Kuhn & Triggs, 2009; McKerchar, Kahng, Cacioppo, & Wilson, 2001) or confirm that behavior was maintained by automatic reinforcement (Moore, Fisher, & Pennington, 2004). In the event that a decision is made to use blocking or protective equipment during an FA, it is important to ensure that they are used consistently across all assessment conditions.

An alternative strategy involves terminating sessions immediately following reinforcer delivery for the first occurrence of problem behavior and using response latency (the time elapsed from the beginning of a session to the first occurrence of problem behavior) rather than response frequency as the index of problem behavior. Thomason-Sassi, Iwata, Neidert, and Roscoe (2011) observed a high degree of correspondence between latency and response repetition measures (rate, percentage of intervals) when conducting FAs of problem behavior. Using latency as the dependent variable in FAs may avoid the potential confounds of the use of blocking or protective equipment during standard FAs of high-risk, dangerous behavior. The occurrence of some types of problem behavior (e.g., elopement, disrobing, and property destruction) may make it such that the behavior cannot recur without restoring the original environmental condition, which introduces a potential confound into the FA. For example, if an individual disrobes, disrobing cannot recur unless clothes are put back on the individual (or the individual redresses independently, which may be unlikely). Further, some problem behavior (e.g., vomiting, urination) may be physiologically limited in the frequency with which it can occur. The use of a latency measure may be especially appropriate for assessing the function of these types of problem behavior. Because sessions are terminated based on the first occurrence of problem behavior, this procedure limits an individual's exposure to assessment contingencies and requires stimulus control to occur more rapidly. Therefore, the use of strategies that increase the individual's ability to discriminate and respond differentially (e.g., programmed stimuli correlated with assessment conditions, the use of a reversal or pairwise

design) may be helpful when conducting a latency FA.

A final strategy to use for situations in which problem behavior poses a serious risk is to conduct an FA of precursor behavior (i.e., less-severe behavior that reliably precedes severe behavior; Smith & Churchill, 2002). Given that providing reinforcement for the first occurring response member of a response class hierarchy is likely to result in decreases in the occurrence of subsequent response members, the likelihood of severe problem behavior occurring is minimized (Richman, Wacker, Asmus, Casey, & Andelman, 1999). First, an empirical analysis of the behaviors that precede severe behavior is required (Borrero & Borrero, 2008). Second, an FA of the identified precursor behavior is conducted. Najdowski, Wallace, Ellsworth, MacAleese, and Cleveland (2008) conducted an FA of precursor behavior (whining, crying) with three subjects who engaged in severe forms of problem behavior (aggression, public masturbation, inappropriate grabbing). For all subjects, results showed that the FA of precursor behavior identified a function and that a treatment based on that outcome eliminated precursor behavior; additionally, severe problem behavior rarely occurred during FA or treatment sessions. Although the function of severe problem behavior is assumed to some extent in this type of analysis, precursor FAs offer a reasonable alternative to an FA of severe problem behavior that poses a serious health and safety risk.

Ambiguous (Inconclusive) FA Results

Although published research indicates that the majority of FA outcomes are clear (in that they identify a function), a small minority of FA outcomes are undifferentiated. Four large-scale studies have reported on the prevalence of unclear (undifferentiated) outcomes. Three of these summaries were conducted on the basis of a collection of clinical data. Iwata, Pace, et al. (1994) found that 4.6% of FA outcomes of problem behavior were undifferentiated in a sample of 152 individuals diagnosed with IDD. Kurtz et al.

(2003) found 12.5 % of FAs of problem behavior were undifferentiated in a sample of 30 children receiving assessment and treatment services in an outpatient clinic. Hagopian et al. (in press) found that 47.8 % of initial FAs were undifferentiated but that 86.7 % were differentiated following additional analysis in a sample of 176 individuals. Finally, one study has reviewed published FA outcomes. Hanley et al. (2003) found that 4.1 % of FA outcomes were undifferentiated in an analysis of FA data on problem behavior for 536 individuals described in articles published in *The Journal of Applied Behavior Analysis* until 2000. Based on these studies, several patterns of undifferentiated outcomes have been identified. Two of the most prominent patterns are behavioral rates in extremes, either high-rate behavior across multiple FA conditions or low-rate (or no) behavior across conditions.

High rates of responding across FA conditions. High levels of problem behavior across all FA conditions may indicate that problem behavior is maintained by automatic reinforcement (i.e., the reinforcer, produced directly by the behavior itself, is present in all conditions). Conducting extended alone (no-interaction) sessions (Vollmer et al., 1995) is the most common strategy to verify a function of automatic reinforcement. If problem behavior is maintained by automatic reinforcement, it will persist across sessions. However, if behavior extinguishes across sessions, problem behavior is most likely maintained by social sources of reinforcement and will require further analysis.

High rates of responding in the escape and play conditions (but low rates in the attention and alone/no-interaction conditions) during FA may indicate that problem behavior is maintained not by escape from the demands presented in the escape condition per se but by escape from (or avoidance of) social interaction. That is, the mere presence of others is the aversive event the individual is engaging in problem behavior to escape/avoid. If this function is suspected, the hypothesis could be confirmed by conducting a social-escape condition in which the therapist provides continuous attention and terminates social interaction for a brief period of time contingent upon problem

behavior (Hagopian, Wilson, & Wilder, 2001; Taylor & Carr, 1992; Taylor, Ekdahl, Romanezyk, & Miller, 1994). An appropriate control condition for social escape would be a no-interaction condition.

Undifferentiated high rates of problem behavior may also indicate discrimination failure (e.g., individual with attention-maintained behavior may also engage in problem behavior during the play and demand conditions due to a history of reinforcement in the presence of adults) or may indicate interaction effects due to the rapidly alternating conditions commonly used in FAs (Barlow & Hayes, 1979). The inclusion of programmed discriminative stimuli (e.g., condition-specific colored t-shirts) beyond those that would naturally signal the availability of a given reinforcer (e.g., the presence of adult in the attention condition signals the availability of attention) may be helpful when discrimination problems are suspected. Conners et al. (2000) correlated a unique therapist and room color with each FA condition and found that doing so facilitated discrimination for four of eight subjects. Another strategy to facilitate clear FA results, described originally by Iwata, Pace, et al. (1994), is to present the FA conditions in a fixed sequence (i.e., alone/no-interaction, attention, play, demand), which arranges a strong EO for the reinforcer in a given condition by preceding it with a condition in which the reinforcer is absent (deprivation). In addition, the appropriate control condition for each social test immediately follows the test (i.e., lack of attention is followed by free access to attention and presentation of aversive social interaction is followed by no social interaction). Hammond, Iwata, Rooker, Fritz, and Bloom (in press) showed that the fixed-condition sequence produced more clear FA outcomes as compared to a random cycle of conditions for three of seven subjects and was more efficient for one subject. In fact, some research and practitioner groups use the fixed-sequence strategy as standard practice (e.g., Kennedy Krieger Institute inpatient unit) for facilitating differential responding during multielement FAs. A final strategy for clarifying undifferentiated FA outcomes, when either discrimination failure or interaction or carry-over

effects are suspected, is to alter the experimental design (i.e., the manner in which clients are exposed to FA conditions). Following an undifferentiated multielement FA, Vollmer, Iwata, Duncan, and Lerman (1993) conducted FA conditions in a reversal design, in which subjects were exposed sequentially to one FA condition at a time. Results were clarified for three of four subjects. Iwata, Duncan, Zarcone, Lerman, and Shore (1994) compared the use of a pairwise design, in which a test condition and the control condition alternated during each reversal phase, to the outcomes of a multielement FA. For all subjects ($N=5$), results showed that the assessment outcomes were either similar or that the pairwise assessment clarified the results of the multielement assessment.

The results of several studies have shown that undifferentiated FAs in which problem behavior occurs in more than one condition are indicative of multiply controlled behavior (Borrero & Vollmer, 2006; Day, Horner, & O'Neill, 1994; Neidert, Iwata, & Dozier, 2005; Smith, Iwata, Vollmer, & Zarcone, 1993). Smith et al. (1993) exposed subjects to "matched" and "mismatched" treatments (i.e., treatment related and unrelated to the hypothesized functions) and observed that the SIB of two subjects was multiply controlled but the SIB of one subject was reduced by only one of the treatments (indicating maintenance by a single function). McKerchar et al. (2001) observed high, undifferentiated levels of SIB in their initial FA suggesting automatic reinforcement. However, in a subsequent FA, in which the subject wore a padded helmet and SIB was blocked, SIB was consistently higher in the attention condition relative to all other conditions suggesting that SIB was also maintained by social positive reinforcement. In their summary, Hanley et al. (2003) found 14 % of 536 reviewed FAs indicated multiply controlled problem behavior but commented that conclusions about multiple control are tentative because the dependent variable (problem behavior) in many of the FAs actually comprised multiple response topographies (a result verified by Beavers & Iwata, 2011). That is, it was unclear whether each topography of aberrant behavior served multiple functions or whether different

topographies served single (but different) functions. Therefore, as previously mentioned, limiting the number of responses in the response class to be assessed (ideally to one response) in an FA is recommended as best practice.

Low-rate problem behavior. Functional analysis results in which problem behavior rarely (or never) occurs are extremely difficult (if not impossible) to interpret. One potential explanation is that the FA procedures did not allow sufficient exposure to the relevant contingencies. Several studies have demonstrated that conducting longer sessions to increase exposure to the programmed antecedent and consequent events (Kahng, Abt, & Schonbachler, 2001; Wallace & Iwata, 1999) or conducting FA sessions only when problem behavior occurs (Tarbox, Wallace, Tarbox, Landaburu, & Williams, 2004) may be useful strategies for assessing low-rate behavior.

Another explanation for low-rate behavior is that problem behavior is maintained by idiosyncratic or unusual sources of reinforcement that were uncontrolled or not programmed in the FA conditions. In this case, conducting (or reconducting) an indirect assessment or a descriptive assessment may be useful to identify idiosyncratic variables that should be included in the FA (Borrero, Vollmer, & Borrero, 2004; Tiger, Fisher, Toussaint, & Kodak, 2009). Numerous studies have described cases in which antecedent events in FA conditions were modified to enhance FA conditions or to identify idiosyncratic sources of influence. Problem behavior may occur in a cyclical or episodic fashion (occurring at both high and low levels), which may suggest the influence of biological variables such as otitis media (O'Reilly, 1997), sinus infection (Carter, 2005), sleep deprivation, and allergies (Kennedy & Meyer, 1996). The presence of such conditions may serve as an EO for a given reinforcer (e.g., escape). It is also possible that these and other conditions (e.g., menses) may establish the value of different reinforcers for problem behavior depending on whether the condition is present or absent. For example, problem behavior might be maintained by escape during menstruation but maintained by attention during all other times.

Other examples of idiosyncratic antecedent sources of influence on problem behavior include task novelty (Mace, Browder, & Lin, 1987; Smith, Iwata, Goh, & Shore, 1995), task difficulty (Call, Pabico, & Lomas, 2009; Roscoe, Rooker, Pence, & Longworth, 2009), rate of demand presentation (Smith et al., 1995), prompting style (McComas, Hoch, Paone, & El-Roy, 2000), divided attention (Mace, Page, Ivancic, & O'Brien, 1986), and the presence/absence of specific people (Broussard & Northup, 1995; English & Anderson, 2004; Flood, Wilder, Flood, & Masuda, 2002; Ringdahl & Sellers, 2000).

A common factor in many of the idiosyncratic antecedent cases is that the EOs originally designed into the test conditions are insufficient, for one reason or another, to evoke or maintain problem behavior, such that a functional relation cannot be identified (Call, Wacker, Ringdahl, & Boelter, 2005). For example, the demands included in the test for social negative reinforcement may not be sufficiently aversive to evoke problem behavior by the individual. Roscoe et al. (2009) suggested that a demand assessment be used to identify instructions that are more likely to evoke problem behavior to minimize false-negative outcomes for escape-maintained problem behavior, in particular. The inclusion of sufficiently aversive tasks in the demand condition is one way the EO can be increased within a session, thereby avoiding false-negative outcomes. Another manipulation to decrease potential false-negative outcomes is to change the amount of time the individual is exposed to the establishing operation prior to sessions. Particularly with social positive reinforcers, the amount of pre-session deprivation can influence the rates of responding within test conditions (although it has also been indicated with automatic reinforcement; Rapp, 2004). McGinnis, Houchins-Juárez, McDaniel, and Kennedy (2010) and O'Reilly et al. (2009) found that pre-session access to attention and tangible items, respectively, resulted in decreased levels of problem behavior during test conditions as compared to pre-session periods of deprivation. Therefore, to avoid potential false-negative outcomes, FA sessions should be conducted when all putative establishing operations are in effect.

Additionally, numerous studies have shown that low rates of problem behavior during an FA are a result of idiosyncratic consequent events that were uncontrolled or not included in the original analysis. That is, problem behavior may be maintained by idiosyncratic features such as the quantity or quality of the reinforcer or by unusual sources of reinforcement. For example, Bowman, Fisher, Thompson, and Piazza (1997) conducted FAs of problem behavior for two children with IDD, the initial results of which were inconclusive. Information from direct observations and anecdotal reports suggested that problem behavior was most likely to occur when the children "did not get their way." The subsequent modified FA showed that problem behavior occurred when caregivers only complied with mands (requests) following problem behavior (social reinforcement) and was absent when caregivers did not comply with mands following problem behavior. Other examples of idiosyncratic consequent sources of influence on problem behavior include the quality and content of attention (Fisher, Ninness, Piazza, & Owen-DeSchryver, 1996), the form of attention (LeBlanc, Hagopian, Marhefka, & Wilke, 2001; Piazza et al., 1999), the source of attention (Jones, Drew, & Weber, 2000), access to wheelchair movement (DeLeon, Kahng, Rodriguez-Catter, Ingibjorg, & Sadler, 2003), and access to stereotypy (Hausman, Kahng, Farrell, & Mongeon, 2009).

In a component analysis of consequent events, Kodak, Northup, and Kelley (2007) described the use of an attention analysis, conducted subsequent to an initial FA that evaluated the reinforcing effects of six types of attention (reprimands, irrelevant comments, tickles, eye contact, praise, and physical attention). Results indicated that different forms of attention differentially influenced problem behavior. Rolider, Iwata, Camp, and Fritz (2007) described the use of a progressive series of manipulations designed to increase the likelihood of low-rate problem behavior. The authors conducted a typical multi-element FA, followed by a multielement FA in which a series of conditions that combined various EOs and reinforcers for problem behavior

were conducted. For example, in one condition the therapist presented demands to the subject in the presence of peers engaging with items/activities that were preferred by the subject. If the subject engaged in problem behavior, the therapist provided escape from the demands, attention, and access to the preferred items/activities. If responding was still low rate, the duration of sessions was extended from 10 to 30 min. Increased session length clarified the results of the FA for three of seven subjects. However, the modified combined conditions were required to determine function for the other subjects.

A large number of idiosyncratic variables have been identified, and as the research involving the application and refinement of FA methodology continues to expand, such idiosyncratic patterns seem to be encountered with increasing frequency. The accumulated evidence of idiosyncratic sources of influence on problem behavior suggests the need for continued research in (a) indirect and descriptive assessment methodology to increase the likelihood of a priori identification of idiosyncratic variables to inform the development of appropriate FA conditions and (b) refinements in FA methodology to allow the design of conditions to test for problem behavior under the control of complex contingencies. For a more detailed review and analysis of idiosyncratic variables in modified FAs during the past decade (2001–2010), see Schlichenmeyer, Roscoe, Rooker, Wheeler, and Dube (in press).

Conclusion

Implications of Functional Analysis

The experimental (functional) analysis approach to the assessment of problem behavior has a strong empirical background involving hundreds of studies describing replication, procedural modification, and extension to a wide array of responses, populations, and settings. The voluminous amount of empirical evidence for the effectiveness of the approach has led many scientific,

governmental, and professional organizations to characterize FBA and function-based behavioral interventions as best practice for individuals with IDD (Plauche Johnson, Myers, & The Council on Children with Disabilities, 2007; Rush & Frances, 2000). For example, the Individuals with Disabilities Education Improvement Act of 2004 (IDEA, 2004) requires school districts to conduct FBAs for children with disabilities in certain circumstances (e.g., problem behavior of a child with a disability results in a disciplinary change in placement). The proliferation of FA methodology is one way to judge the value of the procedure; however, the social validity of FAs has also been directly evaluated—although only on a limited scale. For example, Langthorne and McGill (2011) surveyed consumers of FA procedures—the parents and teachers of children engaging in problem behavior—and found the FA to be rated as socially acceptable.

The most beneficial aspect of FA is that the identification of functional reinforcers directly informs treatment development. Once the maintaining reinforcer is identified, practitioners are then able to develop function-based treatments that directly alter the variables responsible for problem behavior. There are three general ways to alter functional environment conditions to decrease problem behavior: (a) manipulate antecedent conditions to decrease the motivation to engage in problem behavior (noncontingent reinforcement, NCR), (b) terminate (or eliminate) the reinforcer for problem behavior (extinction), and (c) replace problem behavior with an alternative, adaptive behavior (differential reinforcement of alternative behavior, DRA). Additionally, some punishment procedures can be function-based. The use of time-out (TO), or the removal of reinforcing events contingent upon problem behavior, should be informed by an FA. Specifically, TO should only be used when behavior is maintained by social positive reinforcement and would be counter therapeutic if implemented for escape-maintained problem behavior. Similarly, contingent demands, restitution of the surroundings, or reprimands would be contraindicated for attention-maintained problem behavior but may be

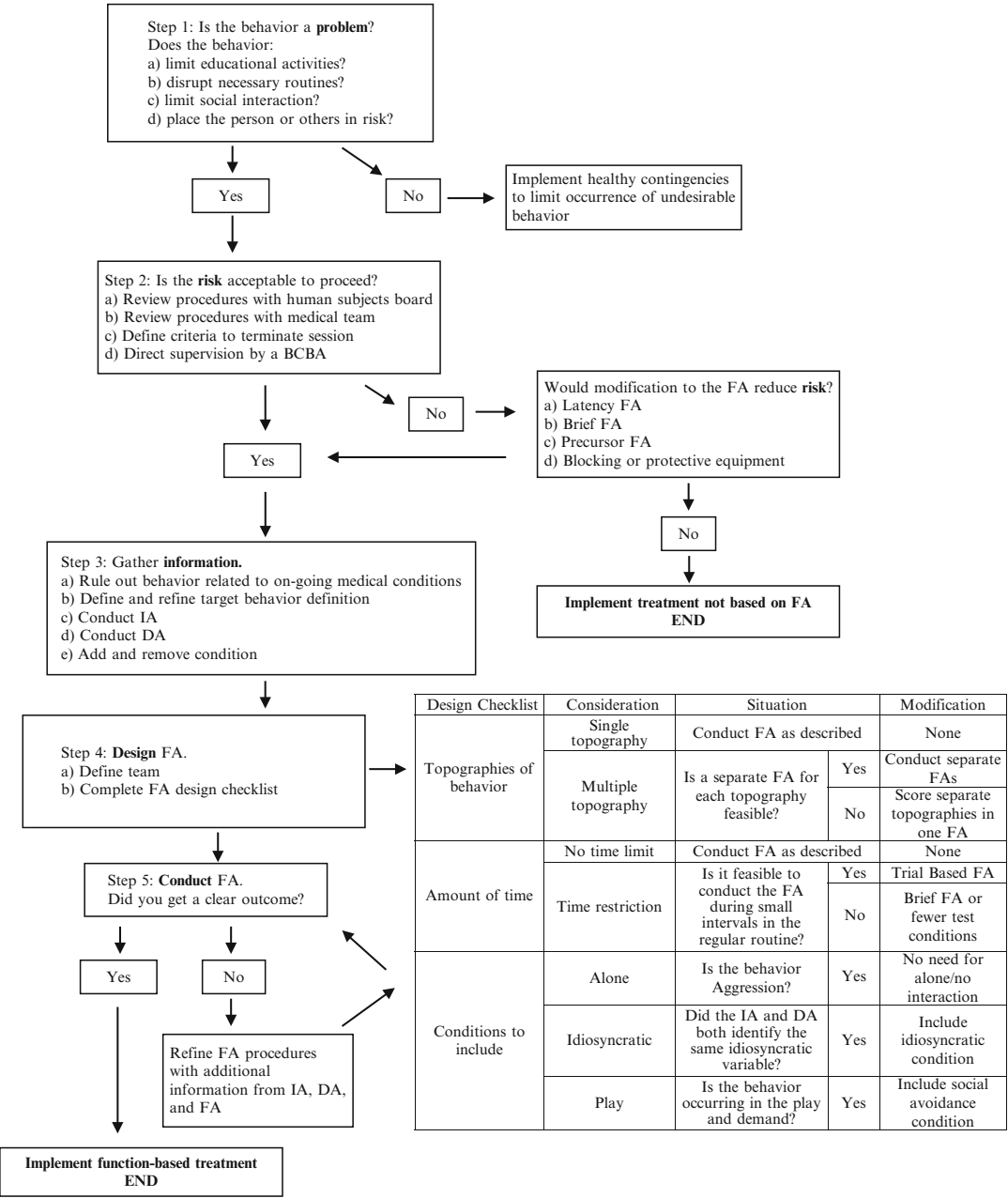
effective for problem behavior maintained by escape. However, punishment procedures, even function-based ones, should be reserved until other less-intrusive interventions have been evaluated and shown to be ineffective and should also include a reinforcement component (Vollmer et al., 2011).

Aside from its obvious immediate benefits in treating problem behavior, FA methodology also creates opportunities for preventing the development of problem behavior. For individuals who have exhibited problem behavior and for whom an FA was conducted, information about sensitivity to reinforcement contingencies can be used to take proactive steps to avoid providing those identified reinforcers after other problematic behaviors. In a more general sense, understanding the potential for various consequences to reinforce and maintain problem behavior can lead to the design of what some practitioners have referred to as “healthy contingencies.” Healthy contingencies attempt to prevent the development of functional relations between problem behavior and potentially reinforcing consequences by explicitly avoiding the delivery of putative reinforcers following problem behavior. Based on accumulated published evidence of common reinforcers for problem behavior and direct classroom observations of preschooler problem behavior, Hanley, Heal, Tiger, and Invarsson (2007) designed a class-wide teaching program that taught children to engage in “preschool life skills.” Specifically, the children were taught to appropriately request attention and preferred items, comply with instructions, and wait for preferred items/activities. Results showed that (a) teaching these appropriate skills decreased problem behavior and potentially prevented the development of more severe problem behavior and (b) teachers who implemented the program rated it highly on several measures of social acceptability. Further research is needed to determine whether such proactive, function-based approaches prevent the emergence of problem behavior on a large scale and with other populations.

Ongoing research investigations continue to refine FA methodology, improving the efficiency

and efficacy of the procedures. Practitioners face numerous challenges to the assessment of problem behavior to which FA methodology may be applied in future studies including (a) assessment of covert behavior, (b) identification of the most effective stimuli to facilitate discrimination under different situations by different individuals, (c) modifications to increase the reliability and validity of FA methods, (d) FA prevalence studies of behavioral characteristics associated with specific clinical syndromes (e.g., autism) to develop neurodevelopmental phenotypes related to behavior, and (e) analysis of problem behavior under the control of complex stimulus conditions. Unfortunately, the clinical demand for FA currently exceeds its availability, and there is little evidence that this status will change significantly in the near future. Due to the numerous complexities involved in developing, conducting, interpreting, and modifying FAs, it is strongly recommended that an expert be involved throughout the assessment. The number of experts, while increasing, is disproportionate to the need for FAs. However, some research programs are investigating ways to remedy this discrepancy. For individuals for whom consulting with a BCBA would require long-distance travel, telemedicine may be an attractive option. Recently, the use of telemedicine has begun to receive increased attention as a mean to disseminate FA methodology (Barretto, Wacker, Harding, Lee, & Berg, 2006; Frieder, Peterson, Woodward, Crane, & Garner, 2009; Machalicek et al., 2009). Barretto et al. (2006) described the use of telemedicine to conduct FAs with individuals who otherwise would be precluded from the provision of behavioral services due to vast geographic distances and the lack of local trained personnel. Although the application of telemedicine technology to applied behavior analysis is newly emerging, the approach seems promising. In addition to this effort by researchers, legislation has begun to require insurance companies to include FBAs in the policies, potentially reducing the cost of these services to the public. As a result, FA methodology will continue to be an essential, and hopefully accessible, means of assessing and treating problem behavior.

Appendix: Steps in Conducting a Functional Analysis of Problem Behavior



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Meeta R. Patel

Introduction

A feeding disorder is identified when an individual fails to eat sufficient quantity and/or variety of foods and/or liquids to maintain his weight and/or grow (e.g., Babbitt, Hoch, & Coe, 1994). More recently, feeding disorders also encompass selective eating/drinking where weight/growth is not compromised but nutritional status is of concern.

Feeding problems occur in about 25–45 % of typically developing children and up to 80 % in children with developmental delays (Gouge & Ekvall, 1975; Manikam & Perman, 2000; Palmer & Horn, 1978; Perske, Clifton, McClean, & Stein, 1977). Certain medical diagnoses or conditions may increase the risk of feeding problems including gastroesophageal reflux (GER), bronchopulmonary dysplasia, congenital heart disease, short-gut syndrome, and childhood cancer (Linscheid, Budd, & Rasnake, 1995). Furthermore, feeding problems may also be more common in children with other gastrointestinal issues (e.g., delayed gastric empty, eosinophilic esophagitis, constipation, diarrhea, vomiting) and food allergies. Swallow dysfunction (dysphagia) may

result in aspiration (i.e., food, liquid, or saliva going into the trachea/lungs; Arvedson, 2008) and contribute to feeding problems. Oral motor delays due to structural abnormalities (e.g., cleft lip/palate) and/or neurodevelopmental disorders (e.g., cerebral palsy, hypotonia) may also increase the risk for feeding problems. Feeding problems are also common in children with specific genetic disorders (e.g., autism spectrum disorder (ASD), Angelman syndrome, Down syndrome, cystic fibrosis, celiac disease, Pierre Robin syndrome, Treacher Collins syndrome). Children born prematurely may also be at risk for feeding problems since prematurity can be paired with a host of medical complications.

Classification

Many children experience a feeding problem at some point during development, but it does not compromise weight or nutritional status. They may only miss a few meals and refuse food on occasion in these instances. However, other children may display more serious feeding problems in which they refuse or reject food/liquid so often that they are at risk for malnutrition, dehydration, impaired development, and/or failure to thrive (FTT; deceleration of weight) (Christophersen & Hall, 1978). Feeding problems can be classified in three distinct categories: eating no to minimal food/liquid by mouth, liquid dependency, and food selectivity.

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Eating No to Minimal Food/Liquid

Individuals who eat/drink minimal food/liquid by mouth may require supplemental feedings for nutrition because they are unable to gain weight and grow through oral feedings. In addition, in these situations the child may also be at risk for dehydration because they are not getting enough fluids by mouth. For example, a nasogastric (NG) tube may be inserted nonsurgically (tube inserted through the nasal canal into the esophagus down the stomach) so the individual can start to get adequate calories and hydration immediately. However, if oral intake still does not improve and it appears that tube feedings will be required for an extended period of time, a gastrostomy (G) tube is typically placed. Placement of the G-tube involves a surgical procedure in which a tube is inserted through the abdominal wall into the stomach. As children become dependent on tube feedings, in some cases motivation to eat/drink by mouth decreases and eventually the child may stop eating/drinking all together.

Liquid Dependency

Individuals who are liquid dependent rely mostly on liquids for nutrition and may consume minimal solid foods, which result in dependency on the bottle or nursing at inappropriate ages. For example, you may see a 5-year-old child who is still drinking from the bottle, although some of these children may be fully equipped from a skill development standpoint to drink from a cup or through a straw. Liquid dependency typically does not result in supplemental feedings because the child is maintaining his/her weight through liquids and is able to stay adequately hydrated. However, liquid dependency may pose a health risk long term because as children get older and require more calories to grow and gain weight, they may not be able to consume enough liquids to meet those caloric requirements.

Food Selectivity

Individuals who display food selectivity may be selective by type, texture, brand, temperature, and/or color (Williams & Seiverling, 2010). Individuals who display food selectivity by type may have a very limited diet which goes beyond typical “picky eating.” For example, a child may only eat chicken nuggets and French fries from McDonalds® or only eat certain carbohydrates. Those who display selectivity by texture may only eat a specific texture of food (e.g., only smooth foods or eating only crunchy foods). Some individuals with food selectivity may only eat food of a certain temperature requiring the food to remain at that temperature throughout the meal. Other children may only eat foods of certain color and reject foods of a different color. Food selectivity also includes ritualistic eating patterns. For example, an individual might eat only foods that are perfectly whole and refuse to consume foods in pieces. Other individuals might consume food or drink only when presented in a specific plate/cup. Children who display food selectivity may not show immediate health risks since weight gain/growth is often not problematic in the short term. However, restricted diets, particularly those that only include unhealthy foods (e.g., chicken nuggets and French fries), may pose long-term health risks such as diabetes or heart disease. In addition, lack of a well-balanced diet may result in anemia and/or vitamin deficiencies.

Behavioral Chain

Eating and drinking involve a complex chain of behaviors. For example, eating starts with opening one’s mouth to a utensil, accepting the food into the mouth, closing one’s lips around the utensil, moving the food from the front of the mouth to the back or to the molars for chewing, and then swallowing the food. Drinking involves a similar chain of behaviors; however, it requires less effort to consume since there is no chewing

involved. Problems in eating and drinking may occur at any point in the chain of behaviors. Assuming a child accepts food being offered, he has the option to move the food around, chew, and swallow or to either expel (i.e., spit the food/liquid out of the mouth) or pack (i.e., retain the food/liquid in the mouth) the bite. Expulsion and packing may be the result of a skill deficit (poor oral motor skills) or a performance deficit (to obtain reinforcement such as avoidance of eating or attention from a caregiver).

Children who have poor oral motor skills may not have the proper tongue movement (tongue lateralization) to move food to the side of the mouth and chew, which in turn can result in expulsion and/or packing. On the other hand, some children may engage in expulsion and/or packing to avoid the next bite (performance deficit). Interruptions of the meal such as these may lead to lengthy meal durations and decrease motivation to eat. Also, some children with feeding difficulties may appear to have a poor appetite which may lead to lengthy meal durations.

In addition to expulsion and packing, children with feeding problems may demonstrate inappropriate mealtime behaviors to avoid eating altogether or to avoid non-preferred foods/liquids. A typical mealtime situation may involve the caregiver presenting food/liquid to the mouth and then the child engaging in some type of refusal behavior (e.g., pushing the food away, turning away from the food, crying, screaming, throwing, hitting, vomiting). A caregiver may remove the food/liquid, provide attention (e.g., verbal reprimand, coaxing the child to eat), or provide a preferred food/toy after the child has engaged in refusal behaviors. As a result, refusal behaviors are strengthened and will continue to occur in the future because they produced the desired outcome for the child (i.e., avoidance of eating/drinking, access to attention or a preferred food/toy). If refusal behaviors persist, poor weight gain and/or tube dependency could result.

Children with a negative experience with eating such as choking/gagging may refuse to eat when presented with solid foods or higher textured

foods. Therefore, caregivers eventually may only present liquids or lower textured foods to avoid refusal behaviors and to ensure that the child is getting some nutrition to grow and gain weight. Caregivers may discontinue presenting non-preferred foods/textures in an attempt to avoid refusal behaviors. As a result, caregiver reaction strengthens selective eating.

In some cases children may engage in these types of refusal behaviors to avoid the caregiver feeding them and in turn may only self-feed preferred foods. Children with developmental delays may also engage in rapid eating which may result in improper chewing and swallowing of food (Williams & Seiverling, 2010). This may cause a health risk because it can result in vomiting and/or aspiration (Williams & Seiverling, 2010).

Etiology

As mentioned previously, feeding problems may develop from medical disorders such as GER (Hyman, 1994) or food allergies. Although GER is common in infants and may resolve itself over time, a small percentage of children with severe GER may experience pain during eating and/or severe vomiting. The same may be true for children with food allergies, which are difficult to detect until a child has eaten something containing an allergen. The child may experience severe pain from an allergic reaction, which could make eating unpleasant. Children who experience pain during eating may learn to engage in refusal behaviors to avoid eating and thereby avoid further pain. Medical complications, such as childhood cancer and cardiac problems, can also result in feeding problems because in these cases the eating process has been halted due to other treatments and/or surgeries. For example, if children are hospitalized for chemotherapy or various other surgeries, it is likely that they are not eating by mouth for an extended period of time. In fact, in these cases it is likely that the child's internal motivation (hunger) to eat dissipates due to feeling nauseous for an extended period of time.

As a result of this interruption, the child may not develop the proper oral motor skills to eat. In addition, the motivation to eat may no longer be present because a common side effect of medications can be a loss of appetite. In addition, eating is often more effortful for children with pulmonary or cardiac issues. It is likely that due to their medical condition it takes more energy to eat which eventually may result in fatigue and not being able to eat enough. Thus, inappropriate mealtime behaviors might develop.

Anatomical abnormalities may also contribute to feeding problems (Palmer & Horn, 1978). For example, a child born with defects to structures necessary for eating may not exhibit sucking, swallowing, and biting reflexes. Without these reflexes, the natural eating process may be interrupted causing delays in oral motor skill development and further interruptions in eating. This may also be the case for children with certain neurodevelopmental disorders who are lacking or have weak suck/swallow reflexes. In both cases eating becomes effortful because the proper oral motor skills are not in place. Subsequently, a child may be more likely to engage in refusal behaviors to avoid eating when he does not display the proper oral motor skills to eat and/or eating is simply just too difficult.

Feeding problems may also develop as a result of a negative experience with eating. As explained above, a child who chokes or gags during meals could develop refusal behaviors to avoid similar mealtime experiences. The same may be true for children who have a history of hospitalizations involving invasive procedures in or near the mouth (e.g., intubation, breathing tubes). Consequently, a child may develop oral aversion (not allowing anything near the mouth including food/liquids due to previous negative experiences). Therefore, children who display oral aversion typically will not respond to force-feeding methods; in fact, aversion may be strengthened in these situations.

Although medical issues may be resolved via medications and restricted diets and anatomical abnormalities may be resolved via surgery and oral motor therapy, feeding problems may persist. Since oral feedings have been paired with

pain/discomfort, trauma, or increased response effort, the child may learn to engage in inappropriate mealtime behaviors to avoid eating. Refusal behaviors may be so severe that they continue despite resolution of the medical/anatomical issue. In these instances, the child has not learned that eating will not be accompanied by pain/discomfort or that eating is less effortful due to his or her avoidance behaviors.

The etiology of feeding problems, such as food selectivity, is not well understood. This type of feeding problem is more common in children with ASD. It is likely that food selectivity is more common in children with ASD because one of the core features of autism is restriction in behaviors (Kanner, 1943). It is likely that selectivity develops because “ritualistic” patterns of behaviors are reinforcing for these children. It is unclear why, for example, a whole chip is more appealing than pieces of a chip, but over time it becomes a patterned ritualistic way of eating. Another plausible explanation is that children with ASD and other developmental delays may be more sensitive to various sensory stimuli and learn to avoid certain food types and textures that may produce unpleasant sensory stimulation in the mouth.

Children learn to eat a variety of foods by repeated taste exposures. These taste exposures are initiated by social contingencies in which a caregiver provides prompts, models, and positive reinforcement (i.e., praise) for trying new foods (Williams & Seiverling, 2010). Eventually, these foods become preferred and become part of the child’s repertoire of foods consumed. However, children with ASD and other developmental delays may not respond to the same types of social contingencies because of their limited language and social skills. Rather, they may focus on past experiences to determine whether a novel food would be accepted or rejected. For example, if the food is similar in visual properties to a preferred food, the child may be more likely to accept that food.

An important consideration to better understand feeding problems is the developmental progression of eating and drinking from birth. Typical eating patterns start with bottle- or breast-feeding from birth to 4 months of age.

Between 4 and 6 months of age, solid foods (Linscheid et al., 1995; e.g., rice cereal) and smooth thin baby foods (e.g., fruits and vegetables) are introduced. Over time food texture is thickened and variety is introduced. In addition, between 4 and 6 months of age children begin to hold the bottle with assistance. Between 6 and 8 months children are able to hold the bottle independently, eat a variety of baby foods, start to develop tongue lateralization when food is presented on the side of the mouth, and can begin to bite off meltable solids such as crackers and puffs with assistance. At 8–10 months of age children are consuming more lumpy foods as well as small pieces of soft table foods. They are also becoming more proficient with meltable solids. At this time tongue lateralization matures but the child is still relying on mashing to consume small pieces of table foods. Self-feeding finger foods also starts to emerge. Between 10 and 12 months children begin eating coarsely chopped soft table foods, finger feeding chopped foods, and experimenting with a sippy or straw cup. They also start to demonstrate rotary chewing (i.e., circular chewing vs. mashing). At 12–16 months of age children begin to eat with utensils with assistance and all foods are at a chopped texture. This is the age where the child may transition from a bottle to a sippy or straw cup and transition from formula or breast milk to whole milk. In addition, rotary chewing is strengthened at this age. Research suggests that feeding problems arise most often between the ages of 12–24 months (Linscheid & Rasnake, 1985). This may be the period where children become more selective with what they will and will not eat. In addition, children age 12–24 months show appetite reduction/variability and more noncompliance during mealtimes as a result of trying to gain independence (Linscheid et al., 1995). At 16–24 months of age all foods are at table texture (i.e., cut up into pieces) and raw fruits and vegetables are presented. During this period, utensil use increases and rotary chewing is completely developed. For typical eaters, chewing is not a skill that is explicitly taught; however, the skill is strengthened when children are presented with different textures of food.

Skill deficits occur if eating has been interrupted at any point in the developmental chain. For example, if medical and anatomical issues have not been resolved, it is likely that the process of eating has not followed a developmental progression because eating was delayed or interrupted. Children with tube feedings also may display skill deficits; since nutrition is coming from enteral support, the child is not required to practice the skills necessary to eat by mouth. The same is true for children who have negative experiences with food or children who display food selectivity; since the child learns to refuse certain foods and textures, they are not practicing the skills necessary to be an efficient eater. These types of interruptions may cause skill deficits in a number of areas related to eating such as improper lip closure, tongue lateralization, rotary chewing, self-feeding, and others.

Medical Evaluation

An extensive medical evaluation is the first step to assessing a feeding disorder. Medical testing can start with simple blood work and/or stool samples to determine vitamin and mineral deficiencies. This type of testing can be initiated by a primary care physician. The primary care physician will also closely monitor weight and height to ensure that the child is gaining weight and growing appropriately.

Thereafter, a primary care physician may refer the child to a pediatric gastroenterologist and/or allergist. Since, in some cases, feeding problems develop as a result of gastrointestinal (GI) problems; it is imperative that children go through testing to rule out any GI issues such as GER. In addition, extensive allergy testing may also be warranted to rule out any food allergies that could be contributing to GI issues.

If food allergies and/or problems with weight gain are evident, then a child may be referred to a dietician. Children who display food selectivity may also be referred to a dietician because they may be lacking certain vitamins and minerals in their diet which may result in medical concerns (e.g., anemia). A dietician may require the

caregivers to complete a food diary so a nutritional analysis can be obtained. In some cases, genetic testing may also be necessary because certain conditions like celiac disease require adherence to a specific diet.

Next, it is imperative that swallow function be assessed. The child may first be referred to an ENT (ear, nose, and throat) doctor to determine if enlarged tonsils and/or adenoids could contribute to feeding problems. Thereafter, a swallow study should be conducted to rule out aspiration or any other swallow dysfunction, known as dysphagia. If aspiration is evident, the child may require oral motor therapy to increase oral motor skills so that swallow function can eventually normalize.

Oral Motor/Oral Sensory Evaluation

Once a child has completed an extensive medical evaluation it may also be helpful to consult with either an occupational therapist (OT) or speech and language pathologist (SLP) who can identify any oral motor or oral sensory deficits. Oral motor delays may include, but are not limited to, the following: inefficient sucking and swallowing via breast and/or bottle, coordination problems with varying textures of foods, difficulty manipulating food with the tongue, packing food in the mouth as a result of poor tongue lateralization (movement of food side to side), vomiting all textures, gagging when food is deposited or after a swallow response, and tolerating oral play with fingers and toys but unable to bite them or to keep them in the mouth (Arvedson, 2008). Sensory motor delays include, but are not limited to, the following: nipple confusion from the breast to the bottle, inability to differentiate tastes, better efficiency with liquids vs. solids, packing food to avoid swallowing due to sensory sensitivity, texture-specific vomiting and gagging, gagging when food touches the lips or tongue, tolerating own finger in the mouth but does not tolerate other's fingers in the mouth, and refusing to brush teeth and lack of mouthing toys (Arvedson, 2008). The American Speech-Language Hearing (2007) has identified several assessment tools to evaluate oral motor deficits

which include Bedside Evaluation of Dysphagia (BED), Dworkin-Culatta Oral Mechanism Exam and Treatment System (D-COME-T), Dysphagia Evaluation Protocol, Establishing Dysphagia Programs, Hines Functional Dysphagia Scale (HFDS), MASA: The Mann Assessment of Swallowing Ability, Oral Motor/Feeding Rating Scale, Oral Speech Mechanism Screening Examination-Third Edition (OSMSE-3), Quick Assessment for Dysphagia, Swallowing Ability and Function Evaluation (SAFE), Test of Oral Structures and Functions (TOSF), and Program for the Assessment and Instruction of Swallowing (PAIS). In addition, there are other assessment tools that evaluate oral and/or sensory motor function (e.g., Palmer, Crawley & Blanco, 1993; Palmer & Hayman, 1993; Reilly, Skuse, & Wolke, 2000; Rogers & Arvedson, 2005). Unfortunately, there is a dearth of literature establishing the reliability of these oral/sensory motor assessments.

Behavioral Assessments

As mentioned previously, many children who display feeding problems engage in a variety of inappropriate mealtime behaviors to avoid eating. Therefore, behavioral assessments may be necessary to evaluate the environmental variables that may contribute to the feeding problem. Some behavioral assessments also include an evaluation of medical and/or oral/sensory motor deficits. Various behavioral assessments used in the literature are summarized below. In addition, other authors have also reviewed the behavioral assessment literature for children with feeding problems (e.g., Lukens, 2011; Seiverling, William, & Sturmey, 2010).

Indirect Measures

Indirect measures refer to assessment tools that do not measure the child's actual mealtime behavior, but rather the caregiver's perception of the feeding problem. Caregiver interview may be the first type of indirect measurement used to assess

a child's feeding problem and includes gathering information about family, medical, developmental, and feeding history (Arvedson, 2008). It may be necessary to review past medical records from other professionals to confirm the caregiver's verbal report.

The caregiver may also be asked to fill out questionnaires/checklists to better understand the feeding problem. There are several questionnaires/checklists that have been validated in the literature. Archer, Rosenbaum, and Streiner (1991) developed the Children's Eating Behavior Inventory (CEBI), which is one of the first objective measures to assess feeding problems in children with a variety of medical and developmental delays. This questionnaire encompasses the child, caregiver, and family factors that may contribute to the feeding problem. It not only examines the frequency and severity of the feeding problem but it also evaluates caregiver stress as it relates to mealtime behaviors. The CEBI consists of 40 items which include questions related to food preference, motor skills, child compliance during meals, caregiver behavior during mealtimes, and questions about how the feeding problem affects the family system. Caregivers will rate each question on a five-point Likert scale which includes a rating of never, seldom, sometimes, often, always. In addition, the caregivers circle "Yes" or "No" to indicate if they consider that particular question to be problematic. The CEBI has been a useful tool to assess feeding problems for children with a variety of feeding problems; however, it has been reported that the CEBI may not address the feeding problems typically displayed by children with ASD (Seiverling et al., 2010).

Crist, Dobbelsteyn, Broussaeau, and Napier-Phillips (2004) developed the Behavioral Pediatric Feeding Assessment Scale (BPFAS) to evaluate inappropriate mealtime behaviors in children with cystic fibrosis and children with no medical issues. This caregiver report measure, like the CEBI, evaluates both child and caregiver behavior around mealtime. The BPFAS was further validated by comparing responses from caregivers of healthy children to those of children who were referred for feeding difficulties (Crist & Napier-Phillips, 2001). This scale consists of 35 items.

The first 25 questions refer to child mealtime behavior, and the remaining ten questions address feelings about or strategies caregivers use to manage inappropriate mealtime behaviors. Caregivers respond to certain descriptive phrases (e.g., "My child eats fruits"; "My child comes readily to mealtimes") using a five-point Likert scale from never to always. They are also asked if that specific behavior is problematic for them by answering "yes" or "no." Crist and Napier-Phillips (2001) showed that the basic pattern of behaviors around mealtimes was similar across healthy children and children referred to a clinic for feeding difficulties; however, the frequency of behaviors was greater for children who were referred to a clinic. Furthermore, the factor analysis on the 25 child-related questions revealed six factors. These factors included picky eaters (how willing children were to try new foods), toddler refusal-general (whining, crying, tantrums, and spitting out of food), toddler refusal-textured foods (problems chewing food, eating only ground soft foods, packing food on the mouth, choking, and/or gagging), older children refusal-general (delayed eating by talking, negotiating what the child will eat, getting up from the table during meals, poor intake at meal but requesting other foods after meals), stallers (packing food in the mouth and/or liquid dependency), and children who require tube feedings.

In order to encompass all aspects of the feeding difficulty, Crist et al. (2004) developed the Pediatric Assessment Scale for Severe Feeding Problems (PASSFP). The validity of this test was evaluated using three groups of children: children who were 100 % tube dependent, children who did eat orally but required some supplemental feedings via tube, and children who displayed feeding problems but who were not tube fed. The PASSFP is a 15-item questionnaire completed by caregivers and includes items related to nutritional, oral sensory, oral motor, behavioral, and quality of life concerns. The PASSFP has two sections; the first section is filled out by all parents, and the second section is only filled out by parents attempting oral feedings. The PASSFP is an assessment tool that can be used to evaluate initial severity of the feeding problem and can

also be used subsequently to assess progress once treatment is initiated.

Matson and Kuhn (2001) developed the Screening Tool of Feeding Problems (STEP) to assess the feeding problems in adults with intellectual disability. This 23-item questionnaire includes five categories (aspiration risks, food selectivity, feeding skills, inappropriate mealtime behaviors, and nutritional concerns) that assess frequency and severity of behavior.

Berlin, Davies, Silverman, and Rudolph (2011) developed the Feeding Strategies Questionnaire (FSQ) to assess family-based feeding strategies, strengths, and mealtime structures for children with feeding difficulties. The FSQ is a 40-item questionnaire which requires caregivers to rate the extent to which they agree or with an item. Factor analyses revealed six factors including mealtime structure, consistent mealtime schedule, child control of intake, parent control of intake, between meal grazing, and encouraging an empty plate. Data indicate that the FSQ is an effective assessment tool for assessing both caregiver and child behavior during mealtimes. In addition, this tool allows one to identify the specific aspect of the mealtime that may require intervention.

The aforementioned studies all include questions about child behavior, caregiver strategies, and mealtime environment; however, since multiple variables are being assessed, it is likely that the frequency of inappropriate mealtime behavior is confounded (Berlin et al., 2010). Therefore, Berlin et al. (2010) developed the Mealtime Behavior Questionnaire (MBQ) to solely evaluate the frequency of child inappropriate mealtime behaviors. The MBQ is a 33-item questionnaire which rates how often or how frequently a behavior occurred during mealtimes from 1 (never) to 5 (always). This questionnaire includes several inappropriate mealtime behaviors including food refusal/avoidance (e.g., demanding another food, eating too slowly, verbally refusing to eat), food manipulation (e.g., throwing/spitting food, packing food), mealtime aggression, and choking/gagging/vomiting.

Davies, Ackerman, Davies, Vannatta, and Noll (2007) developed the About Your Child's Eating

(AYCE) which is a 25-item questionnaire that focuses on caregivers beliefs and concerns about their child's eating behaviors. This assessment tool targets the frequency of inappropriate mealtime behaviors, caregiver's interactions during meals, and overall feeling about mealtimes.

Hendy, Williams, Camise, Eckman, and Hendemann (2009) created the Parent Mealtime Action Scale (PMAS) which also targets child and caregiver mealtime behaviors. In addition, it also focuses on the frequency that caregivers eat and present certain foods to their children. Unlike the other assessment tools mentioned above, the PMAS does not focus on parent feelings/attitudes about mealtime behaviors. Rather the focus of this instrument is on actual parent mealtime behaviors including limits to snacking, positive encouragement, availability of fruits and vegetables, use of reinforcement, insisting that the child eats, snack modeling, presenting alternate meals, reducing fat, and giving many food options. The caregiver will rate how often a specific behavior occurs within a given a week. This assessment tool allows users to identify caregiver behaviors that affect inappropriate mealtime behavior of the child.

Although the previously mentioned assessment tools can be used with children with ASD, the Brief Autism Mealtime Behavior Inventory BAMBI (Lukens & Linscheid, 2008) is more specifically targeted for the types of feeding difficulties typically displayed in children with ASD (e.g., aggression, self-injurious behaviors, ritualistic eating patterns, and severe food selectivity). The BAMBI is an 18-item questionnaire scored from 1 (behavior never occurs) to 5 (behavior always occurs). Food preference inventories have also been utilized with children with ASD to determine what foods to target in treatment (Seiverling et al., 2010). Typically these inventories assess the foods the family eats and the foods the child consumes prior to treatment and posttreatment.

It is important to understand that indirect measures can be helpful in developing a starting point for treatment; however, these assessment tools do not assess actual mealtime behaviors but rather the caregiver's perception of the behaviors.

These accounts are more anecdotal and may not always be factual. These measures alone should not be used when trying to develop a comprehensive treatment plan.

Direct Observation

With direct observation, a trained practitioner records actual mealtime behaviors instead of relying on third-party subjective impressions. Specific behaviors must be identified and operationally defined so that reliability can be obtained across data collectors. For example, the operational definition for acceptance may include any food that enters the mouth within 5 s of its presentation. This definition allows all data collectors to record acceptance in the same exact manner.

Direct observation often includes opportunities to present food in a systematic way in order to collect data of interest. For example, Babbitt et al. (1994) describe a direct observation baseline involving age-appropriate portions of food given to a child combined with verbal prompts to take a bite. Consequences were not delivered for any behavior, and the meal was terminated after the volume of food was consumed or 20 min elapsed. Children unable to self-feed were presented a bite of food at the mouth every 30 s with the verbal prompt to take a bite. Food presented was repeated 40–50 times, rotating through all of foods. Baseline data collection included recording data on acceptance, inappropriate mealtime behaviors, negative vocalizations, and premeal and post-meal food weights. These baseline sessions were individualized to each child and altered based on the child's needs.

The Mealtime Observation Schedule (MOS) developed by Sanders, Patel, LeGrice, and Shepherd (1993) is an objective coding system to systematically collect data on both caregiver and child behavior during mealtimes. The MOS has 17 categories of child behavior (e.g., noncompliance, complaints, holds the food, spits/vomit, requests food, prepares food, bites, chews) and 15 items of caregiver behavior (aversive contact, aversive prompt, praise, removes food). In order

to collect data on these behaviors, one must review and record from a 20-min videotaped meal.

Stark et al. (2000) developed a similar assessment to the MOS called the Dyadic Interaction Nomenclature for Eating (DINE), which was created to specifically collect mealtime behavior data for both children with and without cystic fibrosis. The DINE incorporates parent behavior (e.g., direct commands, physical prompting, reinforcement), child behavior (e.g., noncompliance with a command, food refusal), and child's eating behavior (e.g., number of bites consumed, number of sips of liquid consumed). These behaviors are scored as either occurring or not occurring within a 10-s interval similar to the MOS. In addition, frequency of certain behaviors is also recorded.

Food preference assessments are another direct measurement tool used with children who display food selectivity. The purpose of preference assessments is to obtain a hierarchy of preferred foods. However, this assessment process may not be useful for children who are tube or liquid dependent since exposure to foods and consumption may be minimal. In a food preference assessment you first compile a list of foods to include in the assessment. Then every food on the list is paired with every other food on the list and offered to the child in separate trials or opportunities. Once the foods are sampled the child is offered a choice between two foods (Babbitt et al., 1994). Data are collected on the number of times a food is chosen and converted to a percentage.

Functional Assessment

Functional assessment analyzes environmental variables contributing to the feeding problem. Functional assessment includes direct observation of behavior as well as recording antecedents (events that occur before inappropriate mealtime behavior such as seating arrangement and texture of food) and consequences (events that occur after appropriate and inappropriate mealtime behavior such as verbal reprimand, ignoring and

keeping the food to the mouth, delivering toy, and providing praise). Two types of functional assessment procedures may be adopted. Descriptive assessment (see Chap. 8 of this handbook for more detail about this assessment process) typically involves analyzing the antecedent, behavior, and consequences that occur under naturally occurring situations. In some cases, descriptive assessment includes manipulating antecedent conditions and collecting data on target mealtime behaviors such as acceptance of foods, expulsion of food, turning head away from the food, and others. Functional analysis, on the other hand, involves systemically manipulating antecedents and consequences so that a functional relation (variables maintaining the feeding problem) can be identified. Chapter 9 of this handbook provides more information about functional analysis of problem behavior.

Munk and Repp (1994) conducted a descriptive assessment in order to differentiate the type of feeding problem exhibited by five individuals with developmental disabilities. An assessment was developed to identify individuals who (1) refuse all foods (total refusal), (2) accept certain foods at all textures (food type selectivity), (3) accept all foods at one texture but refuse the same food at another texture (food texture selectivity), and (4) exhibit both food type and texture selectivity. Data were collected on acceptance, refusal to open mouth to the spoon, expulsion, and negative behaviors such as stereotypy and self-injury. Ten to 12 foods were presented at varying textures (refined pureed texture, coarser ground texture, chopped texture), and data were collected on mealtime behaviors for each food and texture. No differential consequences were delivered for either accepting the food or for rejecting the food. This assessment allows one to identify the antecedent variables that contribute to inappropriate mealtime behaviors.

Descriptive assessments have also been conducted to determine the consequences that are more frequently delivered by caregivers. For example, Piazza et al. (2003) and Borrero, Wood, Borrero, Masler, and Lesser (2010) evaluated inappropriate mealtime behaviors of children with feeding problems in a hospital setting.

In addition, caregiver responses to these behaviors were also evaluated. Caregivers were given instructions to feed their child how they typically would at home. The experimenter gave the caregivers all of the materials they needed to conduct the meal including food, utensils, or toys. Data were collected on specific child behavior (e.g., acceptance, inappropriate mealtime behavior, expulsion, gagging) and caregiver behavior (delivery of escape (removal of the bite), attention (verbal reprimand, coaxing), and/or tangible item (giving access to a preferred toy or food) contingent on inappropriate behavior mealtime behavior). Data from the Piazza, Fisher, et al. (2003) study indicated that all caregivers delivered attention and escape contingent on inappropriate mealtime behaviors rather than appropriate behaviors and only three of the six gave access to a tangible item contingent on inappropriate behavior. Similar results were obtained by Borrero et al. (2010). Although the descriptive assessment identified various consequences parents used when dealing with inappropriate mealtime behavior, it was difficult to determine the effects of any one consequence since consequences were not systematically manipulated (Piazza, Fisher et al. 2003). Casey et al. (2009) also evaluated the use of a descriptive assessment when treating two children with FTT who displayed food refusal. Results indicated that positive reinforcement in the form of praise, social interaction, and preferred activities were delivered contingent on acceptance of food which was a contrast from the studies mentioned above. However, negative reinforcement in the form of escape was delivered contingent upon inappropriate mealtime behaviors similar to the Piazza, Fisher, et al. (2003) and Borrero et al. (2010) studies. Treatment was implemented based on the existing schedule of escape.

Once a descriptive assessment has been performed, it may be necessary to conduct a functional analysis to determine the function of the inappropriate mealtime behavior. In a functional analysis specific antecedents and consequences are isolated and manipulated to verify the behavioral mechanism responsible for the

maintenance of the inappropriate mealtime behavior. Functional analysis has been used for a variety of problem behaviors including self-injury, noncompliance, and aggression; however, it has not been widely used for inappropriate mealtime behaviors. Piazza, Fisher, et al. (2003) conducted a functional analysis for 15 children diagnosed with a feeding disorder. The functional analysis consisted of a trained therapist conducting sessions. Each meal session was 10 min in duration and a bite was presented every 30 s. Each session consisted of a different consequence for inappropriate mealtime behavior. In the positive reinforcement in the form of attention condition, the therapist delivered coaxing statements (e.g., “you like this,” “don’t cry, you can do this”) contingent on inappropriate mealtime behaviors. In the positive reinforcement in the form of tangible items condition, a preferred toy was delivered contingent on inappropriate mealtime behavior. In the negative reinforcement in the form of escape condition, the bite of food was removed contingent on inappropriate mealtime behavior. These data suggested that 90 % of the children’s inappropriate mealtime behaviors were maintained in part by negative reinforcement in the form of escape. Data show that the typical consequence that is used by parents (i.e., removing the food and allowing escape from eating) worsened behavior.

Functional analyses have also been conducted with children with ASD who display food selectivity (e.g., Levin & Carr, 2001; Najdowski, Wallace, Doney, & Ghezzi, 2003). Like the Piazza, Fisher, et al. (2003) study, this research reveals that inappropriate mealtime behaviors were maintained by negative reinforcement in the form of escape from non-preferred or new foods. Although functional analysis identifies consequences maintaining inappropriate mealtime behaviors, it does not give us information on the antecedent conditions that make certain foods aversive. Future research may want to examine changing antecedent conditions and keeping consequences the same so that more information can be gathered about the aversive properties of eating.

Treatment Options

If the child’s feeding problems have an oral and/or sensory motor etiology, more traditional feeding therapy may be warranted. Although traditional feeding therapy is commonly initiated by an OT or SLP, since feeding problems are etiologically heterogeneous the expertise of several professionals is often required. The treatment of choice for more severe feeding problems has been intensive feeding therapy using an interdisciplinary treatment model (Piazza & Carroll-Hernandez, 2004). These interdisciplinary feeding programs are typically housed within a hospital (see Chap. 22 of this handbook for more details), but this model has also been implemented in the home environment (Patel, 2008). Most interdisciplinary feeding programs have a behavior analyst on staff since most feeding problems are maintained in part by various environmental variables.

Typically all children who go through an intensive feeding program will require a series of behavioral assessments. Once behavioral assessment data have been collected those data should inform the best treatment option. Typically, these assessments will yield information about the environmental variables that may be contributing to the feeding problem. Therefore, a specific behavioral treatment will then be initiated. Indirect measurements are subjective and may not be accurate so it is critical that direct observation data be collected before determining the course of treatment. Once direct observation data are collected it may be necessary to conduct a more specific analysis which may involve either a descriptive assessment and/or a functional analysis. Functional analysis is the “gold standard” because it is the only assessment that identifies a functional relation between environmental variables and inappropriate behavior, which leads to more effective and efficient behavioral treatment.

Behavioral treatments have shown to be the most scientifically effective (Kerwin, 1999) for feeding problems in children. There is a growing literature showing various behavioral treatments

that have been effective for increasing acceptance of food/liquid and decreasing inappropriate mealtime behaviors (e.g., Ahearn, Kerwin, Eicher, Shantz, & Swearingin, 1996; Cooper et al., 1995; Patel, Piazza, Martinez, Volkert, & Santana, 2002; Patel et al., 2007; Piazza et al., 2003; Reed et al., 2004; Rivas, Piazza, Patel, & Bachmeyer, 2010). In addition, behavioral treatments for food selectivity in children with and without ASD have also been shown to be effective (e.g., Buckley & Newchok, 2005; Najdowski et al., 2003; Patel et al., 2001, Piazza et al., 2002). Although there is a breadth of literature showing positive treatment outcomes with the use of behavioral techniques with children with feeding problems, it is imperative that recommendations from other disciplines be taken into consideration when developing a treatment plan. As mentioned previously, feeding problems develop as an interaction between many factors (medical, biological, psychological, social, and behavioral) and in order to treat all aspects of the feeding problem an evaluation by various disciplines is warranted.

Conclusion

Resolving medical issues and identifying feeding problems early may be critical to long-term success. Typically the medical model uses the “wait and see” approach; however, it is important that feeding issues be addressed early before a child’s health and well-being are compromised. Since eating and drinking follow a developmental model, it is imperative that feeding issues be resolved quickly so skills do not become further delayed, further increasing health risks.

Once the problem has been identified, a clinician must determine the most appropriate assessment tools for a specific child. This chapter discusses many indirect measures to assess feeding problems, but depending on the child’s diagnosis and specific type of feeding problem, a particular assessment may be more useful. After gathering indirect measurement data it will be imperative to collect direct observation data via functional assessment. Once an extensive assessment has been conducted then the most

appropriate treatment can be identified. Once an appropriate treatment has been identified then caregivers must be trained to implement that treatment plan in their natural environment. The utility of these assessment tools has been identified, but more research is necessary on how to link assessment and treatment data in the most efficient manner.

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Unique Considerations of Prader-Willi Syndrome

11

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Prader-Willi syndrome (PWS) is a genetic, neurodevelopmental disorder, occurring in approximately 1 in 12,000–15,000 live births, that has specific physical, medical, and behavioral characteristics (Dykens & Cassidy, 1996; Milner et al., 2005; Wigren & Hansen, 2003). This syndrome has been reported in all races and ethnic groups, although it is reported disproportionately more in whites (Thompson, Butler, MacLean, Joseph, & Delancy, 1999). Approximately 70 % of PWS cases involve a deletion on the long arm of the paternally derived chromosome 15 [del 15 (q11–q130)], often including the whole Prader-Willi/Angelman Critical Region (PWACR; Cassidy et al., 1997). Most of the remaining cases of PWS (approximately 25 %) are attributed to maternal uniparental disomy, which results when both chromosome 15s are derived from the mother. A small proportion of cases (less than 5 %) is due to a mutation affecting the imprinting center. In these cases, the paternally derived PWACR is present but is not imprinted. Despite these differences in genetic etiology, all subtypes of PWS are the result of a non-expression of paternal genes in the PWACR (Whittington et al., 2002). Although the presence of multiple physical, medical, and behavioral

characteristics suggests PWS, genetic testing is necessary to make a diagnosis (Whittington et al.).

In this chapter, we will review the clinical and behavioral features of PWS with a focus on (a) hyperphagia and associated food-related problem behavior, (b) physical activity levels, (c) self-injurious behavior (SIB) (e.g., skin picking), and (d) other problem behaviors (e.g., physical aggression) that interfere with quality of life. We will also discuss assessment and treatment of these behavior disorders with a focus on behavior analytic methods involving functional analysis methodology and function-based treatment. Finally, we will discuss some of the unique considerations for assessment and treatment of behavior disorders in PWS.

Clinical Features and Symptoms

Individuals with PWS have common physical characteristics including short stature, small hands and feet, narrow forehead, almond-shaped eyes, hypogonadism, hypopigmentation (i.e., fair skin and hair), and a small mouth with downturned corners (Dykens, 1999; Dykens & Cassidy, 1996). In addition to physical characteristics, the development of symptoms is quite unique in this syndrome. Infants with PWS show hypotonia (weak muscles), poor reflexes, and difficulty sucking, which often results in “failure to thrive” and the need for tube feeding (Dykens, 1999; Dykens & Cassidy, 1996; Dykens, Lee, & Roof, 2011).

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Infancy is followed by a very large increase in appetite (hyperphagia) between ages 1 and 6 years (Cassidy et al., 1992; Thompson et al., 1999), which continues throughout the lifespan (Dykens, Maxwell, Pantino, Kossler, & Roof, 2007). Finally, many individuals with PWS show global developmental delays (e.g., delayed language and motor development) by age 6 (Dykens & Cassidy, 1996), and approximately half are diagnosed in the mild to moderate range of mental retardation with an average IQ of 70 (range, 40–105; Dykens, Hodapp, Walsh, & Nash, 1992; Dykens & Shah, 2003; Thompson et al., 1999).

The most serious and pervasive concern for individuals with PWS and their families is hyperphagia (overeating), which is hypothesized to be due to abnormal functioning of the hypothalamus (Dykens & Cassidy, 1996). Hyperphagia coupled with reduced metabolic rates and low physical activity of individuals with PWS results in rapid weight gain and obesity (Dimitropoulos et al., 2000; Dykens, 1999). In fact, individuals with PWS are reported to have 40–50 % body fat (two to three times more than in normal individuals) and low levels of lean body mass with the heaviest amount of fat in the trunk region and limbs (Thompson et al., 1999). Morbid obesity is associated with serious health concerns including hypertension, diabetes mellitus, congestive heart failure, and sleep apnea (i.e., pauses in breathing during sleep; Butler, 1990; Butler et al., 2002). In addition, eating large amounts of food quickly may result in choking or gastric dilation or rupture (gastric necrosis; Dykens et al., 2011; McAllister, Whittington, & Holland, 2010; Thompson et al., 1999). Finally, individuals with PWS rarely vomit or report gastrointestinal pain, making it difficult to determine an emergency situation such as some of those listed above. Thus, without intervention, hyperphagia is extremely dangerous and is the major cause of premature death in this population (Einfeld et al., 2006).

Behavioral Disorders

Individuals with PWS engage in various behavior problems related to hyperphagia that include food-seeking behaviors such as hoarding or

stealing food, eating inedible or unpalatable items (i.e., pica), and stealing money to purchase food. However, individuals with PWS have also been reported to engage in other problem behaviors that are unrelated to food, including (a) SIB, (b) sedentary behavior (i.e., low levels of physical activity), (c) ritualistic behaviors that are often described as “obsessive compulsive,” and (d) other problem behavior (e.g., physical aggression, tantrums, and property destruction) that may or may not be related to gaining access to food (Dykens & Cassidy, 1996; Dykens & Shah, 2003; Thompson et al., 1999).

Hyperphagia and Food-Seeking Behavior

Hyperphagia is defined as an insatiable and voracious appetite. In fact, studies have shown that individuals with PWS do not have normal satiety or feelings of fullness (e.g., Holland et al., 1993; Holland, Treasure, Coskeran, & Dallow, 1995; Lindgren et al., 2000; Zipf & Berntson, 1987). For example, Holland et al. (1995) provided individuals with and without PWS unlimited access to sandwich quarters and measured the amount of food consumed by each participant. Results showed that individuals with PWS consumed three times as many calories as those without PWS and reported a delay in satiety (i.e., did not report “feeling full” until 40 min after access to food and only after eating an excessive amount of food).

Given their insatiable appetite, it is not surprising that individuals with PWS are reported to steal and hoard food and consume inedible items (pica). The results of several large-scale surveys, questionnaires, and interviews have suggested that individuals with PWS engage in food stealing and unhealthy food consumption (i.e., consumption of unappealing or dangerous items such as pet food, frozen chicken, rotten food, and vitamins; Dykens, 2000; Greenswag, 1987; Holm & Pipes, 1976). Greenswag (1987) provided structured questionnaires to 275 caregivers of adults with PWS and found that the majority of the caregivers reported that the individual with PWS engaged in food stealing and hoarding, which oftentimes necessitated the need to “lock

up” all food in the home. In addition, several experimental studies have shown that when left alone in a room with food items (and told not to eat the items), individuals with PWS will consume the “prohibited items” (Maglieri, DeLeon, Rodriguez-Catter, & Sevin, 2000; Page, Finney, Parrish, & Iwata, 1983; Page, Stanley, Richman, Deal, & Iwata, 1983). Dykens (2000) conducted an interview to determine whether individuals with PWS would be willing to eat contaminated food, partially contaminated food, unusual food combinations (e.g., hot dog and whipped cream), or inappropriate items (e.g., pasta and paint). In the interview, pictures were used to present different desired foods in the above situations, and the participants were asked to report their willingness to eat the item. The authors found that participants with PWS were more likely than others with and without intellectual disabilities to report that they will (a) eat contaminated food, (b) consume inedible items, and (c) eat unusual food combinations. However, it is important to note that consumption of these items may be most likely to occur under conditions of restricted access to food.

Sedentary Behavior

In addition to food-related problem behavior, another behavior that contributes to the obesity and overall health of individuals with PWS is their reported sedentary behavior (Greenswag, 1987; Hodapp & Dykens, 1994; Nardella, Sulzbacher, & Worthington-Roberts, 1983; Rankin & Mattes, 1996). Nardella et al. (1983) reported that parents of children with PWS indicated that their children were lethargic and tired for no apparent reason. Eiholzer et al. (2003) used pedometers to measure daily activity of a group of individuals with PWS and a group of typically developing adults. The experimenters found significant differences between the groups in their average daily activity levels, with members of the PWS group, on average, more sedentary. In a study by van Mil et al. (2000), the authors evaluated the amount of energy expenditure during both rest and activities and found differences between individuals with PWS and a control

group of individuals with similar heights and weights. Using basal metabolic rate (BMR) and average daily metabolic rate (ADMR) measures, the authors found that individuals with PWS expended significantly less energy than their matched pairs in the control group. These data suggest that whether or not individuals with PWS are more sedentary than their typically developing peers, they overall expend less energy while active and at rest, which puts them at a higher risk for obesity. Lower activity levels, as well as lower levels of energy expenditure, in individuals with PWS may contribute to health problems.

Self-Injurious Behavior

SIB is defined as any behavior directed toward one's own body that produces injury (Tate & Baroff, 1966). Various topographies of SIB have been reported to occur in individuals with PWS including hand biting, headbanging, hairpulling, and rectal digging (Symons, Butler, Sanders, Feurer, & Thompson, 1999). However, the most common form of SIB is skin picking, which is reported to occur in 65–97% of individuals with PWS (Dykens, Cassidy, & King, 1999; Symons et al., 1999). Skin picking is defined as scratching, pulling, digging, or gouging one's own body (Lang et al., 2010). Individuals with PWS have been reported to mostly pick the front of legs, head, and arms (Symons et al., 1999). Obviously, there are several health risks associated with skin picking (and other forms of SIB) including contusions and lacerations, infection, and scarring (Ho & Dimitropoulos, 2010). In addition to health risks, these behaviors often interfere with learning, independence, and quality of life. For example, the appearance of visible sores or wounds may prevent individuals with PWS from forming new relationships. If wounds become infected, the infection may impede the individual from interacting with others, which can hinder both social and skill development by preventing access to other people and activities (e.g., school, work). Finally, SIB that results in contusions and lacerations often requires constant supervision that may result in decreased independence (e.g., placement in restrictive settings).

Obsessive-Compulsive Behavior

Some individuals with PWS are reported to have symptoms similar to those diagnosed with obsessive-compulsive disorder (OCD; Dykens & Shah, 2003). In fact, individuals with PWS tend to score in the clinically significant range on instruments that measure the extent and severity of obsessive and compulsive behaviors (e.g., Yale-Brown Obsessive Compulsive Scale; Dykens, Leckman, & Cassidy, 1996). Obsessive-compulsive behaviors in individuals with PWS include hoarding (e.g., paper, toiletries), ordering and arranging items by specific characteristics, questioning repeatedly, being concerned with exactness and sameness, and redoing things (e.g., rereading, rewriting) (Dykens & Cassidy, 1996; Dykens & Shah, 2003; Dykens et al., 2011). Dykens et al. (1996) reported a significant association between obsessive-compulsive behaviors and PWS, and Dimitropoulos, Feurer, Butler, and Thompson (2001) found that individuals with PWS show significantly higher levels of compulsive behaviors than individuals with Down syndrome and typically developing individuals. In addition, Dykens et al. (1996) found that these behaviors were time-consuming and distressful for a high percentage of individuals with PWS and their families.

Other Problem Behavior

Individuals with PWS are reported to engage in other problem behaviors such as tantrums, property destruction, and physical aggression. Dykens et al. (1999) conducted a survey of a large sample of individuals with PWS and found that 88% engaged in tantrums (e.g., yelling, screaming, and noncompliance), 42% engaged in property destruction (e.g., throwing objects, breaking objects, hitting walls), and 34% engaged in physical aggression (e.g., hitting, kicking, or biting others). Although these behaviors may occur to gain access to food, they may also occur for other reasons (to gain access to other social and nonsocial reinforcers such as attention from others or

escape from aversive situations; see a more detailed description of these possible functional reinforcers in the *Assessment and Treatment of Behavior Disorders* section below). As is the case with SIB, these problem behaviors are often stressful for the individual and their families and caregivers and may affect learning, independence, and overall quality of life. For example, individuals who engage in aggression and property destruction may be precluded from going to certain places (e.g., museums or the mall) or attending certain events (e.g., concerts) out of fear that the individual with PWS may destroy expensive items or harm others. In addition, if the individual with PWS requires constant supervision, caregivers may be precluded from engaging in preferred social events. Therefore, severe problem behavior may lead to outcomes such as reduced quality of care, increased caregiver turnover, and placement in restrictive settings.

Assessment and Treatment of Behavior Disorders

A common treatment for hyperphagia and other behavior problems displayed by individuals with PWS is pharmacological intervention. However, no consistently effective pharmacological strategies have been developed for the treatment of individuals with PWS (Dykens & Shah, 2003). Recently, several studies (e.g., Craig et al., 2006; Hoybye, Hilding, Jacobsson, & Thoren, 2003) have found that growth hormone (GH) therapy may be effective over the longer term in reducing body fat, increasing lean body mass, increasing height velocity, and increasing overall height in individuals with PWS; however, it has not been shown to have any effect on eating behavior (McAllister, Whittington, & Holland, 2010). It is important to note that side effects and risks associated with GH therapy should be considered (Dykens et al., 2011; Dykens & Shah 2003). The major focus of this section will be on environmental manipulations and behavioral assessment and treatment of behavior disorders in PWS.

General Weight Management

Individuals with PWS eat more, require less calories to maintain an appropriate weight, and engage in lower levels of physical activity (with less energy expenditure) than typically developing individuals. Common weight management strategies have emerged from research and case studies that are regarded as best practice and include (a) implementation of a low-calorie, individualized diet with vitamin and calcium supplements (as determined by a dietician/nutritionist), (b) frequent weigh-ins (at least weekly), (c) participation in exercise (approximately 30 min per day), and (d) environmental manipulations to restrict access to food (close supervision in all settings, locks on food cabinets and refrigerators) or money to purchase food (Dyken et al., 2007; Dyken & Cassidy, 1996; Dyken & Shah, 2003). Although these strategies tend to be rigorous and require a major lifestyle change for individuals with PWS and their families, these strategies have shown modest success in reducing weight and maintaining healthy eating habits of individuals with PWS.

Notwithstanding evidence that the above strategies have been shown to be somewhat effective, compliance with these strategies by individuals with PWS and their families may not occur. Thus, behavioral interventions involving antecedent- and consequent-based manipulations have been implemented to ensure compliance with weight management programs. These interventions have included (a) nutrition education (Holland et al., 1995; Mullins & Vogl-Maier, 1987; Pipes & Holm, 1973); (b) positive reinforcement in the form of earning preferred items and activities contingent upon compliance with the weight management program (e.g., prescribed diet, exercise, weight loss, and the absence of food stealing; Marshall, Elder, O'Bosky, & Liberman, 1979; Mullins & Vogl-Maier, 1987); (c) response cost (i.e., loss of items or activities) contingent upon the occurrence of noncompliance with the weight management program (Altman, Bondy, & Hirsch, 1978; Marshall et al., 1979; Thompson, Kodluboy, & Heston, 1980); (d) self-monitoring of weight,

exercise, and caloric intake (Burke et al., 2011; Chambliss et al., 2011; Altman et al.); and (e) contingency contracting (Altman et al.).

For example, Marshall et al. (1979) showed that a treatment package implemented on an inpatient unit with four individuals diagnosed with PWS was effective for producing weight loss. The treatment package involved smaller meal portions, loss of meals contingent upon consumption of unapproved food (response cost), and contingent access to preferred activities for weight loss and the absence of consuming unapproved foods for 1 week (differential reinforcement of other behavior, DRO). In addition, Altman et al. (1978) showed that a combination of self-monitoring of daily caloric intake, weight, and exercise; nutritional education (i.e., participants were taught to determine caloric points for particular foods); contingency contracting in which individuals with PWS were provided a contract that outlined the dietary program and the consequences for compliance and noncompliance of the program and weight loss (i.e., earning access to preferred items and activities for compliance on a daily or weekly basis and withholding of these items and activities for noncompliance); and response cost (e.g., monetary fines, loss of privileges) for food stealing resulted in a decrease in weight for two participants. Furthermore, weight loss was maintained when the program was faded to only self-monitoring and reinforcers for weekly weight loss and exercise adherence.

Special Considerations for Weight Management

Although various strategies and intervention packages have been effective at weight management in PWS, research has suggested that special considerations may need to be taken into account for optimal effects of a weight management program. First, research has shown that the composition of a prescribed diet may affect the likelihood of compliance with the diet. Second, food stealing may need to be specifically targeted to reduce weight and maintain weight

loss. Third, specific interventions may need to be used to increase and maintain physical activity levels of individuals with PWS to result in better weight management.

Food Preferences and Diet

As mentioned above, dietary management and intervention must include a low-calorie diet; however, it is unclear how this diet should be composed to be most effective for adherence and weight loss. Early reports suggested that individuals with PWS were indiscriminate in their food preferences (Holm & Pipes, 1976; Pipes & Holm, 1973); however, several research studies have shown that individuals with PWS have a preference for some foods over others (e.g., Caldwell & Taylor, 1983; Fieldstone, Zipf, Schwartz, & Bernston, 1997; Rankin & Mattes, 1996). For example, research has suggested that individuals with PWS have preference with respect to the quality of food. That is, they prefer sweet foods over salty, sour, or plain foods (Caldwell & Taylor, 1983; Taylor & Caldwell, 1985); high-carbohydrate foods over high-protein foods; and high-protein foods over high-fat or lower calorie foods (Fieldstone et al., 1997).

In addition to quality, several studies have shown that other variables (e.g., amount or magnitude of food) may affect preference (e.g., Caldwell & Taylor, 1983; Glover, Maltzman, & Williams, 1996; Joseph, Egli, Koppekin, & Thompson, 2002). For example, Glover et al. (1996) showed that individuals with PWS prefer a smaller amount of high-preference food over a larger amount of low-preference food; however, when comparing a smaller amount of high-preference food to a larger amount of mixed-preference (mix of medium and low preference) food, individuals with PWS preferred the large amount of mixed-preference food. This latter pattern of choice was in contrast to control participants who continued to choose the smaller amounts of high-preference food. In addition, Joseph et al. (2002) showed that individuals with PWS were more likely to choose a larger quantity of food (three pieces) as compared to a smaller quantity of food (one piece), even when the delivery of the larger quantity was delayed for a small period of time

(15, 30, and 60s). This pattern of choice was in contrast to the choices of obese control participants who chose the different food options on an almost equal number of choice opportunities. Based on the results of study 2 of Glover et al., however, it is possible that choice of larger quantity over smaller quantity is affected by the relative preference of foods (e.g., large quantities of very low preferred foods may not be chosen over small quantities of high preferred foods). In summary, previous research has suggested that the quality and quantity of food may affect food preferences for individuals with PWS, and an interaction of these variables may affect preference (e.g., quantity may affect preference when foods are similarly preferred but not when foods have large differences in preference).

Although the controlled laboratory studies mentioned above suggest certain global preferences for the population of individuals with PWS, it is likely that the provision of a larger number of food choices and different quantities of food would result in idiosyncratic preferences with respect to different foods and variables that may affect food choices. Thus, assessment of food preferences and the variables that may affect food preferences might be an important assessment package to determine individualized diets for individuals with PWS that may, in turn, increase dietary adherence and reduce food stealing (Rankin & Mattes, 1996). Depending on the results of this assessment for a particular individual, dietary options might involve (a) shifting preferences toward lower calorie foods that have the same (or similar) quality as preferred foods, (b) interspersing larger amounts of low quality (and most likely low-calorie foods) with very small amounts of high-quality foods (while keeping within the daily caloric intake), (c) providing small amounts of high-quality foods several times throughout the day, or (d) providing a small amount of high-quality food for consuming lower quality food throughout the day or at a specified period of time.

A final point regarding preferences and food consumption is related to reports that individuals with PWS consume inappropriate foods and other items. Given that quality of food is an important

variable for food choices among individuals with PWS, it is surprising that they have been reported to consume unpalatable foods or inedible items. However, it is possible that the consumption of these foods is due to an ongoing state of food restriction due to current weight management programs, which may establish these foods or items as sufficient when all other food is unavailable. If this is the case, then it is possible that providing individuals with PWS access to no-calorie or extremely low-calorie foods throughout the day might decrease the occurrence of food stealing or consumption of inappropriate items.

Food Stealing

Assessment and treatment of food stealing may be challenging in individuals with PWS because this behavior is often covert (i.e., it occurs in the absence of others; Page, Finney, et al., 1983; Page, Stanley, et al., 1983). Assessing the variables that may affect food stealing and determining the effectiveness of treatment on this behavior are only possible by observing the occurrence (or some product) of food stealing. Thus, a challenge to assessing and treating food stealing is how to measure food stealing when it occurs covertly. Therefore, several measurement procedures have been successfully employed for measuring covert food stealing of individuals with PWS and other intellectual and developmental disabilities (IDD) and include using a room with a one-way mirror for observation and scoring of food stealing (e.g., Page, Finney et al., 1983), videotaping (via hidden camera) and scoring the occurrence of food stealing at a later point in time (e.g., Ringdahl et al., 2002), and measuring the permanent product of food stealing (e.g., weighing food or counting the number of food objects before and after sessions; Maglieri et al., 2000; Page, Stanley et al., 1983).

Using one of the above measurement procedures to evaluate the occurrence of food stealing, several studies have demonstrated the effectiveness of behavioral interventions based on differential consequences including reinforcement and mild punishment (e.g., verbal reprimands, response cost). Page, Finney, et al. (1983) were the first to measure and directly intervene upon

food stealing behavior of individuals with PWS. These experimenters recorded the occurrence of food stealing and consumption of prohibited food (via monitoring through a one-way observation window) by two children with PWS. The experimenters implemented a DRO procedure to reduce the occurrence of covert food stealing. That is, the observers watched into the session room from a one-way observation mirror and, contingent on the absence of food stealing for a prespecified interval, entered the session room and provided praise and a token. If the participant engaged in food stealing during a particular interval, observers entered the room at the end of that interval and told the participant that he would not get a token because he stole food. If the participant earned ten tokens during a session, the tokens could be traded at the end of the session for preferred items or a low-calorie snack. Results showed that the DRO procedure was effective for reducing food stealing, even as the DRO interval (i.e., the period of time in which participants had to refrain from food stealing to earn the reinforcer) was systematically increased. Although the DRO procedure was effective for reducing food stealing, procedures were not employed for generalization and maintenance, and the reduction in food stealing did not seem to generalize to other settings.

In an extension of the intervention by Page, Finney, et al. (1983), Page, Stanley, et al. (1983) showed the effectiveness of a behavioral intervention on the covert food stealing of an individual with PWS and evaluated a program for generalization of the effects to more naturalistic settings. In this study, the first phase involved evaluating the effects of a DRO token program on reducing food stealing in three hospital settings on an inpatient unit. During this phase, food theft was measured by baiting the session rooms with food items and taking inventory of these food items prior to and after the session. The DRO intervention involved earning a token (to be exchanged for low-calorie snacks at the end of the session) for the absence of food stealing for a prespecified period of time and a verbal reprimand for food stealing. This intervention was effective for reducing food stealing even when

the DRO interval was slowly increased to 15 min; however, generalization did not occur to settings in which the intervention was not implemented. In the next phase, the program was expanded throughout the day to include contingencies for exercise, changes in weight, and food stealing on the inpatient unit. Tokens were earned for weight loss of at least 1 lb at weigh-ins (conducted twice per week), and response cost (token fine) was implemented for food stealing on the unit or during scheduled sessions as conducted in phase I. Results showed that the participant had a decrease in weight during this phase. Finally, a similar program was implemented when the participant was transferred back to her group home. That is, the same contingencies for exercise, weight loss, and food stealing were implemented by group home staff. Specifically, the participant could earn tokens three times per day for the absence of food stealing. In addition, tokens were provided contingent upon exercise (e.g., walking, swimming, or stair climbing) and self-monitoring (written records of food consumed and graph of body weight). The results of this phase suggested that reductions in food theft and weight loss were generalized and maintained in a more naturalistic setting.

Although the results of these studies suggest that food stealing can be successfully measured, behavioral intervention can be used to decrease food stealing and reduce weight, and procedures can be employed to result in maintenance and generalization of the effects, most interventions and maintenance programs continue to involve continuous and close supervision of individuals with PWS, which is often difficult, if not impossible. To increase the likelihood of maintained effects, we need procedures that will result in maintenance of reductions of food stealing in the absence of continuous direct supervision (Maglieri et al., 2000). One such procedure involves stimulus control. Maglieri et al. (2000) measured the occurrence of food stealing by weighing food in a session room before and after each intervention session. The initial intervention involved the use of verbal reprimands delivered either within session (for each instance of food stealing) or at the end of

session. Both interventions were effective in reducing food stealing. To increase the generalization and maintenance of low levels of food stealing, the experimenters used a stimulus control procedure, wherein they paired reprimands with a warning stimulus (i.e., they placed an orange sticker on containers with items that the participant was forbidden to consume and told the participant that she was not allowed to eat the foods in the container with the orange sticker). The warning stimulus was used to help the participant discriminate between permitted and prohibited foods during sessions. At the end of the session, the experimenter came into the room and weighed the prohibited food container. If there was a difference in weight (food was missing), then the experimenter provided a verbal reprimand. The intervention resulted in a decrease in food stealing from containers labeled with the warning stimulus. In addition, the authors evaluated whether this decrease in food stealing would generalize to a different situation. They placed the sticker on a refrigerator containing pudding cups and found that the participant did not engage in food stealing. In a similar study with an individual with IDD, Piazza, Hanley, and Fisher (1996) showed that pairing response interruption with a purple card resulted in a decrease and maintenance of low levels of pica in the presence of the purple card (even when response interruption was no longer implemented).

Exercise

Participation in exercise is particularly important for individuals with PWS. Exercise facilitates weight loss and decreases loss of lean body mass, which is especially important for the health of individuals with PWS. Common prescriptions for exercise in this population include at least 30 min per day of exercise with an individualized exercise regimen prescribed in conjunction with a physician and fitness coach. Common exercise programs include walking on a treadmill, biking on a stationary bike, or other ongoing cardiovascular activity (e.g., dancing).

Given the danger of morbid obesity in this population, it is surprising that very few systematic treatments have been employed to increase

physical activity levels of individuals with PWS. One example of an effective treatment for increased exercise of individuals with PWS was described by Caldwell, Taylor, and Bloom (1986) in which the authors evaluated the effect of providing preferred foods contingent upon completing all required exercise on a given day. Results showed that highly preferred foods were effective in increasing the activity level of 7 of the 11 participants with PWS. In addition to actual food, calories may be earned contingent upon compliance with an individualized, daily exercise regimen. For example, a small amount of calories could be provided for every *X* amount of calories expended for exercise on a particular day (e.g., 25 cal for every 100 cal expended; Caldwell et al., 1986).

Although food and calories may be an effective reinforcer for increasing and maintaining exercise, their use may seem counterproductive to the goals of weight loss and dietary management for this population. Thus, once increases in exercise have occurred, the provision of edibles or calories should be faded to social reinforcers (e.g., interaction from others, access to preferred items and activities). Another possible intervention that has been shown to be effective for increasing exercise in individuals with other IDD and typically developing individuals is to provide access to preferred items and activities (e.g., preferred TV shows, movies, music) while exercising (i.e., as long as the participant is engaged in the exercise activity at criterion levels) to increase the likelihood of engaging in the exercise behavior (Caouette & Reid, 1991; De Luca & Holborn, 1992; Flittering, Martin, Gramling, Cole, & Milan, 1988; Lancioni et al., 2003; Wysocki, Hall, Iwata, & Riordan, 1979).

Self-Injurious Behavior

Due to infection, SIB such as skin picking should result in immediate and routine care including topical creams and bandaging. Simple manipulations might include cutting fingernails and limiting time in the contexts in which the problem behavior occurs (Stokes & Luiselli, 2009).

In addition to these general safety procedures, assessment procedures and interventions based on learning principles have shown to be the most effective for treating SIB (including skin picking; Iwata, 1994). Determination of the interventions most likely to be effective for decreasing SIB (as well as other topographies of problem behavior) is derived from conducting a functional analysis (Iwata, Dorsey, Slifer, Bauman, & Richman, 1982/1994) in which participants experience different conditions for the purpose of determining the situations under which SIB is most and least likely to occur. Specifically, a participant is exposed to multiple “test” conditions in which potential maintaining consequences (e.g., delivery of attention, escape from demands) are withheld and delivered for the occurrence of SIB. The levels of SIB in each test condition are compared to a control condition in which the same reinforcers are delivered independent of behavior. Test conditions in which high levels of SIB occur as compared to the control condition indicate that problem behavior occurs to access that reinforcer. The functional analysis allows clinicians to determine whether SIB is maintained by social positive reinforcement (in the form of attention or access to preferred items or activities), social negative reinforcement (in the form of access to escape from difficult or aversive situations such as work tasks), or automatic reinforcement (in the form of sensory stimulation or pain attenuation) (see Betz & Fisher, 2011; Hagopian, Dozier, Rooker, & Jones (2013); Iwata & Dozier, 2008; Iwata, Kahng, Wallace, & Lindberg, 2000; Neidert, Bayles, & Miller in this handbook for a review of functional analysis methodology). Once the function of problem behavior is identified via functional analysis, a function-based treatment may be used to decrease the occurrence of SIB. Function-based treatment strategies involve (a) no longer providing the functional reinforcer for problem behavior (extinction; EXT), (b) providing the functional reinforcer for engaging in an alternative behavior (differential reinforcement of alternative behavior, DRA) or for the absence of problem behavior (DRO), and (c) modifying antecedent conditions that evoke problem behavior for the purpose of

decreasing motivation to engage in problem behavior (e.g., noncontingent reinforcement, NCR). See Carr, Coriaty, and Dozier (2000); Iwata and Dozier (2008); and Hagopian et al. (2013) for a detailed review of function-based interventions.

In a review of behavioral treatments for skin picking in individuals with IDD, Lang et al. (2010) reported that treatment approaches have included various antecedent- and consequent-based interventions similar to those mentioned above (i.e., DRO, DRA, and NCR). Other treatments involve the use of protective equipment (e.g., helmet) or materials (e.g., bandages, gloves) to prevent the occurrence of skin picking, which can be placed on the individual following skin picking or worn at all times. Finally, several forms of punishment have been used to reduce the occurrence of skin picking. These procedures have included verbal reprimands, response interruption, and overcorrection (e.g., contingent exercise). It is important to note that after the seminal article on functional analysis methodology was published by Iwata and colleagues in 1982, published studies on the assessment and treatment of skin picking (as well as other self-injurious and severe problem behavior) have moved toward less intrusive procedures that are based on the function of behavior (Lang et al., 2010); however, mild punishment and prevention procedures are still used if reinforcement-based procedures are ineffective.

Several studies have suggested that skin picking is often maintained by automatic reinforcement and, like food stealing, occurs mostly in the absence of others (i.e., covertly; Didden, Korzilius, & Curfs, 2007). Given the parts of the body that are most often targeted for skin picking (legs and head), it is possible that individuals with PWS pick areas of the body that are not easily visible to others (Symons et al., 1999). Didden et al. (2007) conducted indirect assessments on the skin picking behavior of 119 individuals with PWS and hypothesized that the majority of individuals sampled had SIB maintained by nonsocial reinforcers (i.e., automatic reinforcement) because the behavior occurred mostly when they were alone. If skin picking is maintained by automatic reinforce-

ment, it occurs either to access some form of sensory stimulation (Rincover, 1978) or to attenuate some painful stimulus (Miltenberger, 2005).

Due to the covert nature of skin picking (like food stealing), measurement of the occurrence of the behavior (for the purpose of assessment and treatment) is difficult. However, similar procedures have been suggested to those mentioned above for covert food stealing (i.e., observation via a one-way mirror, videotaping, and permanent product measures of SIB). For example, Iwata, Pace, Kissel, Nau, and Farber (1990) created the Self-Injury Trauma (SIT) scale to determine the occurrence of SIB by measuring tissue damage (a permanent product measure). The SIT scale is a rating scale that allows one to determine the location, type, number, and severity of tissue damage caused by SIB. Thus, the scale could be administered prior to, during, and after treatment to evaluate the effects of treatment on the occurrence of SIB.

To determine whether SIB is covert, a modified functional analysis could be conducted (with an observation procedure used to be able to measure possible covert behavior). In the modified functional analysis, two conditions could be implemented to assess for SIB maintained by automatic reinforcement. Both conditions would include a barren environment and no programmed consequences for engaging in SIB. However, one condition would involve the presence of another person (no interaction condition) and the other condition would involve the absence of others (alone condition). If higher levels of SIB occur in the alone condition as compared to the no interaction condition, then this would suggest that the behavior is covert. For example, Paisley and Whitney (1989) measured the occurrence of pica of a female adolescent with IDD under several conditions including an alone and a no interaction condition. Results of the assessment showed that the highest level of pica occurred in the alone condition, suggesting that her pica was covert. In a recent study, Toussaint and Tiger (2012) compared the levels of skin picking displayed by a 12-year-old boy with multiple diagnoses in an alone and no interaction condition. Results showed that much higher levels of skin picking

occurred in the alone condition, suggesting that his skin picking was covert.

Assessment and treatment of behavior maintained by automatic reinforcement is often difficult (regardless of whether it occurs overtly or covertly) because the automatic reinforcer(s) maintaining the problem behavior is not under the immediate control of the therapist (Vollmer, Marcus, & LeBlanc, 1994). One treatment that has shown to be effective for decreasing automatically reinforced problem behavior (including SIB) in individuals with IDD is NCR (DeLeon, Anders, Rodriguez-Catter, & Neidert, 2000; Roane, Kelly, & Fisher, 2003; Roscoe, Iwata, & Goh, 1998). NCR as a treatment for automatically reinforced problem behavior involves providing free access to preferred items and activities that might compete with the occurrence of SIB (see Carr et al., 2000; Tucker, Sigafos, & Bushell, 1998; Vollmer & Borrero, 2009 for a review of NCR for treatment of problem behavior). When using NCR, preferred items are initially delivered continuously or on a dense reinforcement schedule. A competing items assessment (e.g., Shore, Iwata, DeLeon, Kahng, & Smith, 1997) may be conducted to determine items that are likely to be highly preferred (i.e., result in high levels of item engagement) and compete with the occurrence of the problem behavior (i.e., result in low levels of problem behavior). Shore et al. (1997) conducted a study on the SIB of three individuals with IDD. Functional analysis results suggested that the SIB of each participant was maintained by automatic reinforcement. Next, the authors compared the effects of NCR (i.e., continuous access to leisure items) to a baseline condition in which no items were available. The authors showed that when NCR was implemented, the participants' SIB reduced to near zero levels. Therefore, it is possible that during times in which an individual with PWS who engages in skin picking is in barren environments or alone, providing access to high-preference items and activities will compete with the occurrence of skin picking or other forms of SIB maintained by automatic reinforcement.

If SIB is covert, there are additional challenges for intervention when constant supervision cannot be provided. Thus, delayed contingencies

(e.g., reprimands for tissue damage or reinforcers for the absence of tissue damage) may be one method for reducing SIB. Grace, Thompson, and Fisher (1996) conducted a study in which the occurrence of SIB by a young woman with PWS was measured via permanent product during three physical exams per day. During the exams, the nurses recorded the appearance of open skin, blood, and objects in the ears, eyes, or nose on a diagram of the body. Treatment involved the delivery of tokens for the absence of tissue damage (DRO) noted during the daily physical examinations, and tokens were exchanged for access to attention, preferred activities, and tangible items. Results showed that the intervention resulted in a significant decrease in SIB (i.e., the percentage of physical examinations with new injuries decreased). Recently, Toussaint and Tiger (2012) implemented an intervention that did not require product measures or continuous observation to determine the occurrence of covert SIB for the purpose of implementing contingencies to reduce the occurrence of the behavior. The experimenters used a variable momentary DRO (VMDRO) procedure in which reinforcers (i.e., a token and praise) were delivered contingent upon the absence of behavior at a particular moment (i.e., at the moment of brief observation). Tokens were exchanged for 30-s access to preferred videos following each session or at the end of the day. Results showed that the procedure was effective for decreasing skin picking even when the DRO interval was slowly increased to 5 min. This procedure may be preferred by caregivers because it does not involve continuous observation or product measures that may not detect some instances of SIB (i.e., those that do not result in tissue damage). It is important to note that it is possible that the brief checks that were conducted to determine whether skin picking was occurring at a particular moment would have been effective without the DRO intervention. That is, the mere presence of a therapist may have decreased skin picking. This is possible given that the behavior only occurred at high levels in the alone condition of the functional analysis, which may have been due to a history of punishment (e.g., verbal reprimand) for skin picking in the presence of others.

Obsessive-Compulsive Behavior

Few studies have evaluated the effects of interventions for treating obsessive-compulsive behaviors in individuals with PWS or other IDD. However, much research has been conducted on treatment for these behaviors in typically developing adults and children. The most common forms of treatment for these behaviors are Exposure and Response Prevention Therapy (a form of cognitive-behavioral therapy [CBT]) and pharmacological intervention (see Mancuso, Faro, Joshi, & Geller, 2010 for a review). Exposure and Response Prevention Therapy has been shown in numerous studies over the past three decades to be the most effective intervention for obsessive-compulsive behaviors in individuals with OCD (Abramowitz, Taylor, & McKay, 2005; Houghton, Saxon, Bradburn, Ricketts, & Hardy, 2010). This therapy involves exposing the participant to the aversive situation (e.g., dirty hands for a compulsive hand washer) and preventing the participant from engaging in the compulsive behavior. It is presumed that obsessive-compulsive behaviors are maintained by automatic negative reinforcement in the form of escape or avoidance of an aversive stimulus (i.e., fear or anxiety). However, it is unclear whether all obsessive-compulsive behaviors across all individuals, populations, and topographies have a similar function. Therefore, it may be important to first determine the function of obsessive-compulsive behaviors displayed by individuals with PWS for the purpose of designing effective treatment. In a recent study, Rodriguez, Thompson, Schlichenmeyer, and Stocco (2012) conducted a study aimed at reducing compulsive behaviors including arranging and ordering of furniture, completeness of tasks (e.g., insisting that drawers and doors stayed closed), and straightening items on shelves or in refrigerators of three children with IDD. The experimenters first conducted functional analyses and found that all three children's compulsive behavior was maintained by automatic reinforcement. Next, the experimenters compared the effects of (a) providing access to matched stimuli (i.e., stimuli that could be arranged and ordered

in an appropriate manner and on a smaller scale) or competing stimuli (i.e., items or activities that were preferred and competed with the occurrence of the compulsive behavior in a competing items assessment), (b) matched stimuli with prompts to engage with the matched stimuli, and (c) matched stimuli plus responses blocking (i.e., the therapist physically blocked the child from engaging in the compulsive behavior) or matched stimuli plus product extinction (i.e., placing the object back in the original position contingent upon arranging and ordering). The results showed that response blocking or product extinction was necessary to decrease compulsive behaviors to low levels, and some participants required continued prompting and reinforcement for engaging with the continuously available matched stimuli. As discussed by the experimenters, it is important to provide individuals with an alternative activity to compete with the occurrence of the compulsive behavior in addition to implementing response blocking or extinction. It is possible that continuous access to potent reinforcers that are otherwise restricted may compete with the occurrence of obsessive-compulsive behaviors.

Other Behavior Problems

Although food-related problem behaviors are the most severe and common behavior problems in individuals with PWS, other behavior problems (e.g., property destruction, physical aggression, and temper tantrums) should be assessed and treated. Functional analysis methodology has been shown to be effective for determining the functions of numerous problem behaviors across various populations (see Hanley, Iwata, & McCord, 2003 for a review). Therefore, best practice involves the use of this methodology to determine an effective function-based treatment that is likely to be effective. As mentioned above, common function-based treatments such as (a) DRA (or functional communication [FCT]) in which the participant is taught to appropriately request the reinforcer and problem behavior no longer results in the reinforcer (extinction [EXT]; Carr & Durand, 1985; Tiger, Hanley, & Bruzek,

2008), (b) DRO in which reinforcers are provided for the absence of problem behavior (Mazaleski, Iwata, Vollmer, Zarcone, & Smith, 1993; Vollmer & Iwata, 1992), and (c) various antecedent manipulations such as NCR to decrease the motivation to engage in the problem behavior (Carr, Coriaty, Wilder et al., 2000; Smith & Iwata, 1997) have been shown to be very effective for reducing various problem behaviors. It is important to note that these behaviors may be high in frequency and severity, which may result in dangerous situations for the individual with PWS and his or her caregivers. Therefore, in addition to function-based interventions, certain safety precautions and crisis management procedures may be necessary to keep the individual with PWS and others safe.

Conclusions

PWS is a multifaceted syndrome that is associated with numerous health and behavioral concerns. It is likely that most individuals with PWS will require some type of supervision for weight management and behavior management. At least initially, environmental safeguards (e.g., locked cabinets and refrigerators, alarms, enhanced supervision) may be required to reduce calorie consumption. However, it is our recommendation that intervention programs also involve nutritional education, self-monitoring of caloric intake and physical activity, frequent weigh-ins, and individualized intervention programs that are based on assessment results for optimal effectiveness as well as maintenance and generalization of effects. For example, food preference assessments that include different types of foods and different variables that may affect food choices can be conducted with a particular individual to determine a dietary program that will be most effective for compliance and ultimate weight loss. In addition, physical activity should be increased by providing potent reinforcers (as determined by individualized preference assessments) for completion of individualized exercise programs. It is possible that food or calorie reinforcers are required, at least initially, to increase

physical activity; however, these reinforcers should be faded over time and be replaced with nonedible reinforcers (e.g., attention, preferred items, and activities). Furthermore, functional analyses should be conducted to determine the conditions under which particular problem behaviors occur for an individual, and these results should be used to create an individualized behavior plan to increase appropriate behavior and decrease problem behavior to access these reinforcers. Finally, special considerations should be addressed for problem behaviors such as food stealing and SIB that may occur covertly.

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The Motivation for Self-Injury: Looking Backward to Move Forward

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Jennifer McComas and Frank J. Symons

Self-injurious behavior (SIB) is among the most disturbing, destructive, and costly behavior disorders among people with developmental, psychiatric, and neurological disorders. In people with intellectual or developmental disorders (I/DD), there are numerous forms including self-hitting, pinching, scratching, and biting (Schroeder et al., 2001). In almost all cases of SIB, the etiology of the behavior disorder is unknown, and any underlying pathogenesis and pathophysiology is only partly understood. The field of behavior analysis has made enormous progress in understanding and treating SIB among individuals with I/DD since the 1970s, but there is still much to do. This chapter will provide a selective review of clinical research findings and a synthesis of the underlying behavioral approach that has led to a better understanding of SIB, its forms, functions, and effective intervention. It is important to note that the review is focused almost exclusively on maintaining factors related to SIB. Discussion of the etiology of SIB is beyond the scope of the chapter. Clinical examples of SIB are used to illustrate practical applications of functional assessment technology and illustrate basic principles of behavior in relation to behavioral mechanisms (e.g., positive, negative reinforcement) as well as the intersection of behavior and biology.

To provide a phenomenological starting point, Fig. 12.1 depicts a quantification of the intensity of chronic tissue-damaging SIB (Newell, Challis, Boros, & Bodfish, 2002). The phase plots show the regularity and the force of blows of an SIB cycle. It is highly patterned and consistent with boxing jabs and boxing cross punches by a heavy-weight boxer (between 400 and 1,000 N). Put another way, during a single bout of self-injury, the impact forces combined with the frequency of blows are the equivalent of dropping a 48 oz (3 lb) hammer on your forehead every second for up to half an hour. Given such striking severity, it is reasonable to wonder “Why would someone do this to themselves?” “Doesn’t it hurt?” and “What can be done about it?”

In 1976, Baumeister and Rollings 1976 reviewed the then-current state of the scientific knowledge regarding SIB and concluded that it was yet unclear whether SIB was a socially reinforced behavior, an avoidance response, or still another class of behavior. Further, the authors reported that the most common method of controlling SIB, particularly in institutional settings, was some form of restraint or punishment including application of a strong aversive stimulus (i.e., electric shock) contingent on SIB. Thus, further study utilizing experimental procedures was clearly warranted for better understanding the various influences on the occurrence of and effective interventions for SIB. Thirty-five years later, research findings indicate that SIB is, in large part, a learned behavior disorder. The hypothesized

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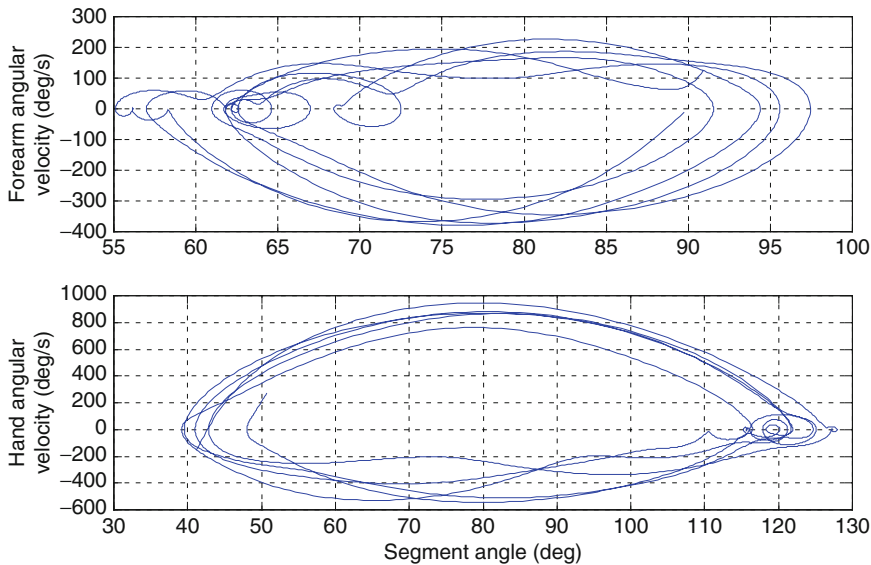


Fig. 12.1 Kinematic analysis of chronic tissue-damaging SIB. Source: Newell et al. (2002). Copyright by American Association on Intellectual and Developmental Disabilities. Reproduced with permission

basic mechanisms responsible for the occurrence of SIB were described conceptually by Carr (1977) and in subsequent experimental methodologies (Iwata, Dorsey, Slifer, Bauman, & Richman 1982/1994; Schroeder et al., 2001).

Conceptual Maintaining Mechanisms and Supporting Empirical Evidence

In 1977, Carr advanced five hypotheses pertaining to the motivation of self-injury. These hypotheses were that SIB is (1) a learned operant, maintained by positive social reinforcement, (2) a learned operant, maintained by negative social reinforcement in the form of termination of an aversive stimulus, (3) a means of providing sensory stimulation, (4) an aberrant physiological process, and (5) an attempt to establish ego boundaries or reduce guilt (i.e., psychodynamic influence). There is no reason to believe that these motivation mechanisms are mutually exclusive; in fact, interactions between two or more of these possible mechanisms should be considered in the case of any individual. The remainder of the chapter is organized in relation to Carr's original hypotheses, with each of these hypotheses revisited ("looking back") and

reviewed in relation to contemporary data sets that are consistent with the hypothesis or extend it ("looking forward").

It is important to note that the analysis model and assessment technology first presented by Iwata and colleagues in 1982, as well as methods that have evolved over time to meet the unique needs of various settings and populations, has allowed the field of applied behavior analysis to rely on a unified approach (functional analysis, functional assessment) designed to identify putative maintaining social reinforcers for SIB consistent with Carr's conceptual models and corresponding hypotheses. In 1992, Derby and colleagues (1992) published a review of the first 79 outpatient cases of functional analysis and SIB at the University of Iowa Hospitals and Clinics. Of those 79 cases of SIB, a social function (reinforcer) was identified during 77% of the initial case analyses. A decade later, Kurtz et al. (2003) identified one or more social functions for 62% of 30 outpatient clinical cases of SIB.

Positive Reinforcement

The introduction of functional analysis technology permitted a systematic analysis via isolation and

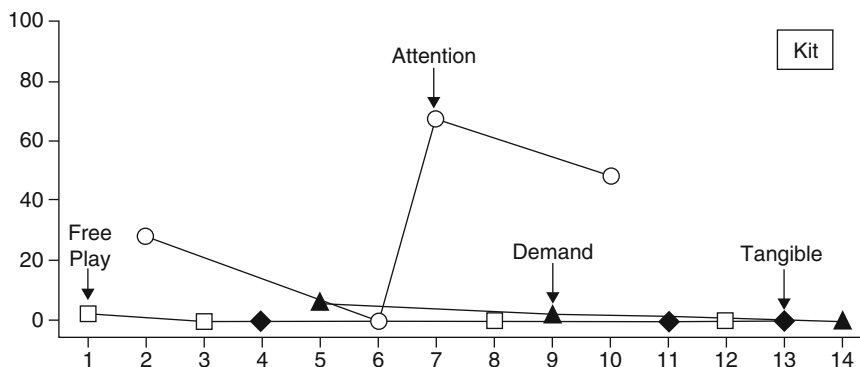


Fig. 12.2 Percentage of intervals of SIB across functional analysis test conditions. Source: Harding, Wacker, Berg, and Winborn-Kemmerer (2009). Copyright West Virginia University Press. Reproduced with permission

manipulation of experimental conditions to test specific hypotheses about the influence of social reinforcers (specifically, positive and negative reinforcement) on SIB. Figure 12.2 is reprinted from an article published in 2009 by Harding and colleagues in the *Education and Treatment of Children* and depicts the percentage of intervals with SIB across three test conditions (positive reinforcement in the forms of social attention and tangible items, as well as negative reinforcement in the form of escape from a task demand) and a control (“free play”) condition in a functional analysis. The differential elevation in SIB in the condition labeled “attention” suggests that the preschool-aged participant’s SIB was a function of contingent attention.

The conceptual and methodological contributions (Carr, 1977; Iwata, Dorsey, Slifer, Bauman, & Richman, 1982/1994) also paved the way for function-based interventions for SIB. Specifically, after the operant reinforcer (i.e., function) of SIB is identified via within-subject experimental (functional) analysis (Iwata et al.), that same reinforcer can be provided as an alternate source of reinforcement (either contingent on another response or response independent) to weaken the existing undesirable behavior (e.g., SIB). The effects of subsequent intervention for Kit (above) are depicted in Fig. 12.3. Intervention was designed to weaken the response (SIB)-reinforcer (positive reinforcement in the form of social attention) contingency by arranging attention contingent on a verbal request (a “mand”) for his mother to play with him, instead of contingent on

SIB. Following baseline, the intervention appears to have virtually eliminated SIB.

Negative Reinforcement

The second hypothesis advanced by Carr (1977) was that SIB is a function of termination of aversive stimulation or negative reinforcement. Aversive stimulation can take many forms, including but not limited to task demands, social interaction, and noisy or unpredictable environments. Figure 12.4 provides an early demonstration of the utility of functional analysis for identifying social reinforcers maintaining SIB and then implementing intervention based on the identified social reinforcers (Steege et al., 1990). In the left panel, elevation was observed in the “demand” condition, in which negative reinforcement (in the form of a brief period of escape from the task demand) was provided contingent on SIB, with very few overlapping data points across the other test conditions in the experimental analysis, suggesting that the participant’s SIB was maintained by negative reinforcement. In the right panel, the effects of intervention that involved delivering the functional reinforcer (negative reinforcement) contingent on a request to “stop” were compared to the effects of negative reinforcement for SIB (baseline conditions). The results provide repeated and compelling evidence that when the functional reinforcer is applied to an alternative response rather than to SIB, the effect is a decrease in SIB.

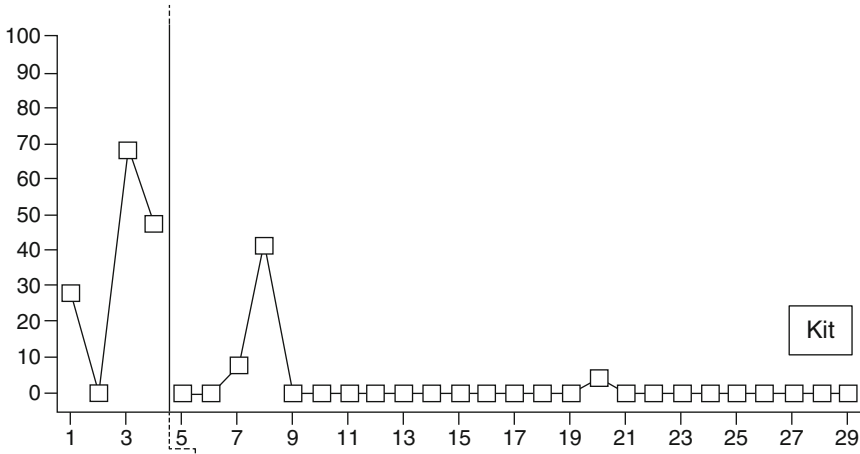


Fig. 12.3 Percentage of intervals of SIB during baseline and function-based intervention. Source: Harding et al. (2009). Copyright by West Virginia University Press. Reproduced with permission

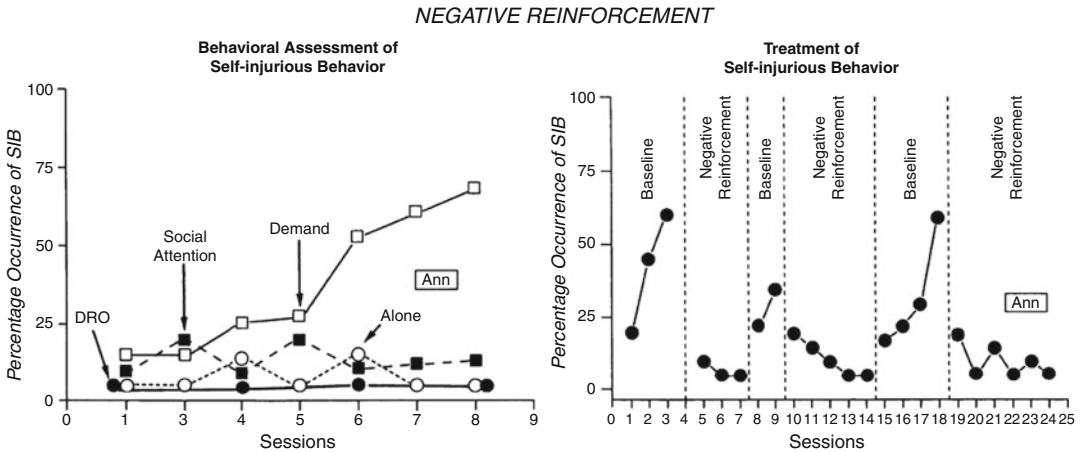


Fig. 12.4 SIB during functional analysis (*left panel*) and subsequent intervention analysis (*right panel*). Source: Steege et al. (1990). Copyright by the Society for the Experimental Analysis of Behavior, Inc. Reproduced with permission

Sensory Stimulation

Regarding the third hypothesis, sensory, or non-social reinforcement, Carr (1977) suggested that future research should separate social reinforcement effects from sensory reinforcement effects. He further indicated that until such research is conducted, nonsocial or sensory reinforcement of SIB remains plausible but untested. The development of functional analysis technology affords researchers and practitioners a method to empirically identify sources of social reinforcement. Simultaneously, the methods allow us to deter-

mine cases of SIB which are not maintained by social reinforcement; by default, those cases are referred to as nonsocially maintained. To date, there is not a reliable technology for further categorizing nonsocially maintained SIB. Nonetheless, several researchers have successfully identified nonsocial (physiological) sources of reinforcement (e.g., visual or other sensory reinforcement) and related or “matched” intervention for individual cases of SIB. For example, Kennedy and Souza (1995) conducted an analysis of eye poking in which SIB was observed to occur exclusively in no attention conditions,

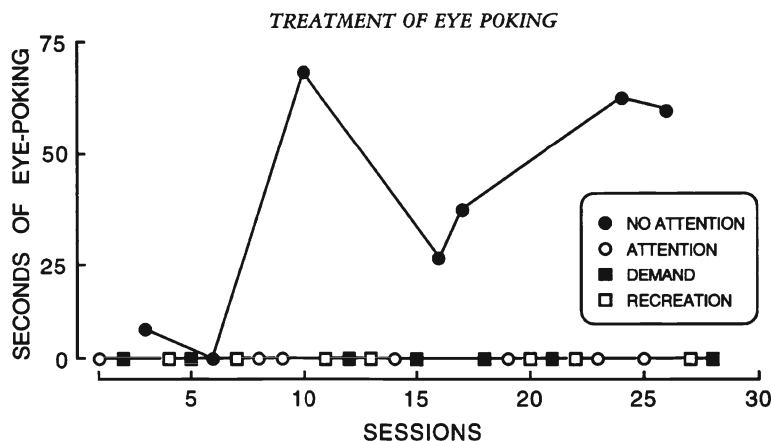


Fig. 12.5 SIB across functional analysis conditions. Source: Kennedy and Souza (1995). Copyright by the Society for the Experimental Analysis of Behavior, Inc. Reproduced with permission

suggesting it was nonsocially maintained (see Fig. 12.5).

These results, coupled with the researchers' hypothesis that eye poking was maintained by visual stimulation produced by the behavior itself, led to a subsequent analysis in which the effects of alternative forms of sensory stimulation were examined. The occurrence of SIB was compared across baseline, visual stimulation (i.e., videogame), and auditory stimulation (music) conditions. Figure 12.6 depicts the results in which the lowest levels of SIB occur in the videogame conditions, thereby supporting the hypothesis of visual reinforcement of SIB and an effective intervention for decreasing the occurrence of SIB. It may be interesting to note that although the operant function of the behavior has emerged as the primary interest with respect to understanding and effectively treating SIB, in this case, after it was determined that the function was not social reinforcement, the form of the behavior (i.e., eye poking) helped inform a hypothesis about the sensory function of SIB for this individual.

The form of SIB, however, cannot always be relied on to suggest the nonsocial functional reinforcer. Figure 12.7 shows another example of SIB (in the form of head hitting), which occurred most frequently in the no interaction condition, suggesting it was nonsocially maintained (Patel, Carr, Kim, Robles, & Eastridge,

2000). Following a preference assessment which identified a thermal massager and manual massage to be two highest preferred stimuli, the investigators presented those stimuli contingent on 15 s without SIB. The results are depicted in Fig. 12.7 and suggest that the differential reinforcement of omission (DRO) procedure involving a highly preferred stimulus effectively reduced the occurrence of SIB to near zero. This is an example of an effective intervention for reducing nonsocially maintained SIB.

Finally, not all nonsocially maintained SIB occurs exclusively in the no interaction (or alone) condition of a functional analysis. Figure 12.8 depicts SIB in the form of hits that occurred across all test conditions, irrespective of the contingencies applied in the conditions. These results suggest that this individual's SIB is not responsive to contingent social reinforcement and, therefore, is presumed to be nonsocially maintained (Lindberg, Iwata, & Kahng, 1999). Effective treatment for this individual, not shown here, was response blocking. Regardless of whether the form of SIB informs effective intervention for nonsocially maintained SIB, when we implement reductive procedures such as DRO or response blocking for SIB in the absence of knowing its function, it is important to note that the long-term effects (or maintenance) of the intervention cannot be predicted.

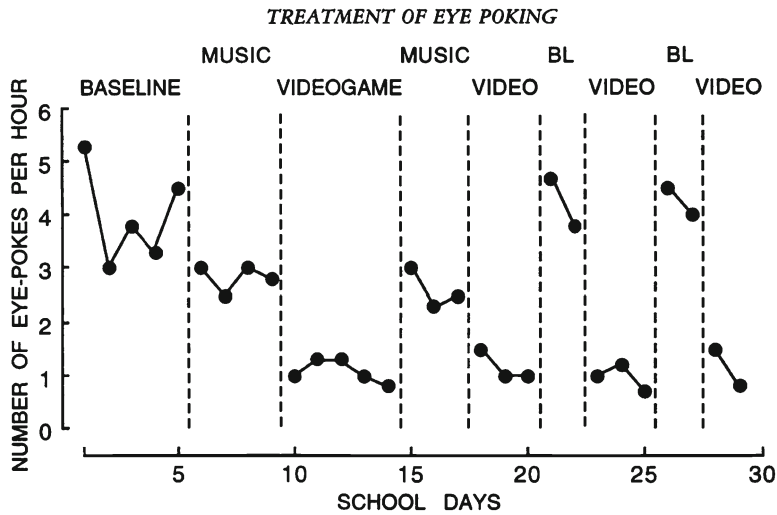


Fig. 12.6 SIB across baseline, matched, and mismatched sensory conditions in intervention analysis. Source: Kennedy and Souza (1995). Copyright by the Society for the Experimental Analysis of Behavior, Inc. Reproduced with permission

Together, the advances in functional analysis technology have facilitated a remarkable advancement of our understanding of the influence of social mechanisms on maintaining SIB leading directly to effective interventions (recall the “unknowns” from the 1976 review). In addition, functional analysis technology has facilitated identification of SIB cases that are not socially maintained. In fact, a review study reported that functional analysis identified sources of reinforcement in 62 % of 30 clinical cases (Kurtz et al., 2003). Although most behavioral treatments for SIB have been shown to be effective for the individuals they were applied to, the disorder persists both in terms of incidence (there are always new emerging cases suggesting we do not fully understand the origins of SIB) and prevalence (despite short-term demonstrations of reduction, SIB can be persistent over longer time scales and maintaining reductions can be difficult). Additionally, we have made far fewer clinical and scientific advances in understanding features of any underlying pathophysiology that may be associated or causally related to SIB.

Physiological Processes

Carr (1977) posited that SIB may be a result of genetic (e.g., de Lang syndrome) or nongenetic (e.g., recurrent pain) physiological processes. Over the past 35 years, a number of physiologic factors have been considered including peripheral (autonomic nervous system function) and central (neurotransmitters, cortical circuitry, pain/sensory transmission) nervous system variables as well as acute and chronic medical conditions in relation to SIB.

In one approach, SIB is conceptualized in relation to autonomic arousal with SIB considered to regulate chronic under- or overarousal; that is, SIB is thought to be a response to an internal state. Heart rate (HR) is among one of several approaches to noninvasively measure arousal. Despite the *idea* of arousal being relevant to understanding the pathophysiology associated with SIB (Romanczyk, 1986), research findings using HR as an index of arousal specifically in relation to SIB have been limited and somewhat inconsistent to date. Freeman, Horner, and Reichle (1999) found increased HR *following*

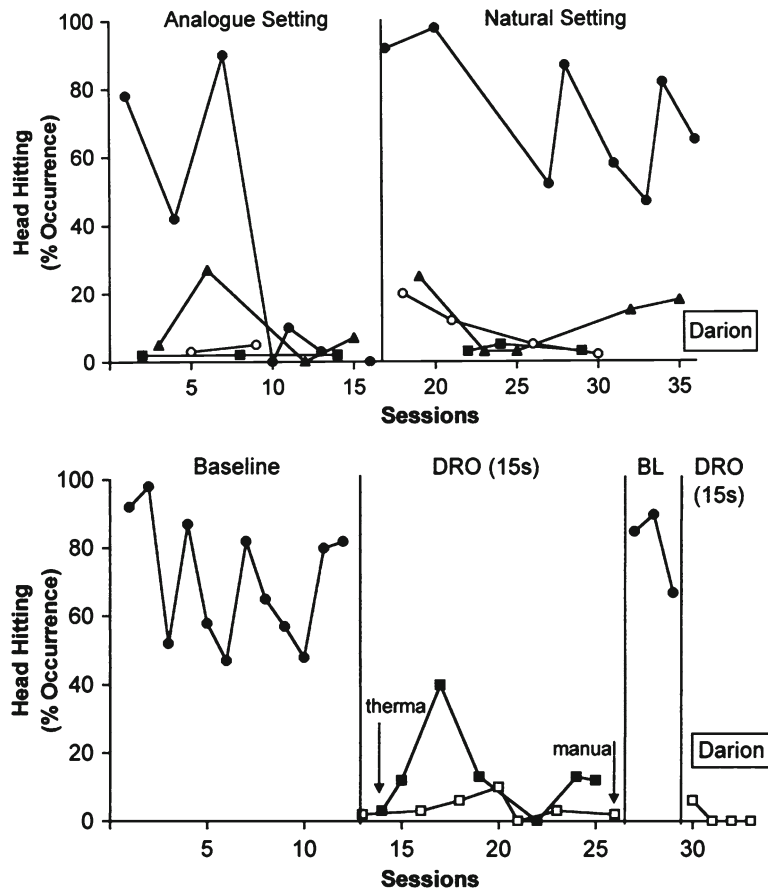


Fig. 12.7 Percentage intervals with SIB across functional analysis conditions (*top panel*) and DRO analysis (*bottom panel*). Source: Patel et al. (2000). Copyright by Elsevier B.V. Reproduced with permission

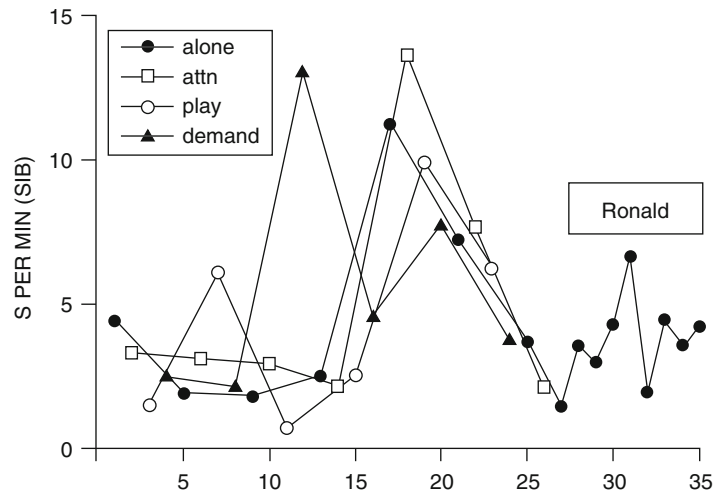


Fig. 12.8 SIB across functional analysis conditions. Source: Lindberg et al. (1999). Copyright by the Society for the Experimental Analysis of Behavior, Inc. Reproduced with permission

SIB, whereas Barrera, Violo, and Graver (2007) found elevated HR *prior* to SIB. In studies of different clinical populations with self-injury (Non-Suicidal Self-Injury; NSSI), Nock and Mendes (2008) used skin conductance, or galvanic skin response (GSR), as a measure of arousal. They compared GSR during stress in two groups of adolescents with different histories of NSSI: one group with SIB and one group without. The group with SIB had significantly higher GSR than the no-SIB group. Whether altered neural regulation of arousal is cause, consequence, or correlate of SIB is unknown and warrants further exploration, including examining the role autonomic arousal might play in the etiology of SIB. In the area of tics, for example, effective treatments have been shown to result from approaches that modulate sympathetic arousal (Nagai, Cavanna, & Critchley, 2009). Further, although clear evidence of a relationship between biological arousal and SIB remains limited, it is worth noting that pain is known to affect autonomic arousal.

Another approach consistent with Carr's "physiology" category has been to examine alterations in neurochemistry (it is beyond the scope of this chapter to review these models in detail; see Rojahn, Schroeder, & Hoch, 2008). Much of the work in this area is indirect in the sense that medications involving dopaminergic, serotonergic, or opioidergic systems are used to treat SIB; based on the effects of a given class of medication, the corresponding neurotransmitter system is therefore inferred to be related to SIB (see the chapter by Schroeder et al. of this volume). Among the different neurotransmitters that have been directly examined among clinical samples (cf. with preclinical rodent models of SIB which focus more specifically on the dopaminergic systems; Breese et al., 1995), the most work has been conducted by Curt Sandman and his colleagues investigating beta-endorphin, one of the members of the endogenous opioid family of neurotransmitters (Sandman, Spence, & Smith, 1999).

Opioids, such as beta-endorphin, occur naturally in different central and peripheral nervous system areas and have morphine-like analgesic properties (hence the name derived by combining

"endogenous morphine"). There is evidence that there are documented altered levels of beta-endorphins in individuals with SIB (Sandman, Barron, Chicz-DeMet, & DeMet, 1991; Sandman, Touchette, Lenjavi, Marion, & Chicz-DeMet, 2003). Indirect tests of the hypothesis that individuals with I/DD have altered beta-endorphin levels have been conducted by administering opioid blockers (antagonist). By administering an opioid antagonist, decreases in SIB allow the clinician to infer that the behavior is, at least in part, a function of elevated opioids. For example, naltrexone, which is a drug that reverses the effect of opioids, might be administered if it is hypothesized that an individual's SIB is maintained, at least in part, by the release of endorphins. In such cases, naltrexone should block endorphins and result in extinction of SIB. There is clear evidence that some individuals with SIB respond to treatment with naltrexone, but it is not entirely clear if we know how to predict who is most likely to benefit (see King, McCracken, and Poland (1991) for an earlier critique of the opioid model; Symons, Thompson, and Rodriguez (2004) for a quantitative review of the effects of naltrexone and SIB; and Sandman et al. (1999) for a potential predictive biomarker for naltrexone response). Results of research in this area have also been somewhat inconsistent in terms of opioids, SIB, and pain (Barrera, Teodoro, Selmecci, & Madappuli, 1994) suggesting more is to be learned about the neurochemical functions of opioids related to SIB.

Physiological sensory mechanisms relevant to pain and itch transmission and regulation have also begun to be considered with regard to SIB among individuals with and without I/DD (see Edelson (1984) for an earlier account). Peripheral nerve damage secondary to viral infection (e.g., postherpetic neuralgia) has been observed to lead to neuropathic itch among otherwise healthy individuals with no psychiatric histories (Oaklander, Cohen, & Raju, 2002) and in corresponding preclinical rodent models (Brewer, Lee, Downs, Oaklander, & Yesierski, 2008). In one dramatic case report, a 39-year-old woman experiencing postherpetic neuralgia painlessly scratched through her frontal skull into her brain

(Oaklander et al., 2002). She reported no pain but severe itch. Quantitative sensory testing indicated a loss of most sensory modalities except itch, and a skin biopsy indicated a 96% loss of epidermal enervation. Similar findings were observed in an experiment with rats injected with quisqualate to model spinal cord injury that produces itch-motivated scratching that is painless because of sensory loss. The affected rats appeared to experience neuropathic itch and loss of protective pain sensations as evidenced by loss of epidermal enervation and presence of immune activity in the form of significantly elevated histamine levels compared to controls (Brewer et al., 2008). This is preliminary, preclinical direct evidence of central nervous system involvement with altered sensory function (itch) related to SIB. In both the clinical case and animal model, scratching was the form of SIB and may be another example of behavioral topography informing the hypothesis regarding the function.

Each of the physiological functions reviewed briefly (autonomic arousal, altered sensory sensitivity due to neurochemistry or neurological injury, neuropathic itch) all have pain pathology (or, at least, potential dysfunction in the systems that regulate pain) as a potential common denominator. From a different perspective, pain is protective (it is the body's signal that something is wrong) and can be related to acute or chronic medical conditions. Bosch, Van Dyke, Smith, and Poulton (1997) found that 28% of 25 individuals with IDD and SIB had previously undiagnosed medical conditions that could be expected to cause pain or discomfort. These included lactose intolerance, dysphagia, aspiration, otitis media, esophagitis, gastritis, duodenitis, severe constipation, moderate rhinitis, and a cocklebur in the nostril; in several cases, more than one condition was identified. They found that six of the seven individuals experienced decreased SIB with treatment of their medical conditions (Bosch et al.). Medical conditions such as these may be divided into two categories: acute and chronic. Temporary or intermittent conditions such as otitis media and constipation would be considered acute, whereas sustained conditions with repeated insult, such as swelling or irritation along the

digestive tract resulting in esophagitis, gastritis, or duodenitis, would be considered chronic.

Medical Conditions Associated with Pain and Functional Analysis

The relation between specific health-related conditions, pain, and problem behavior, including SIB, has been an important area of focus and reviewed by Kennedy and O'Reilly (2006). Functional analysis technology can be used creatively to examine specifically the influence of acute medical conditions associated with pain on SIB. Below (Fig. 12.9) is an example in which the occurrence of SIB was examined in a series of conditions in which otitis was present or not present. SIB was never observed in conditions in which otitis was absent, whereas it was always observed, in at least one series of test sessions, when otitis was present. The findings suggest that otitis sets the occasion for this individual's SIB, and may have served as a motivating operation for negative reinforcement (O'Reilly, 1997).

In a second clinical example, an individual diagnosed with severe hydrocephaly had a shunt that frequently malfunctioned, resulting in intermittent extreme intracranial pressure. When intracranial pressure was characterized as "high," the occurrence of SIB was elevated compared to periods of "low" intracranial pressure (Hartman, Gilles, McComas, Danov, & Symons, 2008) (Fig. 12.10).

Many conditions are more chronic in nature and are presumed to be associated with some level of pain or discomfort such as gastroesophageal reflux, gastritis, or ulcers. In such cases, one would hypothesize that SIB would occur irrespective of manipulations of the social context or consequences but, instead, would be elevated across all conditions. A comprehensive review on the state of the science of detecting pain in individuals with I/DD and the systematic inquiry into the relationship between SIB and chronic pain is beyond the scope of this chapter. But, it should be noted that there have been advances in measuring pain among nonverbal individuals with significant intellectual disability (LaChapelle, Hadjistavropoulos, & Craig, 1999) that have been extended to study pain and self-injury in I/DD

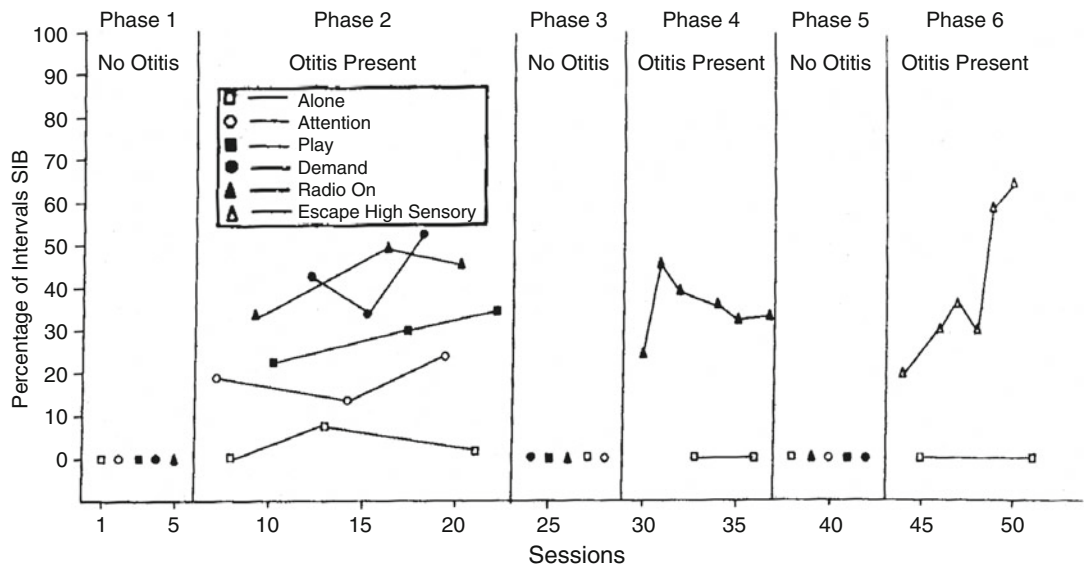
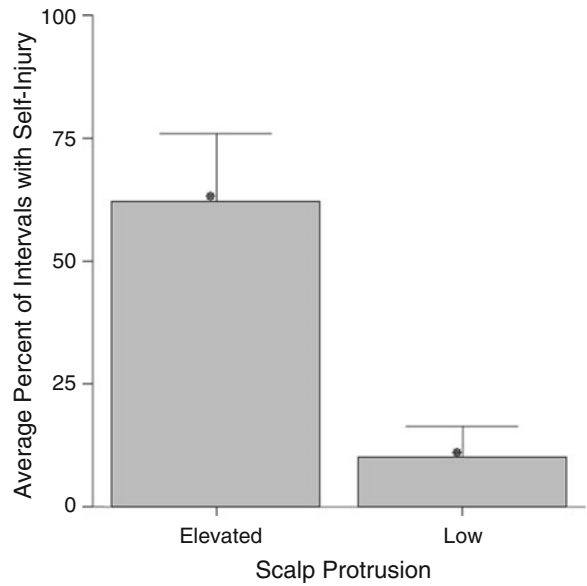


Fig. 12.9 SIB across functional analysis conditions with otitis present and otitis absent. Source: O'Reilly (1997). Copyright by the Society for the Experimental Analysis of Behavior, Inc. Reproduced with permission

Fig. 12.10 Average SIB during high and low intracranial pressure conditions. Source: Hartman et al. (2008). Copyright by SAGE Publications. Reproduced with permission



(Breau et al., 2003). There has also been biobehavioral work designed to incorporate the nonverbal measurement of the expression of pain/discomfort into studying pain and self-injury. In one example, Symons, Shinde, Clary, Harper, and Bodfish (2010) found that individuals with chronic SIB were more (not less) reactive to an

array of calibrated standardized sensory stimuli—including noxious—compared to a matched (age, gender, developmental level) control group. A subgroup of the SIB sample was also included in an initial investigation of peripheral innervation based on epidermal skin biopsies (Symons, Wendelschafer-Crabb, Kennedy, & Bodfish, 2009).

Individuals with chronic SIB had clear differences in the pattern of sensory nerve densities (epidermal nerve fibers that are small unmyelinated fibers) in their skin along with elevated levels of substance P positive fibers and extensive mast cell degranulation (see Symons (2011) for a review). What do these findings tell us about SIB? Although the results do not definitively confirm or refute a subgroup model, they do suggest possible significant differences in sensory nerve fiber innervation density and corresponding physiology in some percentage of chronic SIB cases. The significance of these findings is underscored by the fact that all skin samples were taken from non-SIB sites with no history of tissue damage.

Psychodynamic Processes

The final hypothesis Carr discussed (1977) pertained to the construct of psychodynamic processes, which, as he suggested, is difficult if not impossible to operationalize and empirically test. Of the five hypotheses presented by Carr, this is the only one which has not seen a growing body of empirical evidence or methodological developments that serve to advance our understanding of its possibilities, at least in relation to individuals with I/DD.

Concluding Comments

Looking back to 1977, researchers have made remarkable advances in understanding the influence of social reinforcement and, to some degree, sensory reinforcement, on SIB. In addition, there have been modest advances in understanding physiological functions, with emerging work in the area of the peripheral nervous system and pain. These advances appear to validate the conceptual framework advanced by Carr (1977), namely, that much of the SIB we observe is learned behavior, reinforced by social contingencies of positive and negative reinforcement, that some SIB is maintained by nonsocial reinforcers, and that still other cases of SIB are more directly influenced by physiological variables, some of

which may be related to stress or arousal and pain mechanisms. It is also very likely that the mechanisms interact in complex ways that are, to date, poorly understood. The importance of understanding interaction is that treatment based on the putative social reinforcement mechanism and altered physiology may combine to produce synergistic effects. The trick is in knowing what the right circumstances are and in what way to combine treatment approaches. Thompson and colleagues have written on a related issue—the behavioral mechanisms of drug action—for many years (Thompson, 1981; Thompson, Moore, & Symons, 2007). Although it is difficult (labor intensive) work to complete, there have been some advances in trying to improve our understanding of whether neuroleptics and other psychotropic medications influence SIB in different ways depending on whether there is a social reinforcer also maintaining the individual's SIB (Crosland et al., 2003; Garcia & Smith, 1999; Symons, Fox, & Thompson, 1998). Looking forward, there is much more to learn, both in the field of I/DD as well as related fields where SIB is observed in varied forms (e.g., cutting, burning). The differential advances in the first four hypotheses compared to the final hypothesis regarding psychodynamic processes should be instructive for future researchers; conceptualizations that can be operationalized and empirically tested will be of most utility.

Acknowledgments Portions of the manuscript were written with support, in part, from NIH Grant No. 44763 & 47201.

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Co-occurring Psychiatric Disorders in Individuals with Intellectual Disability

13

Joseph N. Ricciardi

Introduction

The presence of a psychiatric disorder in an individual with intellectual disability (ID) represents a challenge to clinicians and service delivery systems. Yet, for many years clinicians believed that people with ID could not also have a mental illness (Matson & Shoemaker, 2011). Consequently this complicated population was grossly underserved (Jacobson & Ackerman, 1989; Reiss, Levitan, & McNally, 1982). Indeed, it has been shown that some clinicians would not consider the possibility of a psychiatric disorder in such individuals, being prone to over-attributing behavioral and mood disturbances to the developmental disorder, a robust phenomenon now identified as “diagnostic overshadowing” (Jopp & Keys, 2001; Reiss, Levitan, & McNally, 1982; White et al., 1995).

Research conducted during the past three decades has established that individuals with ID suffer from mental illnesses at least as often as the general population with some disorders possibly occurring with greater frequency (Borthwick-Duffy & Eyman, 1990). Psychiatric disorders have been shown in children and adolescents with ID as well (Dekker & Koot, 2003). Early rates of comorbidity were often reported as 10–39% (Borthwick-Duffy, 1994). Unfortunately, significant methodological problems

in the early studies limited the ability to make accurate prevalence estimates (Kerker, Owens, Zigler, & Horowitz, 2004). Contemporary research has produced more reliable findings using epidemiologic methodologies allowing for better comparison with general population samples (Einfeld, Ellis, & Emerson, 2011). Further, researchers have moved toward studying clinical subpopulations such as people with autism spectrum disorders (ASD) (Brereton, Tonge, & Einfeld, 2006).

The term “dual diagnosis” has been applied to individuals with ID and concomitant psychiatric disorder (Reiss, Levitan, & McNally, 1982) as a way of indicating that both conditions are of equal importance (Cmic, et al., 2004). However, the term may be confusing as it implies two diagnoses (e.g., “dual”) while there should be no such limiting implications as multiple symptom clusters and diagnoses are common (Kozlowski, Matson, Sipes, Hattier, & Bamburg, 2011). Alternative terms such as “coexisting,” “comorbid,” and “co-occurring” mental illness are used as well and are preferred.

Psychiatric Disorder and Intellectual Disability

Co-occurrence in Adults with Intellectual Disabilities

Psychiatric co-occurrence has been found in large samples of individuals with ID receiving state-supported services. Jacobson (1982, 1990) reviewed

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a database of over 30,000 cases receiving community-based or institutional services in the state of New York and reported co-occurrence in 17 % of adult cases and many diagnoses including schizophrenia. Borthwick-Duffy (1994) reviewed a database of over 78,000 cases receiving similar services through the state of California and reported an overall prevalence of 10 %. Both studies were important at the time because they established the phenomena of co-occurrence in large-scale population studies challenging the long-held fallacy that individuals with ID could not suffer from a psychiatric disorder. However, both studies used chart review methods fraught with threats to validity. A more recent study analyzed a large database of over 240,000 registered cases served by government-sponsored services in Australia and found 31.7 % with co-occurring psychiatric disorder (Morgan, Leonard, Bourke, & Jablensky, 2008). Again, a study like this establishes that psychiatric disorders are being diagnosed in the population but lacks a standard diagnostic process, verification of cases, and control over sample biases.

Other early studies sampled institutional populations suggesting that the full range of psychiatric conditions may be seen in persons with ID in these settings as well (Crews, Bonaventura, & Row, 1994). Reiss (1990) found high comorbidity in a sample of adults with ID receiving therapeutic day services. The authors reported different rates of diagnosis depending on the method used: 39 % were considered having a psychiatric disorder when using a screening instrument, 60 % using clinical interview methods, and 12 % using case record review only. This discrepancy is an important finding and one seen to this day: individuals with developmental disorders will attract various diagnoses depending on how a diagnosis is made, by whom, and depending on which criteria are applied (Levitas, Hurley, & Pary, 2001; Silka & Hauser, 1997). This is one unresolved concern over prevalence research (Kerker et al., 2004) and it affects clinical practice as well (Levitas et al., 2001). However, the major concern with these studies is the validity of extrapolating population prevalence from a clinic

population. Institution and clinic-based samples will arguably show more pathology than community-dwelling cases since the setting may be intended for severe clinical challenges. Several researchers have discussed other methodological limitations in the early studies as well (Kerker et al., 2004).

The current generation studies have avoided many threats to validity by employing stratification and other systematic population-sampling methods and by using standardized methods for diagnosing cases. Deb, Thomas, and Bright (2001a) randomly selected a subset of an entire population of community-dwelling service recipients within a geographic area and then applied a standardized screening tool followed by a structured clinical interview using ICD-10 criteria (WHO, 1993). A clinician blind to initial screen results conducted the interviews. Results revealed psychiatric comorbidity (point prevalence) in 14.4 % of individuals with ID, a rate of co-occurrence not significantly different from the rate of psychiatric disorder in the general population. However, some disorders were more common in the ID population compared to reported rates for the general population (the authors compared prevalence to a government-sponsored study of households in Great Britain, Meltzer, Gill, Petticrew, & Hinds, 1995). Specifically, the rate for schizophrenia was 4.4 % of the sample (compared to 0.4 % reported for the general population, Meltzer et al.) and the prevalence for phobic disorder was 4.4 % (compared to 1.1 % reported for the general population, Meltzer et al.) (Deb et al., 2001a). The finding of elevated occurrences of schizophrenia was found in a later case record review of a large sample of persons with ID (Morgan et al., 2008).

Cooper, Smiley, Morrison, Williamson, and Allan (2007) examined co-occurrence in 1,023 individuals with ID using several clinical and structured interview methods. Participants were individuals with ID age 16 and older living in the greater Glasgow (Scotland) area, selected from a database of persons with ID receiving local funding for support services, housing supports, or referred by a health care provider. The range of

referral sources was unique, capturing cases for inclusion from many vantages, not simply the most likely to be disturbed such as those in treatment centers or institutionalized service recipients. The authors found a diagnosis of co-occurring psychiatric disorder in 40.9% of individuals when a clinical diagnostic interview was employed and a similar rate of 35.2% when the DC-LD, *Diagnostic Criteria for Learning Disability* (RCP, 2001), were applied. However, the prevalence rate was less when standard diagnostic criteria were employed (e.g., ICD-10 = 16.6%, DSM-IV-TR = 15.7%) (APA, 2000). These rates were similar to prevalence in the general population. The authors suggest that the standard criteria are not sensitive to the effect of functional developmental level on psychiatric presentations of persons with ID. Additionally, the authors report that the occurrence of a psychotic disorder varied from 2.6 to 4.4%, depending on diagnostic method.

Similar methodologically to Cooper et al. (2007), Smiley et al. (2007) studied mental health disturbances in adults with ID recruited from a range of sources and all community dwellings. A multitiered diagnostic process was employed using screening tools, checklists, and clinical interview. The 2-year point prevalence for co-occurring psychiatric disorder was reportedly 12.6% when based on psychiatric clinical interview and with lower rates when standardized criteria were applied (LD-DC = 11.8%, ICD-10 = 8.4%, DSM-IV-TR = 6.8%). Again, the finding is of general occurrence rate similar to the general population and that diagnostic method can affect detection of cases. Occurrence of a psychotic disorder varied from 0.9 to 1.4%, depending on diagnostic method.

In summary, research on the prevalence of psychiatric disorders in adults with ID has established that individuals with ID can suffer from mental illness. More contemporary studies have employed appropriate epidemiologic research methods permitting estimations of whole-population prevalence rates similar to those for the general population (Cooper et al., 2007), with inconsistent finding of increased occurrence of schizophrenia and other psychotic disorders (Morgan et al., 2008). Finally, a recent study

suggests that co-occurring psychopathology in adults with developmental disability is considered a stable phenomenon. Horovitz et al. (2011) examined stability of symptoms in persons with ID and evidence of psychopathology. Symptoms of psychiatric disorder did not fluctuate significantly over a 1-year period.

Adults with Intellectual Disability and Autism Spectrum Disorder

The co-occurrence of psychiatric disorder in adults with ID and an ASD is a relatively new area of research. An initial study to use population-sampling methods was Morgan, Roy, and Chance (2003) who evaluated co-occurrence in a community-based sample of 164 individuals with ASD. Using ICD-10 criteria, the authors reported an overall point prevalence of psychiatric disorder of 35%, a finding higher than expected for the general population. In addition, the rate appeared to increase with the severity of ASD symptoms. However, level of ID was not statistically controlled for, and other potential confounds were not considered, limiting what conclusions might be drawn (see Tsakanikos et al., 2006).

Tsakanikos et al. (2006) reported psychiatric co-occurrence in 147 adults with ASD compared to 605 adults with ID referred for services to a mental health clinic. Although we have raised concerns about extrapolating whole-population prevalence from clinic samples, making comparisons between those with ASD and ID and those with ID alone may be reasonable since both groups would be affected by the clinic-referral bias. In this case, the authors reported no difference in rate of diagnosis of psychiatric conditions in the samples, once differences in level of ID, gender, age, and psychotropic medications are controlled for. This study is important as it establishes the influence of certain between-group differences confounding results; accordingly, the suggestion is that group differences in occurrence of psychiatric comorbidity between individuals with ID and ASD may be due to other factors than the developmental disorder itself.

A later study compared a subset of the data from Cooper et al. (2007), specifically comparing data from adults with autism and ID and those with ID alone (Melville et al., 2008). Diagnostic criteria were the DC-LD, ICD-10, and DSM-IV-TR, as previously described. In this case, the samples were matched for level of ID, age, and gender. In addition to prevalence rates, the authors evaluated recovery rate, that is, the absence of a clinically significant disorder after 2 years since an initial diagnosis had been made. These authors found no statistically significant difference in point prevalence of mental illness between the autism sample and the ID without autism sample. Two-year incidence of mental ill-health was found to vary depending on the method of assessment used: 16 % when diagnosis was based on clinical interview, 12 % by DC-LD, 8 % by ICD-10 criteria, and 4 % based on DSM-IV-TR, though the authors excluded phobic disorders from these prevalence rates. The authors noted that the adults with autism did show higher occurrence of problem behaviors than those with ID alone. However, adults with autism show a lower 2-year recovery rate for problem behavior than the ID alone and matched population (e.g., those with autism were more likely to continue display problem behavior than the comparison groups). In addition, the authors report a somewhat surprising finding that psychiatric comorbidity in the ASD population may be lower than ID alone once the occurrence of problem behavior is factored out. (However, the finding was of “trend” without statistical significance.)

Finally, a recent study evaluated co-occurrence in adults with Asperger syndrome (Lugnegard, Hallerback, & Gillberg, 2011). There were 54 men and women with Asperger syndrome, but without ID, who were recipients of community supports or evaluation through two outpatient service centers. Diagnoses were based on DSM-IV criteria using a structured clinical interview. The researchers report that 70 % of the sample met criteria for at least one occurrence of major depression during their lifetime; 56 % of the sample suffered from an anxiety disorder (with generalized and social anxiety disorders

occurring most prevalently, both at 22 % of individuals). While the high reported rates might be due to the sample bias, it is important as one of few looking specifically at co-occurrence in Asperger syndrome and as suggestive of high occurrence of anxiety and depression in individuals with ASD.

At this time, it appears that psychiatric comorbidity in adults with ID and an ASD occurs at least as often as adults with ID alone. Some research suggests that differences in comorbidity rates between these groups may be accounted for by gender (ASD is more common in males) or age (for various reasons research samples of individuals with ASD may be younger than samples of individuals with ID) or the greater co-occurrence of challenging behavior seen in individuals with ASD. Once these variables are controlled for, the co-occurrence rates may be statistically the same. This research is at an early stage, and much replication is needed.

Co-occurrence in Children and Adolescents with Intellectual Disabilities

Nearly all forms of childhood psychiatric disorders can be observed in children and adolescents with ID (Dekker & Koot, 2003; Szymanski & King, 1999; Volkmar & Dyken, 2002). The most recent decade has advanced valid prevalence findings for children and adolescents with ID. These more contemporary studies have employed sophisticated epidemiologic methods for sampling and bias control, standardized diagnostic criteria, often used peers without ID as a comparison group, or employed longitudinal designs (for instance, Emerson, 2003; Emerson et al., 2001; De Ruiter, Dekker, Verhulst, & Koot, 2007). The general finding is high prevalence of co-occurring psychiatric disorder and stability of psychopathology in children and adolescents with ID (Dykens, 2000).

Emerson (2003) used a stratification and randomization sampling method across over 10,000 children and adolescents and compared rates of

psychiatric disorders in ID ($n=264$) vs. non-ID groups. Diagnoses were made using ICD-10 and DSM-IV-TR criteria during interviews conducted with caregivers (the child's mother in 94 % of cases), the child himself (age 11 and over), and through questionnaire completed by the child's teacher. The principle finding was of significantly increased risk for psychiatric disorder in general in the ID group when compared with non-ID peers using ICD-10 criteria (the authors note the DSM-IV-TR results were virtually identical). Specifically, the authors reported the overall rate for a diagnosed comorbid condition was 39 % in the sample with ID and 8.1 % in the non-ID. However, these figures included conduct disorders and tics; when emotional disorders were compared separately, the rate for comorbidity was 9.5 % in children and adolescents with ID vs. 4.1 % for those without. A particular value of this study was the use of the comparison group studied during the same period, using the same method resulting in a more persuasive finding of increased comorbidity in the intellectually disabled group. The sample was enlarged by another 7,977 cases several years later and results reanalyzed with similar findings (Emerson & Hatton, 2007).

Children with borderline to moderate intellectual disability show rates of comorbid mental health problems greater than children without an intellectual disability (Dekker & Koot, 2003). Employing a population-sampling method across a geographic region, the authors assessed 968 children and adolescents with ID for the presence of psychiatric disorders based on DSM-IV criteria. They report the prevalence for any DSM-IV disorder to be 38.6 %, with 21.7 % showing severe impairment of at least one area of everyday functioning as a result. The impairment finding is important, as it distinguishes cases that simply met listed criteria from those with a clinically significant (impairing) condition. Anxiety and disruptive behavior disorders were most commonly found. However, since disruptive behavior disorder might be an alternative label for "challenging behavior," the finding may reflect a greater rate than would occur if challenging behavior were excluded. For instance, 5.1 % of

subjects with co-occurrence at the impaired level were diagnosed with a disruptive behavior problem (with oppositional-defiant disorder [ODD] the most commonly diagnosed in the group).

A more recent study of children diagnosed with borderline intellectual functioning only found concerning evidence of psychopathology as well (Emerson, Einfeld, & Stancliffe, 2010). These children were diagnosed with borderline ID at age 4/5 years and reassessed for mental health problems at age 6/7 and findings compared to same-aged children without ID. Significantly higher rates of mental health problems were noted in the borderline ID group. Additionally, the authors reported that when analyses controlled for socioeconomic variables, the between-group differences in mental health ratings remained significant. The researchers did not obtain psychiatric diagnoses using standard criteria but instead used the *Strengths and Difficulties Questionnaire* (SDQ; Goodman, Tamsin, Simmons, Gatward, & Meltzer, 2000) as a screen for identification of psychiatric disorder, and findings should be interpreted as "mental health problems" but not psychiatric disorder.

Psychopathology in young persons with ID has been found to be stable, with only modest change into adulthood, particularly in those with severe intellectual disability (Einfeld et al., 2006; Kozlowski et al., 2011). The cohort rate of prevalence of major psychopathology or definitive psychiatric disorder reduced by only 10 % over the course of one 14-year longitudinal study (Einfeld et al., 2006). Other longitudinal research has demonstrated that psychiatric disorders in persons with ID emerging during childhood may become chronic: while the level of psychopathology may decline through adolescence, clinical problems in childhood often remain significant into adulthood (De Ruiter et al., 2007).

Yet, despite the stable presence of a psychiatric disorder, many young persons with ID may not be receiving adequate treatment. Einfeld et al. (2006) reported that during the study period of 14 years, only 10 % of those with definitive psychiatric disorder received a treatment specifically targeting the disorder (Einfeld et al.). Similarly,

Dekker and Koot (2003) found that only 27 % of individuals received treatment for the comorbid disorder. Some of the subgroup analyses the authors provided are stunning. For example, in the group of children and adolescents significantly impaired by a mood disorder, over 63 % had not received a treatment specifically for the condition in the past 12 months (Dekker & Koot). Thus, while the risk of co-occurring disorders is known to be greater for children and adolescents with ID and the disorder is likely to be chronic, most afflicted persons are unlikely to be receiving adequate treatment.

In summary, research on psychiatric co-occurrence in children and adolescents with ID has employed rigorous epidemiologic methods with replication of major findings (Einfeld et al., 2011). This research suggests increased risk for the development of mental illness in the population. Furthermore, it has been argued that these results may in fact underestimate prevalence because those psychiatric problems characterized as “internalizing disorders” (depression and anxiety, for instance) rely heavily on patient self-report and self-report is not possible for many children with ID (Handen, 2007). In addition, there is evidence that psychiatric disturbances emerging in childhood continue into adulthood in children with ID (De Ruiter et al., 2007). Despite this observation, it appears that too many of these individuals do not receive treatment for the condition, at least not during childhood and adolescence. The reasons for this are unclear, though the lack of specialized clinicians and difficulty accessing treatment options are significant contributing factors (Nageswaran, Parish, Rose, & Grady, 2011).

Children and Adolescents with Autism Spectrum Disorders

Children and adolescents with autism have been a focus of specialized comorbidity research. A well-designed study using a population-derived stratification of 10–14-year-old children with an ASD found high rates of DSM-IV-TR disorders (Simonoff et al., 2008). Specifically, the researchers reported that over 70 % of the sample met criteria

for a DSM disorder during the past 3 months; anxiety or mood disorder comprised over 44 % of the sample. There was no difference when comparing autistic disorder vs. any other ASD. Similarly, autism severity did not predict a co-occurring diagnosis. The finding is important as it suggests additional sources of complexity in cases of autism beyond the developmental disorder itself.

Because there is significant co-occurrence of ID in children with ASD, a central question would be to differentiate psychiatric comorbidity that can be accounted for by the presence of an ID from conditions and prevalence unique to persons with ASD. Dekker and Koot (2003) compared children with ID to those with pervasive development disorder (PDD)/ID and found the presence of an impairing DSM-IV-TR disorder was twice as likely in the PDD subsample. Further, those with PDD were 3.7 times more likely to have an impairing anxiety disorder than those with ID alone. This finding that children and adolescents with ASD show greater co-occurrence of psychiatric disorders than children with ID alone is supported by later research. For example, Bradley, Summers, Wood, and Bryson (2004) compared adolescents with autism to adolescents and young adults with severe ID using the DASH-II (*Diagnostic Assessment for the Severely Handicapped-Revised*; Matson, 1995) as a measure of psychopathology. The degree of disturbance was found to be four times higher in the group with autism than the ID alone group. A later study (Brereton et al., 2006) found higher rates in children and adolescents with ASD compared to those with ID alone as well. Using the *Developmental Behavior Checklist* (Einfeld & Tonge, 1995), researchers compared occurrence of psychopathology to previously published data on psychopathology in children with ID alone using the same instrument (Einfeld & Tonge, 1996). Although the scale did not yield specific psychiatric diagnoses, as a group, the individuals with ASD showed psychopathology scores well above the criteria for psychiatric condition and significantly greater levels of psychopathology than those with ID alone.

In addition to finding psychiatric disorders and elevated psychopathology in general, specific states of irritability and anxiety may be prevalent

in children and adolescents with ASD. Parents and caregivers have noted this for some time: mothers frequently report anxiety and irritable mood in their child with autism more often than mothers of typically developing children or children with a diagnosed anxiety disorder (Mayes, Calhoun, Murray, Ahuja, & Smith, 2011); teacher and other caregivers frequently report irritability in children with an ASD (Lecavalier, 2006). Kim, Szatmari, Bryson, Streiner, and Wilson (2000) reported increased occurrence of both anxiety and depression in a small sample, but the finding revealed a difference when compared to rates for children with ID alone. Another study reported that clinically significant anxiety, crying, depression, and sleep disturbances occurred more often in children and adolescents with ASD than those with ID alone (Brereton et al., 2006). A recent meta-analysis of comorbidity studies reported 39.6% of children and adolescents with ASD with at least one DSM-IV anxiety disorder (van Steensel, Bögels, & Perrin, 2011). A small sample, drawn from a controlled population sample study, found that young persons with ASD were more likely than a matched comparison group with ID alone to be diagnosed with a mood disorder, and the tendency was for the mood disturbance to last significantly longer in ASD than ID (Bradley & Bolton, 2006).

At this time, it appears that children and adolescents with ASD may be at greater risk for psychiatric co-occurrence than their peers with ID alone. Furthermore, it may be that anxiety disorders, mood disorders, and irritable mood states account for some of this difference (Brereton et al., 2006; Dekker & Koot, 2003). However, because problem behaviors occur frequently in the child ASD population, it may be that the presence of problem behaviors confounds prevalence findings as has been observed in adult ASD research (McCarthy et al., 2010; Melville et al., 2008).

Issues in Assessment

Diagnostic Challenges

Diagnosing psychiatric disorders in persons with ID remains a clinical challenge. As previously ref-

erenced, some clinicians may be biased toward over-attributing the presenting problems and symptoms to the developmental disorder. In these cases, the diagnosis of ID overshadows the presentation and as a result, psychiatric disorders are not considered when in fact they ought to be. This bias has been called *diagnostic overshadowing* (Reiss, Levitan, & McNally, 1982). A meta-analysis of 13 published studies reported consistent effect sizes between studies and an overall effect size that fell between “small and medium” ($r=0.19$) based on traditional effect size ranges (White et al., 1995). The authors noted that the clinical significance of this bias could be a 19% drop in diagnostic accuracy for the population or a reduction in sensitivity to the presence of mental illness (Jopp & Keys, 2001). These phenomena would be more likely to be exhibited by those without familiarity or specialty training in the psychiatric issues of persons with intellectual disability. A recent case review supports this in finding significant differences in diagnostic patterns between psychiatrists with specific training in ID and those without (Lunsky & Bradley, 2007).

It is understandable why specialized training and population experience are essential. An immediate concern is that the diagnosis of a psychiatric disorder requires certain language and cognitive developments that many individuals with ID do not possess. These limitations are especially true with the heavily language-dependent ICD-10 and DSM-IV-TR classification criteria. Certain psychiatric symptoms can be reliably reported only by an individual with a developed ability to think abstractly and self-observe. In particular, internalizing disorders such as depression and anxiety might go unnoticed without clear self-report (Handen, 2007). This limitation is especially problematic when evaluating for psychosis since the current standard method is patient self-report (Barnhill, 2008). For instance, hallucinations are routinely assessed by asking, “Do you hear voices” or “Do you see things that are not there?” and similar questions that would be too cognitively complex for many individuals with ID (Hurley, 1996). A severely language-impaired or profoundly non-verbal individual could not provide the information required, and inferences about “responding to

internal stimuli” based on outward signs would be highly speculative (Barnhill, 2008).

The phenomena of language and cognitive delays interfering with the usual diagnostic process have been called *intellectual distortion* (Sovner, 1986). One strategy to address this challenge has been to conduct a parallel interview, where the patient is interviewed side by side with a caregiver who has significant familiarity with and knowledge of the patient (Costello & Bouras, 2006). In this procedure, the caregiver interjects to clarify, restate questions, and correct inaccurate reporting. Obviously, diagnosing a psychiatric disorder in an entirely nonverbal individual would not permit self-report as part of the diagnostic process, so a knowledgeable caregiver might be called upon to describe mood and activity changes from baseline. Others have pointed out the need for multidisciplinary teams to contribute specialty data in order to make an accurate diagnosis (Davis, Barnhill, & Saeed, 2008).

Social-developmental differences may complicate the diagnostic process as well. For instance, significant social skills delays or a lack of socially normative developmental experiences may distort how symptoms are expressed, a phenomena Sovner (1986) referred to as *psychosocial masking*. Accordingly, actual symptoms may not appear as vivid or as concerning to clinicians, or mood states may appear bland (Weisblatt, 1994). In part, this situation may be due to a social desirability effect, where the person with ID tends to acquiesce to questioning, becomes overly agreeable, or displays “yea-saying” during a clinical interview, masking severity and adversely affecting the reliability of findings (Silka & Hauser, 1997).

In some cases, social development may be severely delayed in a particular area, such as an adult who is fixated on imaginary friends or prone to talking to self frequently and loudly. Such behaviors can be misinterpreted as psychosis though they might be properly understood as normal within the individual’s developmental level (Hurley, 1996).

Cognitive limitations may impede the ability of the person with an ID to provide an accurate history of their own functioning and mood states over

time, limiting the critical assessment of course of the disturbance (Barnhill, 2008). Accordingly, a major tool for clinicians to assess pre-morbid functioning and establishing a self-reported baseline will be unavailable. Again, caregivers must be engaged to provide the baseline description. In some cases the individual may be receiving services in an applied setting and in these cases actual behavioral data may be available for this purpose (Singh, Sood, Sonenklar, & Ellis, 1991). Behavioral data can provide a more reliable method for establishing a baseline and monitoring treatment changes as well (Matson, Mayville, & Laud, 2003).

These challenges may be amplified in persons with ID and autism. First, individuals with autism may show higher occurrence of challenging behaviors compared to individuals with ID alone, though this may not be an indication of psychopathology (McCarthy et al., 2010). Accordingly, clinicians will require more careful observations and data gathering to avoid falsely interpreting behavioral features as indications of psychiatric disorder. Further, the core symptoms of autism include features that are similar to certain psychiatric conditions though they are believed to be accounted for by autism alone. For instance, certain ritualistic and repetitive behaviors occur in autism, though they are *not* obsessive-compulsive disorder (Barnhill, 2008); moodiness, irritability, and anxiety are beginning to emerge as complications in some cases of autism, but not necessarily warranting a distinct diagnosis (Mayes et al., 2011); and atypical symptom presentations are the norm rather than the exception in ASD (Underwood, McCarthy, & Tsakanikos, 2011). Further, persons with autism may show more severe impairment with the self-report of affective states and a range of communication impairments beyond those seen in ID alone (Matson, Dempsey, LoVullo, & Wilkins, 2008).

Semi-structured interviews have been used as an aid in making a clinical diagnosis in persons with ID and may help avoid some of the pitfalls described above. *The Psychiatric Assessment Schedule for Adults with Developmental Disabilities* (PAS-ADD; Moss et al., 1993) is one such tool used to determine a diagnosis based on ICD-10 criteria or as a screen for a potential case

using an abbreviated checklist version (Moss et al., 1998; Sturmey, Newton, Cowley, Bouras, & Holt, 2005). Its structure, format, and grammar have been adapted to the unique cognitive needs of persons with ID (Sturmey, 2007).

In some cases structured self-report tools have been used with reported success. The *Youth Self-Report* (YSR), a self-report subset of the well-known *Child Behavior Checklist* (Achenbach, 1991), was used by Douma et al. (2006) with persons from moderate to borderline ID. The YSR appeared suitable for individuals with an IQ of 48 or above, depending on reading achievement level. The results suggest some individuals with ID can be called upon for self-report of emotional and behavioral problems. This is an important finding as much previous research and expert opinion has warned of the difficulties individuals with ID have making accurate self-report. This and similar studies remind clinicians that self-report may be possible in some cases.

Finally, there is the issue of heterogeneity in developmental disorders (Davis et al., 2008). Every person differs on level of impairment and developmental differences across a range of domains; the etiology of ID will differ across people, being unknown in most cases; and there will be a range of comorbid medical issues to consider, each of which can impact differential diagnosis (Szymanski & King, 1999). Clinicians will require longer assessment time and will require the input from multiple disciplines. Davis et al. (2008) recommend multimodal assessments where input from medical, psychiatric, and behavioral specialists are coordinated in the assessment process in response to the clinical complexities generally seen in ID.

Overall, the current research suggests that making an accurate psychiatric diagnosis of individuals with ID is a clinical challenge. An ID includes cognitive, language, and social-developmental delays that impede typical participation in the clinical interview method. In some cases, self-report may be possible; however, often caregivers should be involved in the process, and specialized interview protocols may need to be used. Other strategies might include drawing inferences from behavioral problems or modifying standardized

criteria to fit the specialized population. These approaches are discussed in the next section.

Behavioral Equivalents and Modified Criteria

The use of behavioral equivalents is a strategy proposed to increase fit between diagnostic criteria and the unique presentations and assessment challenges seen in individuals with ID. In this approach, certain behaviors are viewed as substitutes for self-report of typical diagnostic criteria or are given greater weight in the absence of reliable and undistorted self-report from the patient. For example, an apathetic facial expression might be viewed as equivalent to self-reported sadness (Hurley, 1996). Less interest in stimuli previously found to be preferred, withdrawal, or refusal to participate in previously engaging leisure activities might be viewed as behavioral equivalents of self-reported anhedonia (Hurley, 1998). Later research has confirmed the behavioral occurrence of self-reported sadness or sad facial appearance, observations of lack of interest or signs of pleasure in previously enjoyed activities (anhedonia), and crying episodes were directly observable behaviors that differentiated depressed persons with ID from other patient groups (Hurley, 2008).

While intuitively appealing, the use of behavioral equivalents has mixed empirical support (Sturmey, 2007). Indeed, the hypothesis that a behavior disorder might indicate the presence of depression in a person with intellectual disability is challenged by conflicting findings from two research groups (Sturmey, Laud, Cooper, Matson, & Fodstad, 2010a; Tsiouris, Cohen, Patti, & Korosh, 2003; Tsiouris, Mann, Patti, & Sturmey, 2003).

Other research has suggested a more limited approach. For instance certain behaviors that might be weighted heavily in the diagnosis of bipolar disorder in persons with an intellectual disability. In independently conducted studies, Gonzalez and Matson (2006) and Matson, Gonzalez, Terlonge, Thorson, and Laud (2007) found that a reported decreased need for sleep

(sometimes noted as waking often during the night, difficulty getting to sleep) and psychomotor agitation (observed as restlessness and increased activity) predicted mania reliably. The finding has been replicated more recently as well (Sturmey, Laud, Cooper, Matson, & Fodstad, 2010b).

Neurovegetative symptoms such as appetite, sleep, and activity are useful diagnostically as they can be directly observed and independently verified. If they represent a significant departure for baseline, they could be indicative of onset of a psychiatric disorder. However, it has been argued that individuals with ID often show disturbances in sleep architecture and routinely show sleep-onset struggles, circadian disorganization, and other factors that appear secondary to the developmental disorder, rather than indications of primary psychiatric disturbance (Barnhill, 2008). Accordingly, while beneficial to evaluate these symptoms, they should not carry the same diagnostic weight as they would for typically developing individuals.

Alternatively, standardized diagnostic criteria have been modified for use with persons with intellectual disabilities. For example, the DC-LD (RCP, 2001), was developed as complimentary to ICD-10, but with modifications to increase validity when used with the ID population (Cooper, Melville, & Einfeld, 2003). The criteria appear to match findings of clinical interviews conducted by experts in the population (Cooper et al.). For instance, one study diagnosed mental illness through clinical interview in 40.9% of a sample and 35.2% when the DC-LD criteria were used. In contrast, mental illness was diagnosed in 16.6% and 15.7% of cases when ICD-10 and DSM-IV-TR criteria were applied (respectively). The authors conclude that the DC-LD criteria were more sensitive to the presence of clinical conditions (Cooper et al., 2007).

The DM-ID (*Diagnostic Manual-Intellectual Disability*; Fletcher, Loschen, Stavrakaki, & First, 2007) is an adaptation of the DSM-IV-TR for use with persons with ID. It was developed to be used with the DSM-IV-TR, providing clarifications and illustrative examples to aid in the recognition of symptom presentations unique

to ID and with differential diagnosis. Symptom equivalents are included, and in some cases, the threshold for deeming a presenting feature clinically significant is changed (Staal, 2011). A field trial study reported that the DM-ID criteria reduced the “not otherwise specified” (NOS) designation that often occurs with persons with ID (Fletcher et al., 2009).

Relationship of Psychiatric Comorbidity to Challenging Behaviors

Challenging behaviors such as aggression, self-injurious behavior (SIB), property destruction, and verbal outbursts occur frequently in individuals with ID (Cormack, Brown, & Hastings, 2000; Crnic, Hoffman, Gaze, & Edelbrock, 2004; Lowe et al., 2007). Research on behavior problems in young children with ID and developmental delays consistently finds that these children are at significantly greater risk for the development of challenging behaviors (Dekker et al., 2002), with one finding of a three times greater risk for clinically significant problem behaviors (Baker et al., 2003).

A well-sampled population-based study found 10–15% of persons with ID (50% of whom were living with their families) displayed clinically significant challenging behaviors (Emerson et al., 2001). Another population-derived sample found severe or frequent aggression, property destruction, or SIB in 23.8% of individuals with ID (Deb, Thomas, & Bright, 2001b). For many children and adolescents with ID the disturbance will persist into adulthood (Totsika & Hastings, 2009). One study reported that the behavior problems in most individuals continued throughout a 26-year longitudinal study (Thompson & Reid, 2002).

Problem behaviors appear to have greater impact on parental distress than the developmental disability diagnostic classification (Baker et al., 2003; Blacher & McIntyre, 2006) or the addition of a psychiatric diagnosis (McIntyre, Blacher, & Baker, 2002). If not addressed, the negative impact of challenging behaviors on families extends into late adolescence and young adulthood (McIntyre et al.). Challenging

behaviors are associated with caregiver stress in a manner that is reactive to the problem behavior and over time may contribute to a downward course of problem behavior itself (Lecavalier, Leone, & Wiltz, 2006). Challenging behaviors are the primary reason why some children and adolescents with ID are removed from their homes and placed in residential treatment settings (Baker et al., 2003; Llewellyn et al., 2005). They constitute the most common reason for referral for outpatient consultation (Barnhill, 2008; Edelstein & Glenwick, 1997).

Grey, Pollard, McClean, MacAuley, and Hastings (2010) conducted one of the few studies to examine the relationship between psychiatric disorder and challenging behavior by evaluating a community-based sample of 159 individuals receiving day support services. Individuals were evaluated for the presence of challenging behavior and psychiatric disorder using the PAS-ADD (Moss et al., 1993). There was no relationship between the presence of psychiatric disorder and challenging behavior. Indeed, over 45 % of the sample evinced some active behavioral problem, yet only 6 % of the sample met criteria for psychiatric disorder. A relationship was found where the most severe behavioral problems were significantly more likely to covary with psychiatric disorder (Grey et al., 2010). Again, this relationship was for behavior problems classified as “intense” and “severe,” and there was no significant relationship to psychiatric disorder for lesser levels of problem behavior.

The Grey et al. (2010) finding argues the possibility that in the more severe cases, there may be a relationship between problem behaviors and psychopathology in persons with severe and profound ID, a phenomena noted by Rojahn, Matson, Naglieri, and Mayville (2004) who reported that psychopathology was correlated with high rate of problem behavior and persons with high rates of problem behaviors were more likely to carry a psychiatric diagnosis. This is similar to prior research which found that psychiatric disorders were more likely to be diagnosed in individuals with ID who displayed more severe problem behaviors (Moss et al., 2000). Diagnoses were based psychiatric symptomatology on a checklist

screen for psychiatric symptoms (Moss et al., 1998) and not by trained clinicians, so these results should be considered suggestive and in need of additional research.

Undoubtedly, the relationship between challenging behaviors and psychiatric disorders is complex and not fully understood (Grey & Hastings, 2005). At this time, it appears that more severe behavioral states may be associated with psychiatric disorders. Yet, challenging behaviors in and of themselves do not constitute a psychiatric disorder, and the presence of a psychiatric disorder is not always associated with challenging behavior (Allen & Davies, 2007; Rojahn et al., 1993). Although this is understood, some researchers have mistakenly included problem behavior when researching prevalence of psychiatric disorder in ID (Allen & Davies). This has led to conflated prevalence rates and possibly misleading diagnoses (Costello & Bouras, 2006).

The possibilities are numerous: In some cases it may be that certain challenging behaviors represent a form of behavioral equivalents for psychiatric symptoms; alternatively, challenging behavior may be unrelated to psychiatric disorder, occurring as a preexisting functional behavior disorder that has been worsened by the putative mental illness (Allen, 2008). Yet in other cases challenging behaviors may be “both”—e.g., while an initial onset of the behavior was driven by psychiatric state, it now operates independently on the environment as a functional behavior disorder. This point was established decades ago (Ayllon & Azrin, 1965; Ayllon & Michael, 1959), though the implications eluded mainstream psychiatry for some time. For example, consider the phenomena of “schizophrenic speech” characterized by bizarre patterns and delusional content that has been shown to be responsive to socially mediated consequences (Travis & Sturmey, 2008).

Data reported on 35 cases admitted to a child psychiatric unit show the pattern of independence between psychiatric disorder and the form of challenging behaviors (Ricciardi, 2009). The 35 cases were children with ID ages 8–15, with ID in the mild to severe levels, and were consecutive admissions to an inpatient child psychiatric unit

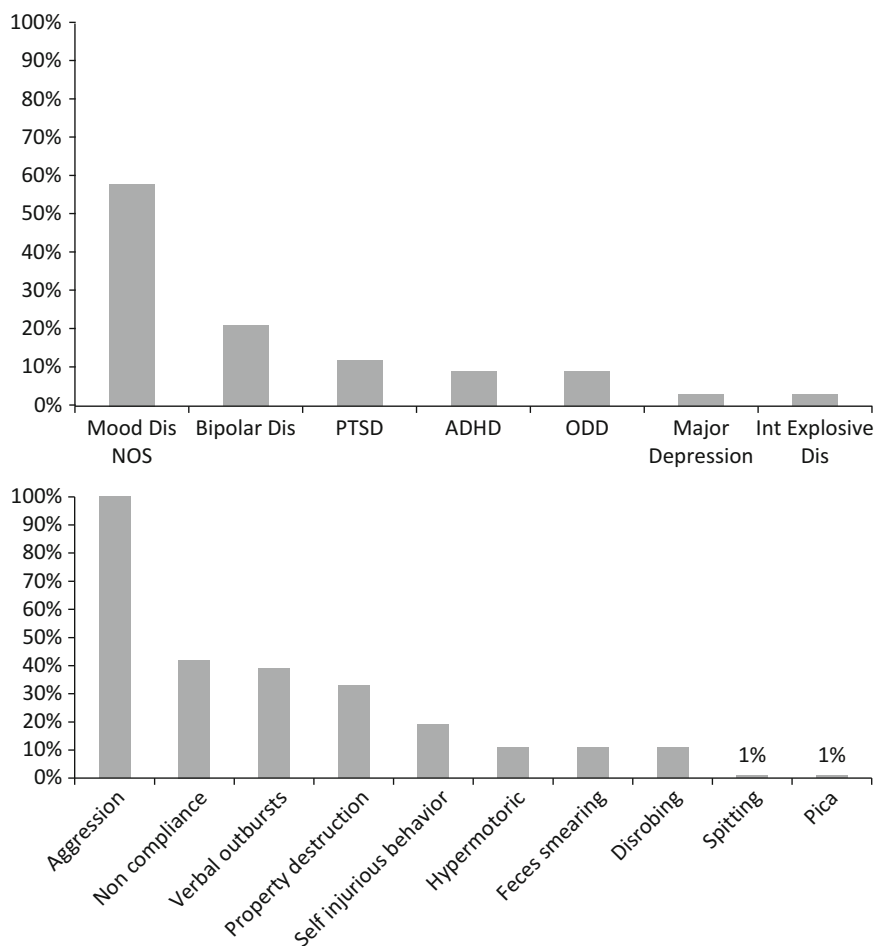


Fig. 13.1 Admissions data from 35 consecutive inpatient admissions, children with ID ages 8–15. *Top graph* shows range of diagnoses on admission. *Bottom graph* shows topography of clinically significant challenging behavior reported on admission. From Ricciardi, J. N., Brown, K.,

Milad, E., Saidel, M., Roberts, B. & Farren, N. (2004). Behavioral intervention for serious behavior disorders on an inpatient psychiatric unit. Annual conference of the Berkshire Association for Behavior Analysis and Therapy, Amherst, MA

collected over a 12-month period. Diagnoses were based on DSM-IV-TR criteria (APA, 2000) and established by specialty trained psychiatrists. Figure 13.1 (top) shows occurrence of a range of diagnoses while Fig. 13.1 (bottom) shows occurrence of problem behaviors in the sample. What is noteworthy is that the range of diagnoses did not distinguish aggression from any other presentation, which occurred in 100 % of the sample. Indeed, severe aggression was the primary reason for inpatient admission in all cases. No individual displayed only one problem behavior topogra-

phy; the modal presentation was two challenging behaviors, with no relationship found between topography or number of challenging behaviors and the primary diagnosis (Ricciardi, 2009).

Still, the presence of severe challenging behavior warrants evaluation at the least to *rule out* the presence of a psychiatric disorder. Tsiouris, Cohen, et al. (2003) and Tsiouris, Mann, et al. (2003) implemented a diagnostic and treatment protocol to 26 individuals with ID, identifying a relationship between previously untreated psychiatric disorder and concomitant SIB. The authors

found that when the psychiatric disorder was diagnosed and an appropriate psychopharmacologic intervention applied, SIB improved significantly, including elimination in 46 % of cases. Presumably, earlier evaluation would have diagnosed many of these cases and led to effective treatment sooner in the course of the disturbance. As noted previously, two studies found that only 10–27 % of children and adolescents with comorbid psychiatric disorder were receiving mental health interventions (Dekker & Koot, 2003; Einfeld et al., 2006).

Finally, there appears to be a complex distinction between challenging behavior in persons with ID vs. those with ID and autism. In a sample of community-living referrals to an outpatient mental health clinic, McCarthy et al. (2010) found that those with autistic disorder were nearly four times more likely to exhibit significant challenging behaviors than those with ID alone. Further, when level of ID, gender, and age were controlled for, there was no significant difference in comorbid psychopathology, suggesting that the presence of challenging behavior was independent of psychiatric disorder (McCarthy et al.). Melville et al. (2008) found that individuals with autism and ID showed similar level of challenging behaviors compared to individuals with ID alone and a similar co-occurrence of psychiatric disorder. However, the individuals with ID alone showed improvement in level of challenging behavior 2 years later, while those with autistic disorder and ID did not. These studies suggest that autistic disorder may be associated with challenging behaviors more so than ID, and this is unrelated to other psychopathology or co-occurring mental illness. Further, challenging behavior in individuals with autistic disorder may be more enduring (Melville et al., 2008). In addition, aggression was recently evaluated in a large ($n=1,380$), well-controlled sample of children and adolescents with autistic disorder (Kane & Mazurak, 2011). Researchers found that 68 % of the sample displayed aggression toward a caregiver at some point in time; 56 % of children and adolescents with autism were currently engaging in aggressive behavior with 35.4 % displaying aggression that was at a definitive level.

This study supports the thinking that persons with autistic disorder may exhibit challenging behaviors more frequently than those with ID alone.

In summary, persons with ID display problem behaviors at a greater rate than the general population and the rate may be even greater in persons with ID and autism (Emerson et al., 1999). Further, challenging behaviors such as aggression and SIB are often the chief complaint when seeking mental health evaluation (Barnhill, 2008), though there may not be a relationship between aggression and a specific psychiatric diagnosis (Ricciardi, 2009). Some early evidence suggests that persons with autism and ID may be at greater risk for challenging behavior, and this may be independent of a psychiatric disorder. Accordingly, a psychiatric assessment must incorporate some assessment of the possible role of a functional behavior disorder.

Functional Behavior Assessment

There is consensus within the professional community that evaluating a psychiatric condition in a person with ID must also account for the functional significance of concurrent problem behavior (Barnhill, 2008; Bouras, 1999; Silka & Hauser, 1997; Singh et al., 1991). Additionally, psychiatric treatments are improved by the ongoing observation, data collection, and progress reporting provided by behavioral clinicians (Harvey, Luiselli, & Wong, 2009; Sevin, Bowers-Stephens, Hamilton, & Ford, 2001; Singh et al., 1991).

A functional behavior assessment (FBA) of problem behavior includes a range of assessment procedures from “clinical approaches” such as clinical interview with caregivers and client, record review, rating scales, and direct observations (Matson & Minshawi, 2007) to the application of “experimental methods” to the functional assessment such as structured and systematic observation and data collection across a range of experimentally controlled and manipulated conditions (Hanley, Iwata, & McCord, 2003). The latter has been referred to as “functional analysis” but might be more accu-

rately called “experimental functional assessment” or EFA (Matson & Minshawi, 2007). Most important, an FBA always includes some establishment of baseline measurement of rate or frequency of a problem behavior, which has pragmatic value in evaluating the effects of psychiatric treatment (Harvey et al., 2009; Singh et al., 1991). A complete description of behavioral assessment and functional analysis methods can be found in Chaps. 8 and 9.

Petursdottir, Esch, Sautter, and Stewart (2010) reported a community-based sample of FBAs conducted with 174 children (26.4%) and adults (73.6%) with ID. Behaviors of concern included physical aggression in over half their sample and other challenging topographies such as verbal aggression, SIB, and property destruction. Behavioral assessment procedures were carried out by board certified behavior analysts (90.8%) or associate behavior analysts and included indirect, direct, and experimental (EFA) procedures at the clinician’s discretion. The principle findings were that a single hypothesized function could be identified in the majority of cases (53.2%), with attention-motivation the most common (26.9%). In addition, no hypothesized function could be determined in only 5.8% of cases. These findings are valuable for mental health clinicians because they depict functional assessment findings in community-dwelling persons with ID and cases that are likely to be referred to community-based mental health settings. Also the methods used by the behavioral clinicians in this study reflect those likely to be used in community-based cases (Matson & Minshawi, 2007). Accordingly, the findings suggest that in most cases, a qualified behavior analyst will be able to determine a functional hypothesis that guides diagnosis and treatment planning for the person undergoing psychiatric assessment.

Various scales have been developed to aid clinicians conducting an FBA. These are described in detail in Chap. 8. One scale in particular should be mentioned here: the *Questions About Behavior Function in Mental Illness—QABF-MI* (Singh et al., 2006) is a development of a previous instrument designed to guide in initial development of a functional formulation of problem behavior in

individuals with serious mental illness (not necessarily ID). In this version, items were modified for applicability to individuals with psychiatric disorder. The researchers reported adequate factor structure and potential utility in developing function-based interventions for individuals with comorbid disorders (Singh et al. 2006). The initial study shows promise for this instrument, though further research is needed.

Essentially, an FBA would aid clinicians by classifying functional aspects of behavioral features of the mental illness. This benefit may seem inconsistent with contemporary psychiatry, which tends toward a biological model of mental illness and its expressions. However, Carr, Smith, Giacini, Whelan, and Pancari (2003) provided an example of how functional assessment can aid in problem behavior driven by a biological event. These researchers showed that severe problem behaviors seen during women’s menstrual cycle covaried with the presentation of demanding tasks. The suggestion was that the problem behaviors were maintained by escape and avoidance of task demands, rather than consideration of a premenstrual dysphoric disorder; improvements followed implementation of a multicomponent behavioral intervention which included non-pharmacologic pain management strategies. Carr et al. (2003) illustrate the utility of behavioral assessment in cases where substantial medical overlap exists. It would be all too easy to attribute behavioral challenges entirely to the biological event and then pursue a one-dimensional treatment plan. However, these authors show that a biological concern can be integrated into behavioral formulation leading to a more comprehensive approach (Carr et al.).

Figure 13.2 shows one such case where the results of an EFA were used to clarify the psychiatric diagnosis and establish the effect of the environment (caregiver interactions) in a severe psychiatric presentation. This was an 8-year-old boy with mild ID who had a well-established diagnosis of reactive attachment disorder and a rule-out diagnosis of mood disorder with psychotic features (Ricciardi, 2009). The latter diagnosis was under consideration due to inexplicable episodes of grossly inappropriate behavior char-

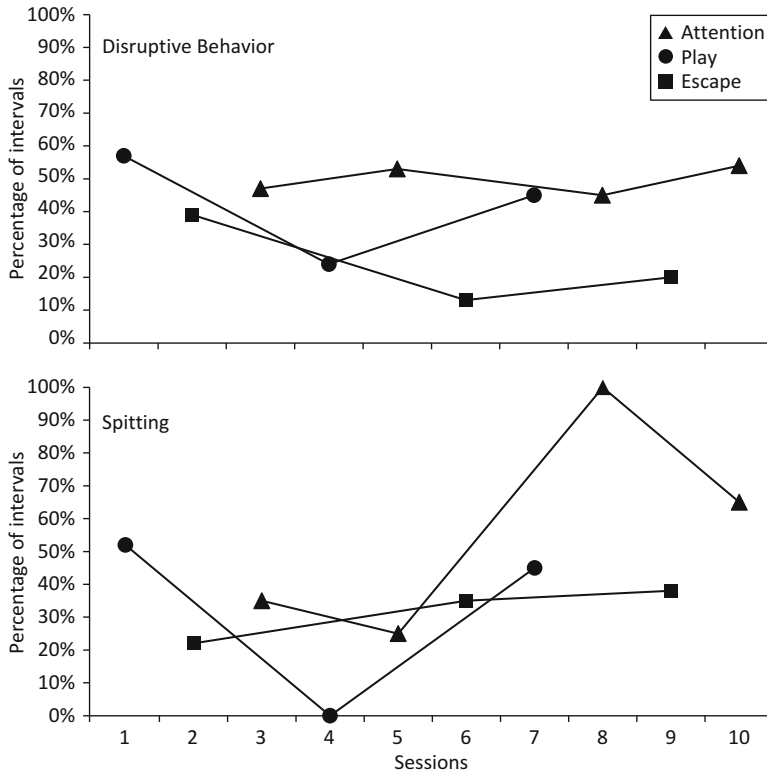


Fig. 13.2 Results from an experimental functional assessment of an 8-year-old boy with mild ID and reactive attachment disorder, R/O mood disorder NOS with psychotic features. *Top graph* shows occurrence of disruptive behavior across conditions; *bottom graph* shows occurrence of spitting. Both behaviors appeared to be reinforced

by contingent attention, disconfirming these behaviors as evidence of psychosis. From Ricciardi, J. N. (2009). Integrated approaches to behavior analysis and psychiatry in children with severe psychiatric and developmental disorders. Annual conference of the California Association for Behavior Analysis, San Francisco, CA

acterized by disrobing, aggression, sexualized aggression (kicking or grabbing at caregiver’s groin), urinating, “gleeful” destruction of toys and materials, and spitting at caregivers. The EFA was conducted in a treatment room on an inpatient psychiatric unit using typical analogue conditions (Iwata, Dorsey, Slifer, Bauman, & Richman, 1982/1994): during the contingent attention condition, the experimenter worked on an activity while the child played and responded to targeted behavior with verbal reprimand “Hey, stop that! That’s not nice.”; during the play (control) condition, attention was freely given every 30 s; during the escape condition, the child was prompted to academic tasks and task demands ceased for 30 s upon display of targeted behaviors. The results indicate a function relationship

between all forms of disruptive behaviors and caregiver attention—the behavior was most reliably elicited and maintained during contingent attention conditions. Most important, his treatment team noted that these putative “transient psychotic episodes” resolved quickly after each session but returned in full force when the attention condition was resumed. These findings and the observation that the episodes were sensitive to environmental events effectively ruled out psychosis and suggested functional behavior disorder.

Others have employed behavior assessment strategies to identify social reinforcement in core features of psychotic disorders in persons with ID. For example, Mace and Lalli (1991) evaluated environmental influences on delusional and

hallucinatory speech in a man with ID and determined the effect of contingent attention in each case; Travis and Sturmey (2010) targeted delusional speech in an individual with ID with a similar finding; and Wilder, Masuda, O'Conner, and Baham (2001) extended the same approach into schizophrenia, without comorbid ID. In summary, these exemplars establish that an FBA can contribute specific findings about environmental influences of severe behaviors, some of which might be considered a core feature of the psychiatric diagnosis. In addition, the FBA may provide observations that clarify the diagnosis. As a result, the FBA can determine the role of environmental factors in the expression of psychiatric symptoms leading to an integrated formulation and, ideally, a comprehensive approach to intervention.

The Integrated Formulation

Advances in behavioral theory and the functional assessment methodology provide an empirically supported rationale for developing a case conceptualization that integrates the presence of the psychiatric condition and a functional behavior disorder. Contemporary research has established that certain intrinsic variables may contribute to the expression of behavior disorder beyond the typical overt antecedents and consequences. These phenomena have been called "setting events" and the underlying behavioral concept has been named establishing operations (McGill, 1999), which has been refined to motivating operations or "MO" (Laraway, Snyckerski, Michael, & Poling, 2003). The concept is well known to behavior analysts and psychologists and has been applied in the assessment and intervention for problem behavior in persons with ID.

Some background information will help explain how this might work. Consider that there are presently ample studies showing the relative effects of medical illness on challenging behaviors (De Winter, Jansen, & Evenhuis, 2011). In these cases, medical problems appear to increase the motivation to escape or avoid

aversive stimuli, thus increasing the rate of the behavior; alternatively, the underlying medical problem may increase the motivation for the person with ID to seek caregiver attention through challenging behavior. At issue is the interaction between the learned behavior (functional behavior disorder) and the medical issue which appears to increase the aversiveness of the task (affecting escape-motivated behavior) or the motivation to secure a caregiver response. This conceptualization has led to behavioral interventions effective for treating problem behaviors associated with menstrual discomfort (Carr et al., 2003), sleep problems, allergies (Kennedy & Meyer, 1996), a range of medical issues contributing to school-based problem behaviors (Carr & Smith, 2006), and numerous other applications (Kennedy & Becker, 2006). In these cases the biological issues function as MOs; behavioral interventions are developed which attenuate the effect of the MO.

Psychiatric disorders would presumably influence a learned behavior disorder in the same manner by functioning as MOs (Friman & Hawkins, 2006; Sturmey, 2007). This proposition makes sense because psychiatric symptoms include disturbances of mood and affect such as irritability, excessive frustration, sadness, fatigue, anxiety, worry, elation, and expansive ideation. While for some time the hidden nature of mood states dissuaded behavioral psychologists from treating them as objects of study, it is no longer the case (Friman, Hayes, & Wilson, 1998). The concept of the MO provides a conceptual basis for formulating the influence of mood on behavior. Accordingly, the presence of a psychiatric condition affecting emotional states or frustration tolerance would influence the motivation to exhibit a range of behaviors. This was clearly the case in Lowry and Sovner (1992) who depicted rapid cycling bipolar disorder in two individuals whose problem behaviors covaried with mood states. In one subject, SIB occurred during the depressive phase and not during manic mood. In the second case, aggression occurred during mania, but not during depressed phases. In each case, the problem behavior was a function of mood state.

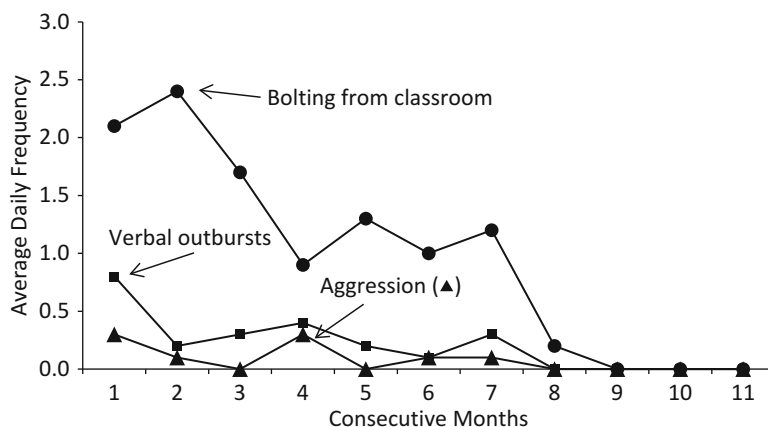


Fig. 13.3 Eleven-month behavioral data of a 12-year-old girl with mild to moderate ID and PTSD. The data depict improving trend in a setting using a behavioral formulation and intervention integrating suspected influence of

history of exposure to traumatizing events. From Ricciardi, J. N. (2011). Unpublished data: 12-year-old girl with PTSD and severe behavior disorder. Seven Hills Devens Academy, Seven Hills Clinical Associates

A case showing the interdependence of anxious mood states and functional behavior problem is depicted in the case of a 12-year-old girl with mild to moderate ID and a history of severe physical and sexual abuse and a diagnosis of post-traumatic stress disorder (PTSD) and ODD (Ricciardi, 2011) (Fig. 13.3). Details of her abuse history included being forcefully restrained by family members and witnessing her siblings harmed in a similar manner. Problem behaviors included outbursts of yelling and threatening educational staff in her school, bolting from her classroom, and physical aggression toward teachers. She was considered by referring sources as defiant, oppositional, and disinterested in school. However, observations revealed that these behaviors were most often triggered by the sight of teachers managing other students in behavioral crises, and the problem behavior effectively led to escape from the situation (bolting) and causing teachers to remain distant from her by yelling and threatening. It was reported that in previous settings attempts to block egress led to prolonged and intense aggression and that she required frequent physical restraint because of this problem. Our setting observed that physical interruption functioned as an antecedent to aggression and suspended this intervention, instead providing visual supervision only. This change appeared to reduce her aggression and while bolting was

observed to be problematic, it did not place her at risk of harm to herself or others.

The formulation was that the behavior was indeed escape motivated, as reported by others. However, the suspected eliciting event was not schoolwork demands, but stimuli associated with her trauma history. The apparent driver of the problem was anxiety conditioned to the sight of teachers physically managing other children in crisis. The intervention entailed permitting escape from the classroom, exposing the girl to the visual stimuli (observing teachers manage the crisis from a distance), and direct reassurance by teachers supervising her out of the classroom. Essentially, the combination of eliminating blocking egress but encouraging her to observe provided an exposure therapy to the putative conditioned stimuli or “exposure therapy” (Taylor et al., 2003). In this case, the presenting problem behaviors were reformulated in light of her psychiatric disorder and history, and the motivation to escape was refined from escape from schoolwork demands and the demand setting to an anxiety-mediated escape. This formulation effectively integrated the functional behavior disorder formulation with the psychiatric history and diagnosis. The intervention was designed to attenuate the MO (anxiety).

Previous settings clearly observed her reluctance to engage in schoolwork, bolting from the

classroom, hostility toward educators, and flagrant oppositionality. However, behavioral assessment noted that while she would sometimes refuse schoolwork and continued prompting might lead to bolting, the more common antecedent was other children in behavioral crises (and the concomitant staff responses to this). Direct behavioral observations contributed to a clarified diagnosis, moving from ODD in favor of PTSD in keeping with the contemporary recommendation for differentiating *oppositional behavior* associated with another condition, from true ODD (Steiner & Remsing, 2007).

Undoubtedly, persons with ID are at risk for challenging behaviors acquired through behavioral learning processes. At the same time, individuals with ID may develop a psychiatric condition. Additionally, the psychiatric condition may contribute to changes in mood states, frustration tolerance, and activity levels each of which can affect the rate of a problem behavior. It is for these interrelated reasons that psychiatric assessment of a person with ID should include a comprehensive behavioral assessment as well (Davis et al., 2008). A comprehensive psychiatric treatment plan will need to include more than psychopharmacology.

Behavioral Intervention in Psychiatric Conditions

The Compatibility of Psychiatric and Behavioral Approaches

Behavioral intervention for challenging behavior in persons with ID is an established practice with significant empirical support, though the body of evidence presently focuses more on individuals with ID and challenging behavior without reference to specific psychiatric states. However, some of the earliest research applying behavioral principles as clinical intervention was conducted with psychiatric populations. For example, Ayllon and Michael (1959) targeted problem behaviors of inpatients on a psychiatric ward; 14 individuals were diagnosed with schizophrenia, and the remaining 5 were considered “mentally defec-

tive” (the then term applied to individuals with ID). (Note that the diagnosis of mental defective at that time was sufficient without identifying a comorbid psychiatric condition, an indication of the then prevailing practice of accounting for abnormal behavior by virtue of ID alone.)

Targeted behaviors included excessive visits to see the nurse, psychotic speech, dropping to the floor, refusal to self-feed, and odd hoarding behaviors (hoarding trash, for instance). These behaviors are not surprising to clinicians with experience with persons with intellectual disability; some appear clearly similar to behavioral oddities seen in severe psychiatric states as well (e.g., hoarding trash, psychotic speech). The range of interventions predate our current terminology but essentially entailed differential reinforcement: combinations of positive reinforcement, negative reinforcement, extinction, and strategies to promote alternative or incompatible behaviors. The authors demonstrated efficacy across all cases using individual behavioral graphs. This early study is important as it establishes the utility of behavioral intervention in cases of severe psychiatric disorder.

One wonders why the emerging field of behavioral intervention eventually left psychiatric centers to focus mainly on the ID population in schools and community settings. Ayllon and Michael (1959) explained that while their results were positive, oftentimes nursing staff complained that the core psychiatric disorder remained despite behavioral improvements—that there was no “permanent cure” or that the behaviors were unlikely to change anyway, so an intervention might not be sustained even after initially promising results. The authors hinted at a difference of paradigm where the role of diagnosis and disease was favored to the point of rejecting any role of environment. The authors noted with frustration that this contributed to poor compliance with intervention procedures or dismissal of positive outcomes. Although research on behavioral intervention for primary psychiatric disorders continued for another two decades or so, the work eventually dwindled, as evidenced by publication trends over the same time period (Scotti, McMorro, & Trawitzki, 1993).

Wong (2006) argued additional reasons for the separation of behavior analysis and intervention from psychiatry noting (a) the biomedical paradigm and its emphasis on medical etiologies at the exclusion of environmental causes, (b) the burgeoning development of psychopharmacology as the principle intervention for psychiatric disorders, and (c) biases in allocation of research dollars.

Changes in the major paradigms of psychiatry occurred during the 1980s. The first major change was the introduction of the DSM-III, which shifted from diagnosis by theoretical etiology, based principally on psychoanalytic theory, toward diagnosis by directly observable symptoms and an atheoretical, descriptive approach to psychopathology (Wilson, 1993). During the same period, health insurers began requiring psychiatry to define and measure outcomes creating further pressure for objectivity (Mayes & Horwitz, 2005). Similarly, clinical psychology began its movement toward empirically supported interventions (Chambless & Ollendick, 2001), a progression that would eventually recognize decades of research of behavioral intervention for challenging behavior in persons with ID as thoroughly empirically supported (Didden, Korzilius, van Oorsouw, Sturmey, & Bodfish, 2006). The recent trend is toward identifying specified components of interventions applied in persons with ID as empirically supported. For example, Petscher, Rey, and Bailey (2009) established differential reinforcement of alternative behavior as an empirically supported intervention, primarily based on research conducted on persons with ID.

These three forces have helped to move psychiatry and behavioral intervention toward compatibility—specifically, an emphasis on descriptive psychiatry (and consequently, devaluing the theory-based approach favored pre-DSM-III), the push for objective outcomes and measurable goals, and the emphasis on empirically supported intervention. Description and measurement are, indeed, the core competencies of behavioral clinicians; the strength of the behavioral approach is its ability to operationalize a problem into directly observable and there-

fore measurable phenomena (Harvey et al., 2009). Further, both approaches favor interventions derived from the research literature with demonstrable empirical support. Finally, contemporary psychiatry and behavioral intervention share a common link in their acceptance of “determinism”—the core belief that behavior can be explained by physical events and scientific discovery. In short, these interdisciplinary factors now favor alignment toward similar therapeutic goals.

Integrated Intervention Procedures and Examples

Behavioral interventions can be applied to target core features of the psychiatric disorder, the chief complaint or “symptom,” or complicating features emerging while in treatment settings. Indeed, as Ayllon and Michael (1959) pointed out, some of the behaviors they effectively targeted may have been acquired within the institutional setting, not necessarily the expression of core psychiatric disorder.

A number of studies have described effective functional assessment and intervention for the aberrant verbal behavior seen in persons with psychotic disorders and a core feature of schizophrenia. For example, Mace and Lalli (1991) reported an effective intervention for delusional and hallucinatory speech in a man with ID. After establishing an attention function for these behaviors, they implemented extinction and non-contingent attention with positive effect and then taught the man more appropriate interactions for engaging others, also with positive results. Lancaster et al. (2004) reported a similar approach and outcome: first, a finding of social reinforcement operating on the behavior of concern in two of four cases and effective intervention when differential reinforcement procedures were applied. In a more recent study, Travis and Sturmey (2010) targeted delusional speech in a person with ID and traumatic brain injury using a differential reinforcement procedure. Improvements were immediate and sustained at 6-month and 1-, 2-, and 4-year follow-up inter-

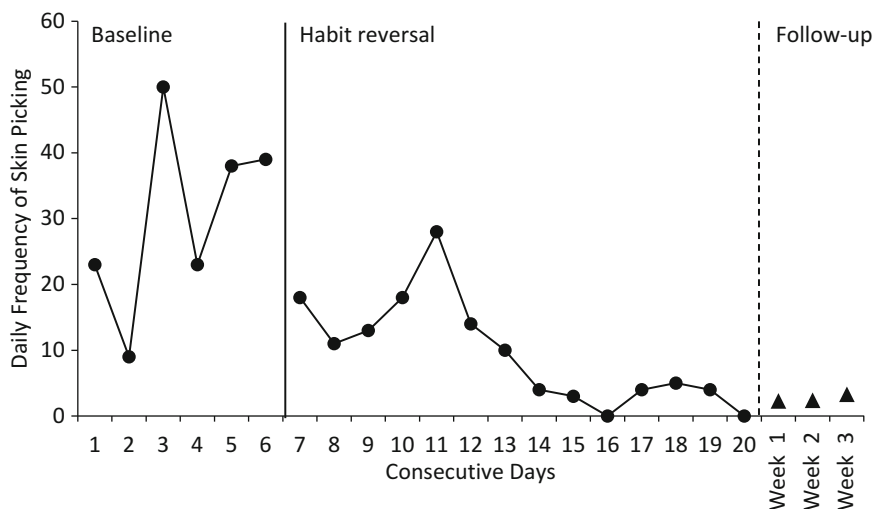


Fig. 13.4 The use of habit reversal procedure, in a 17-year-old woman with a diagnosis of mood disorder, NOS, who displayed compulsive skin picking resulting in over 17 open lesions on the surface of her body. From Ricciardi, J. N.

(2009). Integrated approaches to behavior analysis and psychiatry in children with severe psychiatric and developmental disorders. Annual conference of the California Association for Behavior Analysis, San Francisco, CA

vals. Additional studies have reported similar improvements with individuals displaying this core symptom, though not concurrent ID (e.g., Wilder et al., 2001). A review of this research area reports the effectiveness of behavioral intervention across a range of settings and clinical populations (Travis & Sturmey, 2008). These studies provide exemplars of behavioral intervention directly targeting a core feature of a psychiatric disorder in persons with ID.

Behavioral intervention may be applied to target the chief complaint or primary “symptom” of the psychiatric disorder in individuals with ID. For example, habit reversal has been shown to be effective in persons with ID in at least 16 studies (Lang et al., 2010). Figure 13.4 depicts an application in a 17-year-old woman with a diagnosis of mood disorder, NOS, who displayed compulsive skin picking resulting in over 17 open lesions on the surface of her body (Ricciardi, 2009). Behavioral intervention was implemented on an inpatient unit and consisted of “habit reversal” (Teng, Woods, & Twohig, 2001), an intervention package that combined repeated interruptions and simple correction, practice of alternative behaviors, and rewards for refraining from pick-

ing for set intervals (DRO). Significant improvements were observed in skin picking and these were sustained for several weeks, until discharge.

Others have effectively applied behavioral intervention for phobic anxiety in individuals with ID (Jennett & Hagopian, 2008). As noted previously anxiety is one of the most prevalent co-occurring conditions in individuals with ASD; one meta-analytic review reported phobia was the most commonly occurring diagnosis in children with ASD, 29.8% of their sample (van Steensel et al., 2011). It has been suggested that the typical cognitive-behavioral approaches used throughout the anxiety disorders may not be applicable in individuals with profound and severe ID and particularly when severe communication problems accompany intellectual impairment (Sturmey, 2005). However, applied behavior analysis has led to effective intervention designs for individuals with ID and avoidance (Jennett & Hagopian, 2008). For example, one report described shaping direct contact with the phobic stimulus over time in small increments, effectively eliminating all signs of phobia (distress, avoidance, and aggression) in a child with autism

(Ricciardi, Luiselli, & Camare, 2006). The procedure avoided any direct cognitive intervention in that the individual was never given direct instruction in restructuring of erroneous cognitions or any other form of talk therapy, providing an example of applicability to individuals with severe impediments to participation in traditional cognitive therapies for anxiety.

As noted previously, some individuals with psychiatric disorder may evince challenging behavior as well. The problem behavior may predate the psychiatric disorder, or it may be a complicating feature of the identified psychiatric disorder. For these individuals, behavioral intervention may be applied to target the comorbid behavior disorder. Unfortunately, the behavioral intervention literature does not often provide details on diagnoses other than the ID. Figure 13.5a, b shows two cases of preadolescents with ID who displayed outbursts of yelling and threatening others and episodes of actual aggression (Ricciardi et al., 2004). The first individual was a 12-year-old girl (Becky) with moderate ID, plus PTSD, mood disorder NOS, and fetal exposure to cocaine and alcohol. The second individual was a 13-year-old boy (Robert) with moderate ID, bipolar disorder, and early childhood exposure to domestic violence. Both individuals were inpatients on a specialty unit for children with ID and co-occurring psychiatric disorder. They exhibited verbal outbursts when denied a requested item or a preferred activity was delayed; aggression appeared following prolonged verbal outbursts and was considered a behavioral “escalation.”

Intervention targeted challenging behaviors by applying differential reinforcement of other behavior (DRO). The DRO intervention was relatively straightforward: for every 2-h interval completed without displaying the targeted behaviors, the children received a token (sticker). Upon securing five tokens, the child chose a small reward from a preselected group of preferred items such as snacks and small toys. Results, presented in Fig. 13.5a (top graph), show an immediate reductive effect of the intervention. As a result of the intervention, the use of restrictive and risk-laden interventions (i.e., as needed sedat-

ing medications, “PRN,” and locked-door seclusion, “LDS”) were reduced as well, shown in Fig. 13.5b (bottom graph). Here the value of behavioral intervention was for reduction of an associated feature—learned aggression in the context of psychiatric condition. A secondary value was that reduction in the severe behaviors naturally led to reduction in medication utilization and the use of seclusion.

Behavioral interventions are widely applied across a range of challenging behaviors occurring in adults and children with ID. Because psychiatric comorbidity may be associated with challenging behaviors, an integrated treatment plan should include behavioral strategies as well. Behavioral interventions may be applied to target specific symptoms of the disorder (such as delusional and bizarre speech), the major features of the syndrome (e.g., in the case of compulsive and repetitive behaviors or phobias), and/or for co-occurring behavior problems (as in the case of functional behavior disorders occurring in the context of a psychiatric disorder).

Additional Psychiatric Concerns in Individuals with Intellectual Disability

Suicidality

Although research on the phenomena of suicidal ideation and acts in persons with ID is sparse, the literature clearly documents that individuals with ID can display suicidality. For instance, Menaloscino, Lazer, and Stark (1989) described cases of depression complicated by suicidality in adults with ID, and Hardan and Sahl (1999) reported suicidal presentations in children and adolescents with ID. Hurley (1998) reported suicidality in two cases of adults with ID and Down syndrome. The report is valuable as a detailed description of cases and forms of presentation. Additionally, the report challenges the accuracy of the stereotyped view of people with Down syndrome as pleasant and affable individuals who could not make an actual suicidal presentation. Indeed, these individuals exhibited suicide attempts that were nearly lethal (Hurley, 1998).

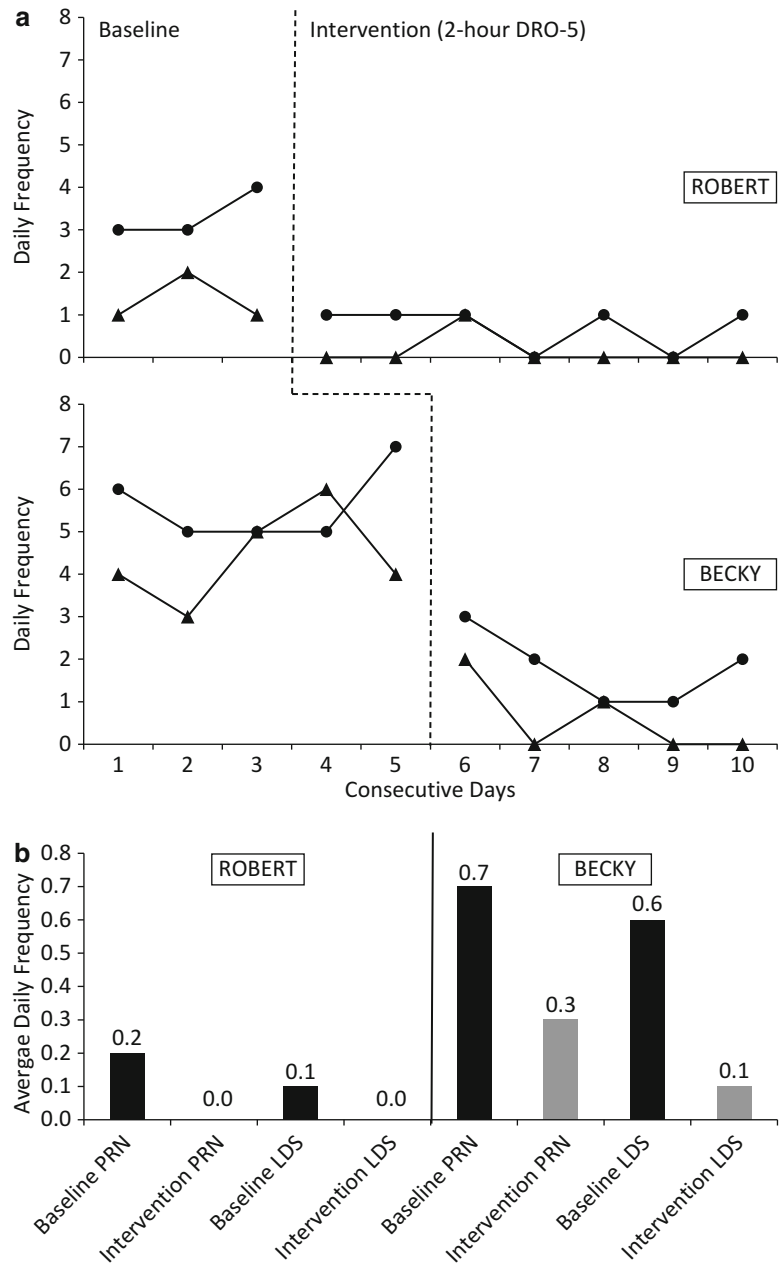


Fig. 13.5 (a) Data showing effect of differential reinforcement of other behavior (DRO) with two children with ID who displayed outbursts of yelling and threatening others and episodes of aggression on an inpatient psychiatric unit. Becky is a 12-year-old girl with moderate ID, plus PTSD, mood disorder NOS, and fetal exposure to cocaine and alcohol. Robert is a 13-year-old boy with moderate ID, bipolar disorder, and early childhood exposure to domestic violence. (b) As a result of the

intervention, the use of restrictive and risk-laden interventions (i.e., as needed sedating medications, “PRN,” and locked-door seclusion, “LDS”) were reduced as well. From Ricciardi, J. N., Brown, K., Milad, E., Saidel, M., Roberts, B., & Farren, N. (2004). Behavioral intervention for serious behavior disorders on an inpatient psychiatric unit. Annual conference of the Berkshire Association for Behavior Analysis and Therapy, Amherst, MA

Suicidality and lethal suicides have been reported in individuals with ID (Luiselli, MaGee, Graham, Sperry, & Hauser, 2008) and ASD as well (Raja, Azzoni, & Frustaci, 2011).

Suicidal presentations in persons with ID are generally similar to those by persons without ID. Walters, Barrett, Knapp, and Borden (1995) described 90 consecutive admissions to an inpatient psychiatric unit for children and adolescents with ID. The sample displayed suicidal thoughts across a continuum of severity from statements of despondence to a capable plan: for instance, "I do not want to live" to "I want to kill myself" to "I want to choke myself." Some individuals demonstrated actual attempts as well. Their presentations were safely managed in the inpatient setting. Other unusual and intense presentations have been reported: Luiselli et al. (2008) described persistent suicidal activity in a person with ID in the form of ingesting lethal substances and objects such as caustic cleaning fluids and broken glass. One case of a socially mediated suicidal presentation was reported by Sturmey (1994) who noted that the typical response to such statements (emergency evaluation and supportive responses) might have been counter therapeutic as they appeared to function as direct reinforcement of the core problem. Alternatively, a systematic approach to supervision and safety was developed which effectively competed with social reinforcement.

Lunsky (2004) conducted structured clinical interviews on 98 adults with borderline to moderate ID from community-living and human service settings. Self-reported suicidal planning was found in 11 % of individuals with methods that matched means to actualize in most cases. Participants reported planning medication overdose, self-cutting, jumping from a height, self-stabbing, and shooting self. About the same amount (11 %) had considered killing themselves, but without any method in consideration. These numbers are concerning, though the sample did include a clinic population (recipients of professionally staffed day programming). Also concerning is the report that an informant care-

giver also participating in the study was unaware of suicidal thoughts for 23 % of cases.

There may be an increased risk of suicide attempts in individuals with ID who experience suicidal thoughts. Hassiotis et al. (2011) studied a population-derived sample of persons with borderline ID and found that the total sample of individuals with ID were more likely to exhibit suicide attempts than the general population. After controlling for age and income, there were no significant differences. Thus, the exposure to economic disadvantage appeared to influence suicidal behavior more than the ID. However, lower IQ scores may, in general, affect longevity of suicidal thoughts (Gunnell, Harbord, Singleton, Jenkins, & Lewis, 2009). While the incidence of suicidal thoughts may not be affected by IQ per se, individuals with ID may experience suicidal thoughts for longer than those with IQ in the average range presumably increasing risk over time.

Individuals with ID receive supports in settings developed and supervised by educators, behavior analysts, and human service administrators not often involving psychiatrists and clinical psychologists. Professionals working with ID should be prepared to refer suspected suicidal presentations to individuals qualified to evaluate a suicidal presentation and direct measures to ensure safety if necessary. Hurley (1998) noted that while it may appear that a person with ID does not have the problem-solving and planning skills to effectuate suicide, most suicides are in fact impulsive acts requiring very little planning and cognitive sophistication. Professionals and clinical specialists without mental health training should consider suicidal presentations carefully.

In summary, suicidal presentations do occur in persons with ID, and lethal suicide has been reported (Merrick et al., 2006). Individuals with ID may be a greater risk for experiencing suicidality, including actual attempts. The particular risk factor may be economic disadvantage, rather than ID itself. However, preliminary research suggests that individuals with low IQ scores may

experience suicidal ideation that is more enduring than those with IQ closer to the average range. A qualified clinician should evaluate a suicidal presentation in a person with ID.

Post-traumatic Stress Disorder and Trauma Sequelae

PTSD can occur in individuals with ID (McCarthy, 2001) and ASD (Mehtar & Mukaddes, 2011). Notably, there is evidence that individuals with ID may experience traumatic life events more often than individuals without ID (Martorell & Tsakanikos, 2008). These events include severe and multiple separations from caregivers at an early age, sexual victimization, physical abuse, prolonged neglectful care, severe bullying, and interminable isolation. Events such as these have been implicated in the development of PTSD in typically developing individuals; thus it appears that individuals with ID are exposed to more potentially traumatizing experiences than those without ID (Martorell & Tsakanikos). In addition, there is some evidence that individuals with lower IQ (but within the normal range) are more likely to experience severe PTSD symptoms when exposed to the same potentially traumatizing events as individuals with higher IQ (McNally & Shin, 1995); one would expect the same or perhaps greater cognitive vulnerabilities to exist in persons with IQ below the normal range.

There are few treatment studies specifically focused on PTSD in individuals with ID in the clinical-scientific literature at this time, though several descriptive, case reports exist. Accordingly, clinicians should consider treatments developed for persons without ID (Mevissen & de Jongh, 2010) though modified on a case-by-case basis. A recent meta-analysis suggests that a range of cognitive-behavioral techniques and eye-movement desensitization have demonstrable efficacy in reducing severity of symptoms (Bradley, Greene, Russ, Dutra, & Westen, 2005). In fact, the current treatment literature is an extension of these interventions with appropriate modifications into the ID population (Mevissen & de Jongh, 2010).

More immediately, whenever there is a confirmed diagnosis or suspected diagnosis of PTSD in an individual with ID, the details of the trauma history should be considered when assessing challenging behavior and designing behavioral interventions. As is the case in PTSD, traumatic events may condition everyday stimuli to function as antecedents to anxious states or MOs with possible impact on overt problem behavior. This was apparently the case previously described, Fig. 13.3. In this case, conditioned stimuli appeared to be other students exhibiting behavioral crises, teachers' responses to safely manage behavioral outbursts, and attempts by educators to physically interrupt the student's own bolting. The "trauma-informed" behavioral formulation led to an avoidance of physical management and other hands-on interventions with the student and the addition of exposure techniques that appeared to be effective. The intervention decisions were achieved after incorporating an assessment of possible trauma-associated stimuli into the typical FBA.

Most settings working with individuals with PTSD vehemently oppose the use of physical restraint or, at a minimum, actively engage in work to limit and reduce utilization. While not specifying PTSD, per se, a growing body of literature suggests that restraint and seclusion can be safely reduced or eliminated in applied settings serving children and adults with severe behavior disorders and ID (Luiselli, 2009); an organization-wide reduction initiative demonstrated 80% reduction was possible in a setting serving adolescents through adults with ID and severe challenging behaviors (Williams & Grossett, 2011).

Conclusion

For several decades, researchers have determined that children, adolescents, and adults with ID suffer from co-occurring psychiatric disorders. However, accurate estimates of prevalence remain mixed, with some research supporting the common understanding that risk for a psychiatric disorder is higher in individuals with ID while some has not. Presently, child and adolescent prev-

alence studies have applied more rigorous epidemiologic methodologies and prevalence studies in this population support the idea of increased risk. These findings have been extended to both child and adults with autism and related conditions as well. Because psychopathology in children and adolescents with ID has been shown to endure into adulthood, it makes sense to expect higher prevalence in adults with ID, even with mixed findings at this time. More concerning is the finding that most individuals with ID and a co-occurring psychiatric disorder do not receive a treatment directly addressing the psychiatric condition.

Most experts recommend a multimodal approach to evaluation that includes, minimally, psychiatric, medical, and behavioral assessment across a range of disciplines (e.g., psychiatry, internal medicine, nursing, behavior analysis, clinical psychology). Assessment is a challenging process, however. Individuals with ID often present unusual expressions of psychiatric disorder and features of the developmental disability interfere with participation in clinical interview strategies. In addition, individuals with ID and suspected psychiatric disorder show significant overlap with medical problems that may be presenting as psychiatric or behavioral changes. Adding further complexity, individuals with ID show high occurrence of serious challenging behavior, which may be a learned phenomenon, unrelated to a psychiatric condition, or may manifest with greater rate or intensity due to a psychiatric condition. Differentiating this requires careful attention to history, baseline, and direct observation whenever possible. Behavior practitioners are often called upon to collaborate in this aspect of assessment.

In addition, behavioral intervention has been shown to effectively target psychiatric symptoms, core features of the disorder itself, or behavioral complications in the context of a psychiatric disorder. Ideally, behavioral and psychiatric formulations are integrated into a case conceptualization and when possible, behavioral data are used when evaluating progress and response to interventions.

Finally, because individuals with ID are often served in settings designed and supervised by

nonmedical staff, human service administrators, special educators, and direct care staff should be vigilant for detection of suicide, a psychiatric crisis that can occur in persons with ID and ASD at any age. Suicide risk should be carefully referred to a qualified clinical specialist. In addition, because individuals with ID may be exposed to traumatic events more than typically developing individuals, clinicians and settings working with children and adults with ID should be trauma-sensitive, ready to evaluate suspected PTSD and modify interventions to fit the unique needs of individuals with a history of traumatizing events.

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Involving Family in the Prevention and Intervention of Behavior Problems in Individuals with Intellectual and Developmental Disabilities

14

Laura Lee McIntyre and Mallory Brown

Individuals with intellectual and developmental disabilities (IDD) are at risk for a variety of poor outcomes, due in part to cognitive, social, and language deficits (Dosen & Day, 2001). The risk for poor outcomes in this population is heightened when there are behavior/mental health problems (McIntyre, Blacher, & Baker, 2002; Reiss, 1994). A dual diagnosis of IDD and behavior/mental health problems is common. Prevalence estimates range between 20 and 50 % (Einfeld & Tonge, 1996; Einfeld et al., 2006; Emerson, 2003; Emerson & Hatton, 2007; Nezu, Nezu, & Gill-Weiss, 1992), which is nearly three to four times that of behavior/mental health problems in individuals without IDD. The number of people with IDD and psychopathology is comparable to those with schizophrenia, making it a major public health concern (Einfeld et al., 2006). Dual diagnosis of IDD and behavior/mental health problems places individuals at dramatically increased risk for social isolation and vocational and residential difficulties (Borthwick-Duffy & Eyman, 1990). Dual diagnosis also places a significant burden on the family and caregivers who are often left to manage their child's behavior on a day-to-day basis as well as during times of crisis (Esbensen, 2011; Lunksy, Tint, Robinson, Khodaverdian, & Jaskulski, 2011; Weiss, Slusarczyk, & Lunsy, 2011).

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Parenting Stress

Not surprisingly, parents of individuals with IDD and co-occurring behavior problems report higher levels of stress, caregiving burden, and depression than parents of children with IDD only (Blacher, Shapiro, Lopez, & Diaz, 1997; Bromley & Blacher, 1991; McIntyre et al., 2002). In fact, behavior problems, more so than delays in cognitive and developmental functioning, have been linked to increased parenting stress (Baker et al., 2003). Parents of children with IDD and both internalizing and externalizing behavior problems seem to be at most risk for reporting negative impact and burden (Nachshen, Garcin, & Minnes, 2005), although less severe behavior problems, such as child demandingness, may also be associated with negative family impact (Brown, McIntyre, Crnic, Baker, & Blacher, 2011).

Parenting stress may be related to child age, with parents of children with IDD reporting more stress than parents of adults with IDD (Baker & Blacher, 2002). Stress may also fluctuate depending on developmental milestones, with the highest stress reported at the onset of adolescence and transition to young adulthood (Blacher, 2001; Wikler, 1986). Thus, parents may be negatively impacted by their son or daughter's behavior problems as well as other life stress, including developmental context, community care, and support (Baker, Blacher, Kopp, & Kraemer, 1997).

In the absence of intervention, behavior problems in children with IDD appear relatively stable over time (Einfeld et al., 2006); however, factors such as family dysfunction and parental mental health problems appear to exacerbate maladaptive behavior in children with IDD (Wallander, Dekker, & Koot, 2006). Left untreated, children's behavior problems may develop into full-fledged disorders and psychopathology (Einfeld et al., 2006; Reiss, 1994; Tonge & Einfeld, 2000) and persist into adulthood (Unwin & Deb, 2011).

Although the majority of children with IDD continue to live at home with family (Braddock, Emerson, Felce, & Stancliffe, 2001), challenging behaviors make costly out-of-home placement more likely (Bromley & Blacher, 1991; Eyman, O'Connor, Tarjan, & Justice, 1972). Severe maladaptive behavior increases parental stress, and heightened caregiver stress and burden increases the likelihood of out-of-home placement (Bromley & Blacher, 1991; McIntyre et al., 2002; Seltzer, Greenberg, Krauss, & Hong, 1997) or the need for intensive, costly crisis intervention or tertiary medical care, including visits to the emergency department (Lunksy et al., 2011; Weiss et al., 2011).

Social Support

In understanding a family's preparedness and ability to effectively manage crises, it is important to consider parent and family well-being and available supports. Parents of children with disabilities are a particularly susceptible population. It is recognized in the literature that parents of children with IDD often experience heightened levels of parenting stress as compared to parents of typically developing children (Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001). This heightened level of stress is likely to contribute to a family's skills in navigating crises and intervening effectively. As Osborne, McHugh, Saunders, and Reed (2008) suggest, high levels of stress may reduce the effectiveness of intervention with children with developmental disabilities. Thus, parent stress is an important consideration for practitioners and service providers when working with families through crisis prevention and intervention.

Implicated in the literature as one possible ameliorator of parenting stress, social support may be a relevant and amenable target of intervention when working with families (Gill & Harris, 1991). A wealth of research suggests that parent stress and social support are highly correlated, indicating that social support may serve as a buffer of parenting stress (e.g., Dyson, 1997; Sharpley, Bitsika, & Efremidis, 1997). Though the directionality of this relation is relatively unknown and likely bidirectional, enhancing the availability and usefulness of social supports may be an important objective for professionals serving families with children with disabilities as they prepare to effectively prevent and intervene during crises. Social support comes in the form of both formal and informal support. Informal supports are described as those that come from a network that may include family, friends, and parents of other children with disabilities. Formal supports are those that are often provided through an organization or agency, such as medical professionals, school staff, and day care providers (Bromley, Hare, Davison, & Emerson, 2004).

Boyd (2002) urges service providers to offer families a continuum of support services, similar to the manner in which educators provide students alternate placements; choices provide parents with the opportunity to find a support system that is best designed to meet their individual needs. Group-based education and parent training may be one effective method of increasing social support (Schilling, Gilchrist, & Schinke, 1984). Parents may need extra help to establish a meaningful network of social supports, and information delivered via lecture, discussion, modeling, and practice may help cultivate the necessary skills. Service providers may also help parents refine their communication skills, so parents are better equipped to access services, advocate for their child, manage conflict, and expand their social support repertoire. Readied with an effective support system, parents may be better able to intervene in times of crisis.

Because parents and caregivers are often in the position of managing complex medical, physical, behavioral, and mental health needs of their family member with IDD, caregivers

may require additional support from professionals. Furthermore, caregivers may function as case managers and coordinate care for their family members across multiple specialists and disciplines. Integrating family in the behavioral support needs of the individual with IDD is crucial, as caregivers are often called on to manage challenging behavioral and mental health needs. Although integrating family members in behavioral supports and crisis management is paramount, we argue that it is important to integrate family in all aspects of prevention and intervention of behavioral/mental health problems.

Family Context

Few studies have examined the underlying mechanisms of psychopathology in individuals with IDD, although evidence suggests that for children, behavioral problems either stem from or are exacerbated by negative parenting practices (Patterson, 1982; Sameroff & Fiese, 2000). Given the established link between parenting and behavior problems, parent education has been used as an intervention mechanism both for children with developmental disabilities (e.g., Baker & Brightman, 2004) and for children with behavior disorders (e.g., Webster-Stratton, 1984). Although a host of biological or genetic factors are associated with topographies of behavior problems in specific genetic syndromes (e.g., self-injury in Lesch–Nyhan syndrome, obsessive compulsive behaviors in Prader–Willi syndrome), taking an ecological-behavioral approach that targets aspects of the environment (antecedents and consequences) to increase or decrease specific behaviors is a practical and effective treatment approach (Carr & Durand, 1985; Iwata, Dorsey, Slifer, Bauman, & Richman, 1994). Given that the family context, and parenting behaviors in particular, may influence the onset and development of behavior problems, an essential ingredient in the prevention of behavioral/mental health problems in children with IDD is to work with family members to use positive parenting practices

that promote healthy outcomes and reduce the risk for developing severe or chronic behavioral disorders. A focus on family involvement may also reduce negative caregiver outcomes including parenting stress, caregiver burden, and depression.

Father Involvement

Although a burgeoning body of literature has begun to investigate the role of fathers in influencing child outcomes, fathers of children with developmental disabilities are frequently understudied in research and underrepresented in intervention. Both mothers and fathers play an essential role in child development and well-being, yet mothers are most often the primary intervention agents. The inclusion of fathers in intervention has been found to decrease the caregiving burden that is often placed upon mothers by reducing stress and, perhaps, increasing family cohesion (Tehee, Honan, & Hevey, 2009). Furthermore, Flippin and Crais (2011) also suggest that the direct involvement of the father in intervention can reduce maternal stress and, as a result, positively affect the family system. Thus, the inclusion of fathers in crisis prevention and intervention should be considered of great importance and value to the entire family.

In order to promote and support paternal involvement in prevention and behavioral intervention efforts, service providers and professionals should be sensitive to the experiences and specific needs of fathers, while allowing them to be a part of the decision-making process and acknowledging their abilities (Parette, Meadan, & Doubet, 2010). Most fathers express interest in greater involvement in supporting their children with disabilities; however, many face barriers, such as work conflicts and scheduling, which limits their ability to be involved (Hadadian & Merbler, 1995). Levine, Murphy, and Wilson (1993) advise programs and professionals to accommodate fathers' schedules as much as possible and serve families with the expectation that fathers want to be involved in the lives of their children.

Sibling Involvement

Siblings of individuals with disabilities can also play an important role in crisis prevention and intervention. Past research has documented that typically developing siblings are able to master some behavior modification skills, implement these skills with their sibling with a disability, and generalize these skills to novel environments (e.g., Cash & Evan, 1975; Schriebman, O’Niell, & Koegel, 1983). Thus, involving siblings in crisis prevention and intervention efforts may be a fruitful endeavor.

Chapter Aims

In this chapter we draw on a prevention framework and discuss integrating family in the prevention and intervention of behavior problems in individuals with IDD. We use a three-tiered model to discuss various levels of prevention and the integration of family at universal, selected, and indicated prevention across the domains of social support, stress management, assessment, and parent education and family behavioral supports.

Three-Tiered Model of Prevention

Our framework draws on the three-tiered model of disease prevention proposed by Gordon (1987) and includes universal, selected, and indicated prevention that progresses from a least intensive to most intensive treatment (e.g., McIntyre & Phaneuf, 2007; Sugai, Horner, & Gresham, 2002). See Fig. 14.1 for a depiction of the three-tiered model proposed by Walker et al. (1996) based on the conceptualization of positive behavior support and the prevention of antisocial behavior in children. The prevention framework we adopt in this chapter provides an update to the primary, secondary, and tertiary model of prevention proposed by the Commission on Chronic Illness (1957). According to Gordon’s three-tiered model of prevention, primary or universal

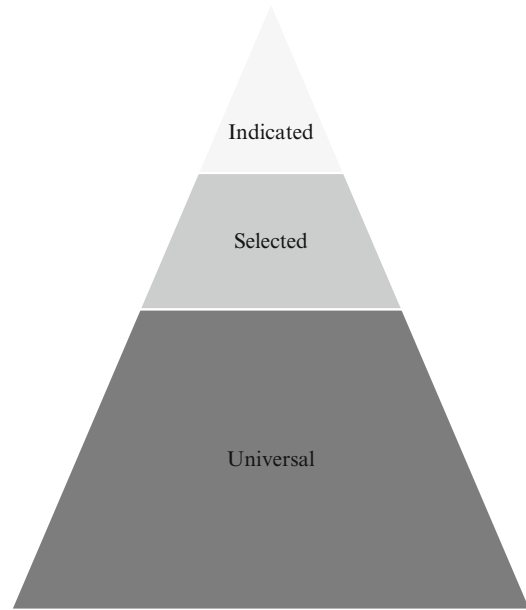


Fig. 14.1 Three-tiered model involving family in prevention

prevention is aimed at everyone in an eligible population with the goal of promoting health outcomes and preventing the onset of disease (or a specific disorder). Secondary or selected prevention is aimed at a subgroup of individuals who are at heightened risk for developing a disease or disorder. The goal of selected prevention is to reduce the onset of the disease in at-risk individuals by reducing specific risk factors associated with the disorder. In tertiary or indicated prevention, efforts are targeted at those who are experiencing symptoms of the disease or disorder with the goal of reducing symptom severity or chronicity (Gordon, 1987).

In the sections below, we describe the application of a three-tiered model to involving family in the prevention and intervention of behavior problems in individuals with IDD.

Universal Prevention

In universal prevention, all individuals in an eligible population are the target of prevention efforts. Thus, all families with children with

IDD would be included in universal prevention efforts. The goal of universal prevention efforts is to promote positive health outcomes. Given the stress and burden often associated with parenting a child with IDD, positive health outcomes in both caregivers and their children are recommended as prevention targets. Table 14.1 describes a number of strategies for use at the universal, selected, and indicated levels of prevention across the domains of social support, stress management, assessment, and parent education/family behavioral supports.

Social Support

At the universal prevention level it is critical to work with families to identify networks of social support that they can draw on to receive emotional support and encouragement. This type of informal social support has been linked to reductions in stress and depression and linked to optimism and hardiness in parents of children with disabilities (e.g., Altieri & von Kluge, 2009; Gill & Harris, 1991; Konstantareas & Homatidis, 1989). Such social support may come in the form of family members, friends, or parents of children with IDD. Because raising a child with a disability may be all consuming and isolating, likely detracting from developing and fostering healthy social support networks, attention to identifying and cultivating meaningful social supports becomes crucial. Thus, being proactive in identifying a social support network (in the absence of major child behavioral challenges) may be an especially relevant preventive activity for families. With respect to formal social support, it may be useful for professionals to work with families in identifying resources available in the community that provide specialized care and support to children with IDD and their families. Proactively identifying available specialty care and services, in the absence of crisis or severe behavior problems, may be helpful in the systematic prevention of family and child behavioral/mental health crises.

Stress Management

Given the link between parenting a child with IDD and increased parenting stress, prevention at the universal level could involve strategies for minimizing daily stress, including identifying the source of the stressor, managing time and commitments, practicing self-care, engaging in meditation and relaxation, and adopting healthy lifestyle and positive coping strategies (Claar & Blumental, 2003). Practicing healthy lifestyle behaviors, such as eating a balanced diet, engaging in regular exercise, and getting adequate sleep, may aid in general stress reduction (Mulder, de Bruin, Schreurs, van Ameijden, & van Woerkum, 2011). Practicing stress management and self-care, in the absence of behavioral/mental health crises, may aid families in their ability to manage stressful life events and work effectively with professionals in intervention and crisis management.

Assessment

At the universal level, we suggest that all children be routinely screened for developmental and behavioral functioning. Such screening and developmental surveillance could occur within the context of specialty care (including developmental pediatric visits) or occur within the context of primary care (e.g., through well-child visits or through annual educational evaluations). The rationale for routine developmental and behavioral screening and surveillance is to identify children who may be at risk for the onset of behavioral problems. Such universal screening, similar to universal screenings conducted in educational settings, can inform professionals and family members about the behavioral support needs of children with IDD.

Parent Education and Family Behavioral Supports

Not all young children with developmental disabilities experience behavior problems; however,

Table 14.1 Strategies for involving family in prevention and intervention of behavior problems in individuals with IDD

	Universal	Selected	Indicated
Informal social support	Identify network of family and friends to provide emotional support and encouragement	Identify network of family and friends to provide emotional support, encouragement, and instrumental support	Regularly utilize network of family and friends for emotional and instrumental support
Formal social support	Identify formal resources available in the community	Use of formal supports, including disability-specific services and specialty care	Use of formal supports, including disability-specific services and specialty care
Stress management	Practice self-care and healthy lifestyle	Practice self-care and healthy lifestyle	Practice self-care and healthy lifestyle, engage in individual or family counseling specifically targeting stress management
Assessment	Developmental and behavioral screening, surveillance, and monitoring	Use behavior-specific assessments (e.g., direct observations, rating scales)	Use functional behavioral assessments or experimental functional analyses developed to inform behavioral treatment
Parent education/family behavioral supports	Widely available materials aimed at promoting positive parenting practices and behavior management	Group-based parent management training	Individual behavioral therapy involving parent-child dyad, individualized video feedback, individualized behavior support plan

programs that support parents in positive parenting practices may help mitigate risk for developing future problems. Parent education programs that are integrated into children's education programs may provide seamless child and family supports in an ecologically valid context that supports both child and family functioning (McIntyre & Phaneuf, 2007). Varying levels of parent education intensity could be provided depending on the strengths, needs, values, and desires of the family (Trivette & Dunst, 2005).

At the universal prevention level we recommend that all families with children with IDD have access to materials designed to promote positive parenting practices, including the use of developmentally appropriate play to support child development, the use of praise and rewards to encourage adaptive behavior, and the use of effective limit setting to reduce behavioral challenges. Our previous work using a three-tiered model of parent education (see McIntyre & Phaneuf, 2007; Phaneuf & McIntyre, 2011) uses reading and audio materials from Webster-Stratton's evidence-based parent training program, *The Incredible Years Parent Training* series (Webster-Stratton, 2001), to promote positive parent-child relationships, positive family climates, and positive behavioral strategies to promote healthy child adjustment. Other evidence-based parent education materials may be used at the universal level, with the understanding that universal supports are used with all families with children with IDD, not just with those experiencing challenges.

Selected Prevention

Subgroups of individuals who are at heightened risk for developing a disease or disorder are the targets of selected prevention. The goal of selected prevention is to reduce the onset of the disease in at-risk individuals by reducing specific risk factors associated with the disorder. Thus, individuals with IDD exhibiting behavioral or mental health concerns are considered at risk for developing a dual diagnosis and are the targets of selected prevention. Family members

of individuals at risk for dual diagnosis may have more significant support needs and will likely be increasingly called upon to manage their child's behavior problems, serve as a liaison across professionals in various disciplines, and engage in family-based behavioral supports. Table 14.1 describes various selected prevention activities in the domains of social support, stress management, assessment, and parent education and family supports.

Social Support

The social support needs of family members at the selected prevention level are similar to the social support needs of family members at the universal level. That is, family members will benefit from identifying a network of support to provide emotional support and encouragement. In addition, identifying sources of instrumental support may become increasingly more important for families experiencing additional risk factors. Instrumental support involves help and assistance with tasks (e.g., providing childcare, cooking meals, running errands) to help the individual cope with a particular stressor (Semmer et al., 2008). Such support can come from an informal network of family or friends or may be provided by formal sources, including disability-specific agencies and services (e.g., respite care). Professionals working with families at the selected prevention level are encouraged to be proactive about helping families identify supports that fill specific areas of need and family priorities.

Stress Management

Studies suggest that behavior problems, more so than cognitive or developmental delays, are associated with parenting stress (e.g., Baker et al., 2003). Thus, caregivers with family members with IDD and behavioral concerns are likely experiencing the additional burden of managing challenging behaviors in addition to the day-to-day needs of their child. Stress management at the selected prevention level is designed to reduce

the collateral risks associated with caring for a high-risk child with IDD. Although the stress management strategies of practicing self-care, health behaviors, relaxation, and healthy lifestyle habits are virtually identical to the health-promoting strategies discussed at the universal prevention level, stress management strategies take on new urgency at the selected prevention level. Some evidence suggests that home-based interventions are less effective for children when their caregivers experience heightened stress (Osborne et al., 2008). Thus, at-risk children and caregivers are presented with a “double whammy” if caregivers are not able to manage the deleterious effects of stress. Professionals who are sensitive to these additional parenting demands experienced by family may be better positioned to support the child within the family context.

Assessment

Unlike universal assessment procedures that involve screening and surveillance, we suggest that assessment at the selected prevention level involve more narrowly focused assessments, including assessment of specific child behavioral and family concerns. Ideally assessments of specific behavioral concerns would incorporate multiple assessment methods (e.g., rating scales, direct observations), using multiple informants (e.g., parent, teacher), across multiple contexts (e.g., community, home, school). Such multi-method, multi-informant, multi-setting assessments are considered best practice to determine the nature and scope of the concern (Merrell, 2008). At the selected prevention level, family member and caregiver concerns should also be included in the assessment, paying particular attention to family priorities and goals (Trivette & Dunst, 2005; Turnbull & Turnbull, 2000).

Parent Education and Family Behavioral Supports

Group-based behavioral parent training programs may be especially useful for children with

emerging behavior problems and for families experiencing significant psychosocial risk. Rather than use one-on-one individualized and intensive therapy, we recommend group-based approaches at the selected prevention level. Group-based interventions cost less than individual psychotherapy and have similar therapeutic benefits (Webster-Stratton, 1984, 1992, 1994). In addition, group training provides a natural source of social support for participants (Dumas & Wahler, 1983). Thus, for children and families at risk for problems, group-based parent training, education, and support may be both cost-efficient and effective (McIntyre & Phaneuf, 2007; Phaneuf & McIntyre, 2011).

Hundreds of studies have been conducted demonstrating the effectiveness of parent training in treating a variety of child behavior problems (see reviews: Barlow & Stewart-Brown, 2000; Kazdin, 1997; Lundahl, Risser, & Lovejoy, 2006; McMahon, 1999; Reyno & McGrath, 2006; Sampers, Anderson, Hartung, & Scambler, 2001; Webster-Stratton & Taylor, 2001). Parent training is grounded in basic and applied concepts of operant theory and behaviorism (Holland & Skinner, 1961) as well as the principles of social learning theory (Bandura, 1977). By reducing parents' ineffective parenting techniques and increasing positive skills, parent training aims to decrease negative parent-child interactions and, in turn, increase positive interactions. Parents are prime candidates to be their child's primary change agents due to the many dyadic interactions that occur across multiple environments. In these dyadic exchanges, parents set the standards, roles, expectations, and demands for their children, allowing for multiple opportunities to respond, reinforce, and promote children's positive behaviors (Wierson & Forehand, 1994). Given parents' extensive involvement within their children's social environments, parent training programs are a highly beneficial approach for parents of young children allowing for professionals to intervene during a time when the children are still young and negative family interactions are malleable (Patterson, DeBaryshe, & Ramsey, 1989). Parents become part of the intervention

process and are thus empowered to partner with professionals in support of their children's behavioral adjustment.

There are several group-based parent training, education, and support programs appropriate for at-risk families with children with IDD at the selected prevention level. For example, the well-known evidence-based The Incredible Years Parent Training (Webster-Stratton, 2001) program has been modified to include adaptations for caregivers of young children with developmental disabilities (IYPT-DD; McIntyre, 2008a, 2008b). Other programs have emerged out of the parent management training literature (Hudson et al., 2003) and are based on the principles of social learning theory, operant theory, and parent-professional collaborations to enhance positive child and family outcomes.

Indicated Prevention

Families need more intensive, individualized support at the indicated prevention level. Children and families may be experiencing crisis or have pervasive support needs across multiple settings. Table 14.1 highlights strategies for involving family in various intervention activities in the domains of social support, stress management, assessment, and parent education and family behavioral supports.

Social Support

Formal and informal sources of support may be especially helpful to families who are facing significant psychosocial stressors and children with dual cognitive and behavioral problems. In indicated prevention, families will benefit from regular use of formal supports, including disability-specific services and specialty care. Such services may include respite, short-term residential services, intensive treatment programs, access to wrap-around programs serving children with complex support needs, and home-based residential habilitation services. Eligibility through state-funded developmental disability

services agencies may be a prerequisite for accessing this care. Thus, available services and supports (and eligibility for such services) should be investigated prior to crisis and indicated preventive care. Professionals supporting individuals requiring intensive support services will do well to collaborate with families and identify immediate needs and priorities.

Stress Management

Although a major focus of family-based treatment has been on management strategies targeting the child with challenging behaviors, typical parent management training programs may not be sufficient to address caregivers' mental health needs at the indicated prevention level. Thus, seeking individual or family counseling to target the reduction of psychological distress may be important for a subgroup of families experiencing significant distress. Evidence-based approaches, such as cognitive behavioral therapy, may be beneficial in addressing parenting stress in parents of children with disabilities (Hastings & Beck, 2004). Furthermore, burgeoning evidence suggests that parent training programs that include multiple component interventions addressing both parent well-being and child behavior management are more effective than programs that emphasize behavioral parent training or parental cognitive behavioral therapy in isolation (Singer, Ethridge, & Aldana, 2007).

Assessment

At the indicated prevention level, comprehensive behavioral assessments involving descriptive and experimental functional assessments should be used to inform intervention development. Evidence suggests that interventions may be more effective if based on functional assessments of behavior (e.g., Ingram, Lewis-Palmer, & Sugai, 2005). Given that functional assessments may be costly and time-consuming, we suggest using them at the indicated prevention level when more comprehensive information about environment

by behavior interactions may be informative. Functional assessments move beyond assessing behavioral topography and are used to determine the function or purpose a behavior serves for that individual. Based on Thorndike's Law of Effect, behaviors that result in satisfying outcomes are more likely to occur and behaviors that produce discomforting effects are less likely to occur (Herrnstein, 1970). Carr (1994) states that problem behaviors are generally conceptualized as being maintained, or reinforced, by attention, escape, sensory reinforcement, or tangible factors. Thus, determining behavioral function allows parents and professionals to identify why a particular challenging behavior continues to occur and provides valuable information for addressing behavioral function in an intervention plan. If, for example, a problem behavior is determined through the use of an experimental functional analysis (e.g., Iwata et al., 1994) to be reinforced by parent attention, professionals can work with parents to provide attention in the absence of the problem behavior and withhold their attention contingent on the occurrence of problem behavior. Readers are referred to Chaps. 8 and 9 of this handbook for more detailed information about functional assessment and analysis.

Parent Education and Family Behavioral Supports

The majority of parent training, education, and family behavioral support programs have been evaluated at the indicated prevention level, given the individualized parent-child supports and one-on-one nature of therapy. For example, the Positive Parenting Program (Triple P; Sanders, 1999) has been adapted for use with parents of children with DD (Plant & Sanders, 2007; Roberts, Mazzucchelli, Studman, & Sanders, 2006) and applied using home visits and one-on-one visits with therapists in support of parents and their children. Parent-Child Interaction Therapy (PCIT) has also been tested with parents of children with disruptive behavior and intellectual disability with promising effects on

child behavior and parenting practices (Bagner & Eyberg, 2007). Several other programs have targeted families with older children and behavior problems (e.g., Feldman & Werner, 2002), children with specific diagnoses such as autism (e.g., RUPP Research Units on Pediatric Psychopharmacology [RUPP] Autism Network, 2007; Tonge et al., 2006), or children with diagnosed severe behavior disorders (e.g., Chadwick, Momciloric, Rossiter, Stumbles, & Taylor, 2001). In the applied behavior analysis literature, parent training procedures have used single case experimental methodology and have emphasized individualized parent training approaches that incorporate technology such as functional analysis (e.g., Lerman, Swiezy, Perkins-Parks, & Roane, 2000). These approaches are especially useful for children and adults with IDD exhibiting severe behavior disorders. Parents have been taught to implement behavior support plans with their sons or daughters (Lucyshyn, Albin, & Nixon, 1997; Lucyshyn, Dunlap, & Albin, 2002; Sanders & Glynn, 1981) and have been trained to implement specific treatment protocols (e.g., Adubato, Adams, & Budd, 1981; Bagner & Eyberg, 2007; Mueller et al., 2003; Phaneuf & McIntyre, 2007; Werle, Murphy, & Budd, 1993). Involving parents and other family members in the tertiary/indicated treatment of the individual with IDD involves training, support, ongoing progress monitoring, and supervision of treatment plan implementation if plans are to be implemented with fidelity (e.g., McIntyre, Gresham, DiGennaro, & Reed, 2007; Mueller et al., 2003).

Summary

Including family in prevention and intervention of behavior problems in individuals with IDD involves a series of integrated steps that increase in intensity depending on family needs, priorities, and goals. For the family with relatively few risk factors, careful proactive planning that includes consideration of family supports, stress management needs, and assessment and child and family treatment may be all that is necessary

to promote positive outcomes. For the family with significantly more risk factors raising a child with chronic, intense, or pervasive behavioral support needs, wrap-around services that include community supports, functional behavioral assessments used to inform intervention, and child and family therapy become ever important. Professionals working to support and involve families in the prevention and treatment of child behavior problems are urged to pay special attention to family needs and priorities and draw on multiple preventive strategies to assist families in achieving positive outcomes. All family members participating in the care of the individual with IDD, including mothers, fathers, siblings, and other relatives, can be included as potential partners for family-based services and supports.

Acknowledgements Preparation of this chapter was supported in part by grant R01HD059838 from the National Institute of Child Health and Human Development awarded to the first author.

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Part III

Navigating the Continuum of Care

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Introduction

Crisis situations can arise in any human service program, and these situations raise critical legal and ethical concerns. Crisis situations require immediate intervention to protect consumers, staff, and those around them. Staff and parents or guardians often respond using ad hoc procedures that violate consumers' rights and may risk liability being imposed on staff and programs, while parents or guardians may run the risk of being charged with abuse or neglect. It is important to address legal and ethical issues to ensure that caretakers use appropriate procedures that do not violate consumers' rights and are legally safe and ethically humane. Appropriate evidence-based interventions should be used that are grounded in the professional literature and prevent more restrictive procedures and placements while concurrently protecting staff, programs, parents, and guardians from the imposition of legal liability.

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Outlined below are legal issues that should be considered in the operation of any program. Recommendations are included to help ensure that programs operate in a legally safe and ethically humane manner.

Constitutional Rights

For many years, there were no legal rights for people with developmental disabilities. In the 1970s, courts began to recognize that individuals with developmental disabilities had legal rights and were in particular need of protection; legislatures soon followed.

One of the first and most important cases to establish the basic constitutional rights of individuals with disabilities in institutions was *Youngberg v. Romeo*, 457 U.S. 307 (1982). In *Youngberg*, the United States Supreme Court first confronted the substantive liberty rights of individuals with disabilities in institutions and the standard for judging whether the state adequately protected the rights of these individuals. While this case applies only to the deprivation of constitutional rights by officials of public, not private, facilities, the decision is an important indicator of how courts view the rights of the developmentally disabled in institutions. In addition, the reasoning of the Court in *Youngberg* has been extended by some courts to apply to individuals who are involuntarily committed by the state and

placed in private facilities. See *Yvonne L. v. New Mexico Department of Human Services*, 959 F.2d 883, 892 (10th Cir. 1992). Courts, however, have declined to extend these substantive liberty interests to individuals voluntarily residing in private care facilities. *Hanson v. Clarke County, Iowa*, 867 F.2d 1115, 1120 (8th Cir. 1989); *Phillips v. Thompson*, 715 F.2d 365, 367 (7th Cir. 1983).

In *Youngberg*, the mother of an individual with profound mental retardation who was involuntarily committed to a Pennsylvania state institution filed a civil rights lawsuit against institution officials for failure to provide her son, Nicholas Romeo, with constitutional rights such as “safe conditions of confinement, freedom from bodily restraint, and training or ‘habilitation.’” Prompted by concern that her son had suffered injuries on at least 63 occasions from his own violence and from the reactions of other residents to his violence, Romeo’s mother brought suit alleging violations of her son’s Eighth and Fourteenth Amendment rights based on institution officials’ failure to take appropriate preventative measures.

The case was eventually appealed to the United States Supreme Court to determine whether the standard applied to state officials entrusted with the care of individuals with developmental disabilities was the lenient “deliberate indifference” standard applicable to prison officials or the “compelling and substantial” standard embraced by the majority of the Court at the time. Choosing a middle ground, the Court adopted the “professional judgment” standard that requires courts to consider whether the official charged with caring for the developmentally disabled individual exercised professional judgment in making his or her decision. The Court also held that an individual involuntarily committed to a state institution for the developmentally disabled did not lose all substantive liberty interests under the Fourteenth Amendment of the Constitution. Specifically, the Court held that involuntarily committed individuals have constitutionally protected liberty interests under the due process clause of the Fourteenth Amendment to “reasonably safe conditions of confinement, freedom from unreasonable bodily

restraint, and such minimally adequate training as reasonably might be required by these interests.” In determining what is “reasonable,” the judgment exercised by a qualified professional is presumptively valid, and courts accordingly show substantial deference. See, e.g., *United States v. Arkansas*, 794 F. Supp. 2d 935 (E.D. Ark. 2011).

In 1990, the United States Court of Appeals for the Third Circuit interpreted the Supreme Court’s decision in *Youngberg*, finding that the *Youngberg* “professional judgment” standard did not apply to every individual charged with caring for developmentally disabled institutionalized individuals. *Shaw by Strain v. Strackhouse*, 920 F.2d 1135 (3d Cir. 1990). Rather, as the Third Circuit noted, the Supreme Court standard applied only to “professional decision-makers,” defined as: “person[s] competent, whether by education, training or experience, to make the particular decision at issue.” The Supreme Court later elaborated that “long-term treatment decisions normally should be made by persons with degrees in medicine or nursing, or with appropriate training in areas such as psychology, physical therapy, or the care and training of the retarded,” while “day-to-day decisions regarding care—including decisions that must be made without delay—necessarily will be made in many instances by employees without formal training but who are subject to the supervision of qualified persons.” *Youngberg*, 457 U.S. at 323 n. 30. Nonprofessional employees who provide care for involuntarily institutionalized individuals with developmental disabilities are subject only to a deliberate indifference standard. *Strackhouse*, 920 F.2d 1135.

Basic Rights

In addition to considering the constitutional rights of individuals with disabilities, courts and legislatures addressed the provision of basic rights for people with developmental disabilities. Basic rights are the minimum items, activities, and conditions that must be provided when offering services to people with disabilities. Basic rights include such things as nutritionally adequate meals, appropriate bedding and sleeping facilities,

physical activity both indoors and outdoors, clothing and personal belongings, access to personal closets and lockers, appropriate toilet and shower facilities, sending and receipt of mail, religious worship, engaging in activities with members of the opposite sex, visitation and telephone communications, and access to recreational activities (Sheldon, 1987).

A presumption exists that people should have access to these basic minimum rights and staff should not be allowed to deprive individuals of these rights. That is not to say that restrictions can never be imposed. However, generally staff should provide these rights non-contingently, without restrictions. If staff propose to place restrictions on any of these rights, staff must justify why the restriction is programmatically justified and why no less restrictive procedure can be used. Thus, a restriction should only occur after documentation of a problem and a determination of the least intrusive way to remedy it. Additionally, a committee established to protect legal rights (e.g., a Human Rights Committee) should review the proposed restriction, and any restriction should be implemented for the shortest period of time practicable (Sheldon, 1987).

Administrative and program staff should ensure that individuals' basic rights are provided. If there is a good programmatic reason for employing some restriction on a basic right, program staff should ask for approval from the person's guardian and also from the program's Human Rights Committee (see below). Additionally, staff should show that the professional literature indicates that the proposed program should be successful and should explain what protections will be in place to ensure that basic rights will be provided. Periodic review should take place to ensure that the person is being successfully treated and that there is not an unnecessary restriction of basic rights.

Staff Treatment of Individuals

The way that staff treat the consumers with whom they work is critically important. All individuals should be treated with dignity and respect, as

individuals who are capable of learning and making a difference in the world. Case law as well as statutory law and regulations prohibit certain staff behavior when working with dependent populations. For example, law prohibits mistreatment, abuse, and neglect. This includes prohibiting staff from using physical, verbal, sexual, emotional, or psychological abuse or punishment. Staff who yell at consumers, use demeaning language, or physically hit or throw objects at consumers can be held liable. Additionally, staff cannot withhold food, hydration, treatment, goods, or services necessary for the health and well-being of the people served. These laws are particularly important for people with developmental disabilities because as a dependent population often isolated from external oversight, they are more vulnerable to abuse and neglect. Courts are especially protective of people's finances and explicitly prohibit any type of financial exploitation. Thus, staff must ensure that they keep accurate records of all consumer expenditures. Finally, programs serving dependent populations are not allowed to hire individuals who have a history of child or client abuse, and any allegation of abuse must be promptly investigated.

One of the main sources for protecting the rights of individuals with developmental disabilities from abuse and neglect is the Developmental Disabilities Assistance and Bill of Rights Act (DDA). Originally authorized in 1963 and last reauthorized in 2000, the DDA seeks to "ensure the humane care, treatment, habilitation and protection of mentally retarded and other persons with developmental disabilities." Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. §§ 15001 et seq. In 1975, after discovering the inhumane conditions of New York's Willowbrook State School for persons with developmental disabilities, Congress reauthorized the DDA, allocating funding to create Protection and Advocacy Systems to protect the legal rights of individuals with developmental disabilities within each state. Pursuant to the DDA, a state cannot receive federal funds for services to persons with developmental disabilities unless it has established a protection and advocacy system within the state "to protect and advocate the rights of

persons with developmental disabilities.” Developmental Disabilities Assistance and Bill of Rights Act, § 141(a)(2)(I), as amended, 42 U.S.C. § 6042(a).

In interpreting the DDA, courts have been willing to read the state’s powers broadly to protect the rights of individuals with developmental disabilities. In 1996, for example, the United States Court of Appeals for the Eleventh Circuit considered whether the Act imposed special requirements upon a protection and advocacy system regarding the source of complaints that would warrant an investigation of a facility providing services to individuals with developmental disabilities. The court held that there were no such requirements. In fact, the court found that even an anonymous telephone call to the protection and advocacy system alleging abuse and neglect in the death of two residents of a facility for individuals with developmental disabilities constituted a “complaint” under the Act and thus warranted an investigation. *Alabama Disabilities Advocacy Program v. J.S. Tarwater Developmental Center*, 97 F.3d 492 (11th Cir. 1996).

Other courts have similarly interpreted the state’s power to investigate abuse broadly, finding that the state’s role is first to protect individual rights and second to oversee the functioning of institutions and facilities. In *Disability Rights Washington v. Penrith Farms*, for example, the Eastern District of Washington made it clear that the state’s power to investigate reports of abuse is not solely limited to instances of abuse in institutions or facilities for the developmentally disabled. *Disability Rights Washington v. Penrith Farms*, No. CV-09-024-JLQ, 2009 WL 777737 (E.D. Wa. Mar. 20, 2009). Quoting the DDA, the court noted that states shall have the “authority to investigate incidents of abuse and neglect of individuals with developmental disabilities if the incidents are reported to the system or if there is probable cause to believe that the incidents occurred....” Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. § 15043(a)(2)(B). The court went on to note that “[t]here is no limitation placed on where these investigations take place; rather the investigatory power is couched in terms of protection of individual rights in any context.” Thus, the state

is empowered to investigate allegations of abuse even within a home that is “clearly not a mental health institution or provider of therapeutic or psychiatric services or even a facility of any form or fashion.”

In ensuring proper staff treatment of individuals with developmental disabilities, programs should monitor hiring to guarantee that no staff member has a history of abuse or neglect. Administrators should conduct periodic visits of each program to observe how staff are interacting with clients and should encourage staff to report any suspected verbal or physical abuse. Often, when working with persons with severe disabilities, the individuals themselves are unable to talk and, therefore, are unable to report abuse. Thus, it is imperative that all staff are vigilant about protecting against and reporting abuse. Administrators should develop a culture of protectiveness, and staff, parents, guardians, and visitors to the program should be encouraged to report any behavior that seems demeaning or abusive.

Restrictive Procedures

Of particular concern is the use of any type of restrictive procedure to control client behavior. There are numerous cases where staff have placed individuals in secluded rooms, physically restrained consumers, or used psychotropic medication to control inappropriate behavior. Courts and legislatures have placed legal limits on the use of these procedures. These restrictions are briefly discussed below.

One common procedure used to decelerate behavior is time-out. Unfortunately, staff have misused time-out and turned it into a potentially dangerous procedure. For example, staff have locked consumers in their rooms for several hours without supervision. In some cases, consumers have harmed themselves, even committing suicide. Often, the courts have referred to this procedure as seclusion and have prohibited its use. Although therapeutic time-out is allowed, staff must follow certain guidelines to ensure that it is properly implemented. Therapeutic time-out must be part of a written treatment program that specifies the behavior that could result in the use

of time-out. The program must also specify that individuals placed in time-out must be in an unlocked room with constant visual supervision, and staff must protect individuals from any hazardous conditions, for example, lamp cords or glass that could be broken. Additionally, time-out should be time-limited, with most regulations requiring that the time-out be under 1 hr in length. Normally, this amount of time-out is not necessary, and a shorter period of time-out will be equally effective. Staff must keep a record of the use of any time-out, and these records should be periodically reviewed to ensure that all safeguards are implemented.

Another procedure that is frequently used to control inappropriate behavior is the use of physical restraint—either a staff member physically restraining a person with his or her arms or using a mechanical or cloth device (such as a strait-jacket) to restrain the individual. In numerous cases, staff have injured, and even killed, people when using physical restraint. Physical restraint should not be used on an ad hoc basis but rather should be an integral part of a treatment plan. Additionally, only staff who have been trained and certified in the use of legally recognized physical intervention programs (e.g., Mandt) should be allowed to use any form of physical intervention. These procedures should ensure proper physical restraint without injury. Staff should also record any use of physical intervention, and these records should be reviewed by program administrators. For more information, see Chap. 7 of this volume.

Case law suggests that physical restraints can be appropriate when they do not preclude the individual from all forms of movement. In *Shaw by Strain v. Strackhouse*, Ricky Shaw, a man with profound mental retardation who resided at the state mental institution in Embreeville, Pennsylvania brought an action for damages pursuant to 42 U.S.C. § 1983 alleging that 24 employees of Embreeville had deprived him of his “constitutionally protected rights to freedom from unreasonable bodily restraint and to safe conditions of confinement.” One of Shaw’s three claims was that he was unconstitutionally restrained when a seatbelt was wrapped around his legs to secure him to his wheelchair.

Citing similarities to the *Youngberg* case before the Supreme Court in 1982, the Third Circuit in *Shaw* determined that the legal standard applicable to bodily restraint is that it is unconstitutional “except when and to the extent professional judgment deems this necessary to assure . . . safety or to provide needed training.” Although this is a very broad definition of the type of permissible bodily restraint, the court provided further direction in holding that a seatbelt, tied around Shaw’s legs making movement “difficult” yet not impossible, was not enough to trigger Shaw’s due process protection under the Constitution. Shaw argued that the court erred in failing to consider expert testimony that the practice of wrapping a seatbelt around an individual’s legs is inconsistent with the exercise of professional judgment. However, the court disregarded these opinions, finding that they were predicated on the assumption that the seatbelt prevented Shaw from leaving his wheelchair entirely rather than merely imposing a degree of difficulty on his ability to do so. *Strackhouse*, 920 F.2d 1135 (3d Cir. 1990).

Whether private institutions can be held liable for violations of an individual’s rights under 42 U.S.C. § 1983 is less clear. Some cases have found that private corporations can be liable for constitutional violations because, as required by 42 U.S.C. § 1983, they act under color of state law “[w]here the state chooses to delegate these responsibilities, and an institution or other private entity chooses to assume them.” However, this is the minority opinion among courts. See, e.g., *Fialkowski v. Greenwich Home for Children, Inc.*, 683 F. Supp. 103 (E.D. Penn. 1987). Nonetheless, a civil suit can always be brought against a private facility alleging harm to an individual, even if there is not an infringement of a constitutional right.

Chemical intervention (e.g., psychotropic medication) commonly has been used to control inappropriate behavior. Courts first addressed this issue with people with mental illness, but the use of psychotropic medication has been widespread with individuals with disabilities as well. Any use of medication must be prescribed by a physician and should specifically address the

particular behavior to be decreased. Medication must be part of a treatment plan and cannot be used in a dose that interferes with daily activities. The benefit of any medication must outweigh any potential side effects. In addition, staff must take data on the frequency of occurrence and severity of the behaviors for which the medication is prescribed. The administration of the medication must be monitored as well as the behavior. Most regulations require that the medication be withdrawn annually unless clinically contraindicated.

Another restrictive procedure that has been used is the application of painful or noxious stimuli. For example, staff spray lemon juice in people's faces, shine bright lights in their eyes, and expose them to loud noises and electric shock contingent on inappropriate behavior. These procedures have received judicial scrutiny and usually cannot be utilized without prior court approval. Even then, some aversive restrictive procedures are barred entirely by statute. In some states, such as Illinois, electric shock treatment as an intervention in a behavioral support plan is explicitly prohibited by statute. Mental Health and Developmental Disabilities Administrative Act, 20 ILCS 1705/15(f). As with other restrictive or aversive procedures, staff must maintain data on the use of these procedures and the occurrence of the behavior that they are designed to decrease.

Courts are likely to uphold legislative restrictions on the use of aversive procedures. In 2009, a mother brought suit on behalf of her son Bradley, a 48-year-old man with autism and intellectual disability, challenging an Illinois statute that barred the use of electric shock treatment for individuals with developmental disabilities and seeking an injunction to require the defendant to use contingent electric shock (CES) therapy to treat her son. The procedural history of the case dated back almost 25 years prior to the initiation of the 2009 lawsuit, when the parties entered into a consent agreement whereby the institution agreed to provide CES as a treatment option for Bradley. As part of the consent decree, the parties noted that CES was "necessary to insure Bradley's right to adequate and humane care in the 'least

restrictive environment'" and that any plan that did not include CES would "either fail to deter Bradley's self injurious behavior or so severely restrict Bradley's activities so as to impair his communicative skills, learning abilities and interaction with his environment." In 2006, however, the residential care facility abruptly stopped Bradley's CES treatment in violation of the parties' agreement.

Bradley's mother subsequently filed suit alleging that the facilities' withdrawal of CES therapy breached the contract between the parties and violated Bradley's right to "adequate and humane care and services in the least restrictive environment." The court disagreed, finding that Bradley's right to care and services was limited by an Illinois statute which explicitly prohibited electric shock treatment. Accordingly, the court found that Bradley did not have a vested right to continue receiving CES therapy while in a private group home. The court also held that the portion of the statute that provided that a mentally ill individual could receive "unusual, hazardous, or experimental services" with court approval and guardian consent was unconstitutional. *Bernstein v. Department of Human Services*, 392 Ill. App. 3d 875 (Ill. App. Ct. 2009).

Overcorrection is another behavioral procedure, developed by Foxx and Azrin (1973) and their colleagues, to decrease inappropriate behavior. It requires that, contingent on displaying an inappropriate behavior, the client must correct anything in the environment that has been harmed by the inappropriate behavior; this is referred to as restitution. Additionally, the client is required to repeatedly practice an appropriate or positive behavior that he or she could substitute for the inappropriate behavior. Overcorrection tasks should be functional and time-limited. Administrators need to have strict guidelines to protect against the misuse of these procedures.

Corporal punishment involves the use of physical punishment. Courts have prohibited the use of physical abuse, including beating, kicking, and slapping residents. Additionally, the use of objects, such as a broom or belt, to physically harm residents is prohibited in most instances. There is much potential for abuse and misuse of

these techniques, and they should be strictly prohibited because organizations can be held liable for the acts of their employees in employing these procedures if courts find that the employee is acting in the scope of his or her employment with a motivation to serve the employer.

In *Davis v. Devereux Foundation*, the Superior Court of New Jersey considered whether a charitable organization could be held liable for the acts of its employee in pouring boiling water on an individual with a developmental disability. At the time the incident occurred, Charlene McClain was a resident counselor at Devereux's New Jersey Facility, an organization providing treatment for people with emotional, developmental, and educational disabilities. One morning, McClain poured boiling water on the plaintiff, Roland Davis, as she attempted to get him out of bed. McClain claimed that prior to the incident Davis had been spitting, kicking, and throwing objects at her.

In considering the case, the New Jersey Superior Court made two important determinations. The first was that charitable institutions housing and caring for people with developmental disabilities do not have a non-delegable duty of care to their clients; therefore, the exercise of reasonable care could potentially shield them from liability. Second, to hold an employer liable for the actions of an employee, the employee must be acting within the scope of employment, meaning the employee's actions must be intended, at least in part, to serve the employer; here, a jury could reasonably find that McClain's actions were motivated not by personal anger or misbehavior but rather in whole or in part by a genuine desire to serve her employer. Accordingly, the court allowed the case to proceed to the jury to determine whether Devereux as an institution could be held liable for the plaintiff's burns. *Davis v. Devereux Foundation*, 997 A.2d 273 (N.J. Super. Ct. App. Div. 2010).

In 2012, the New Jersey Supreme Court overruled the Superior Court's second finding and held that no rational fact finder could determine that McClain's actions were conducted within the scope of employment. Therefore, the employer could not be held liable for McClain's actions.

Davis v. Devereux Foundation, 209 N.J. 269, 278 (2012).

Whenever any of the above-described procedures are used, there must be protocols designed to manage and review these procedures as well as to safeguard client rights. First, prior to utilizing any of these procedures, staff must document that all other potentially effective less restrictive alternatives have been tried and shown to be ineffective. Next, staff should provide evidence that the best professional clinical practice indicates that less restrictive alternatives would not be effective. Staff should also implement safeguards to minimize the risks related to the use of any of these procedures and should take proactive and remedial actions to minimize, reduce, or avoid the use of these procedures. Additionally, these procedures cannot be used for punishment, retribution, the convenience of staff, or as a substitute for treatment. Rather, these procedures must always be part of a specified treatment program where it is clear that clients are being taught appropriate behaviors. Staff must always have the voluntary informed consent of the person or the person's guardian.

Crisis situations require that staff respond immediately to protect the people in the environment. Often, staff respond using procedures that have not been approved for use but rather seem likely to deescalate a situation quickly. Administrators should be aware that this can be a common practice, and they should identify potential problem situations and have staff practice what approved and appropriate procedures can be used. Practicing these procedures should help staff feel confident in their use, and they should become fluent in carrying them out. This preemptive practice can help reduce the use of ad hoc procedures that might cause harm to clients or staff.

Involuntary Servitude

Involuntary servitude involves requiring people to engage in labor that benefits the facility and program and not justly compensating them for that labor. Previously, people residing in facilities

serving individuals with developmental disabilities were required to engage in labor such as cooking, cleaning, washing dishes, doing laundry, and caring for other residents. Not only were they required to engage in this labor but they were often not adequately compensated for it and, at times, not allowed to leave the residential facility. Courts quickly found that this practice violated the Thirteenth Amendment's prohibition on involuntary servitude. They subsequently mandated that facilities no longer require people to engage in this type of labor and must properly compensate individuals who desire to engage in some type of work. The amount of compensation was in dispute for a number of years. Often, it takes an individual with a disability longer to complete a job than it does a nondisabled worker. Thus, if the law required employers to pay workers with a disability the same amount as workers without a disability, the result was employers refusing to offer jobs to people with disabilities. Courts addressed this issue and determined that a person with a disability could be paid less if a wage and hour study was completed, looking at the length of time it took both a nondisabled worker and a worker with a disability to complete a job, and the person with the disability was paid an amount commensurate with his or her ability and the prevailing wage.

The first source of protection against forced labor for individuals with disabilities is the Thirteenth Amendment's prohibition against involuntary servitude. In interpreting an individual's rights under the Thirteenth Amendment and to what extent labor is forced, courts can take into consideration an individual's disability. For example, in *United States v. Kozminski*, the United States Supreme Court held that involuntary servitude exists only where there is threatened or actual use of physical or legal coercion to compel labor or fraud or deceit where the individual is a minor, immigrant, or legally "mental incompetent." *United States v. Kozminski*, 487 U.S. 931 (1988). On its face, this decision appears to limit the type of coercion that is recognized as a means of compelling involuntary servitude prohibited by the Constitution, excluding psychological pressure or influence that is a common

means of controlling individuals with developmental disabilities. However, the Court went on to note that "a victim's age or special vulnerability may be relevant in determining whether a particular type or a certain degree of physical or legal coercion is sufficient to hold that person in involuntary servitude." It further provided that "it is possible that threatening an incompetent with institutionalization . . . could constitute the threat of legal coercion that induces involuntary servitude." In making this statement, the Court recognized that what would amount to a mere psychological threat to an adult of normal intellectual functioning not sufficient to produce involuntary servitude could constitute a threat of legal coercion sufficient to find involuntary servitude to someone with a lesser functional capacity.

The forced labor of individuals with developmental disabilities is further protected under the United State's forced labor statute, 18 U.S.C. § 1589, which provides in relevant part that

Whoever knowingly provides or obtains the labor or services of a person [in any of the following means shall be fined and/or imprisoned for up to twenty years].

1. By means of force, threats of force, physical restraint, or threats of physical restraint to that person or another person;
2. By means of serious harm or threats of serious harm to that person or another person;
3. By means of the abuse or threatened abuse of law or legal process; or
4. By means of any scheme, plan, or pattern intended to cause the person to believe that, if that person did not perform such labor or services, that person or another person would suffer serious harm or physical restraint.

In a recent case, the United States Court of Appeals for the Tenth Circuit found that a husband and wife who operated a group home for individuals with mental illness and disabilities violated both the forced labor statute and the constitutional prohibition on involuntary servitude when they forced residents to engage in labor without compensation. *United States v. Kaufman*, 546 F.3d 1242 (10th Cir. 2008). In this case, the Kaufmans forced men and women with

mental illness and developmental disabilities to work, often in the nude, on their farm. Although the Kaufmans argued that there was insufficient evidence that they “coerced” labor as required by the statute, the Tenth Circuit disagreed. Relying on the Supreme Court’s holding in *Kozminski*, the court found that because the individuals suffered from severe mental illness, they were “highly susceptible” to the Kaufmans’ directives, thus allowing a jury to find that their work was compelled “by the use or threatened use of physical or legal coercion.”

Another issue involves specifying exactly what home tasks a person with a disability can be asked to complete. Courts reviewed this issue and determined that a person with a disability can be required to complete personal housekeeping (e.g., making one’s bed and cleaning one’s room). Additionally, people with disabilities can be asked to complete home housekeeping, such as cooking and cleaning, if the tasks are part of a designed treatment program and benefit all individuals within the home. Thus, programs established in a family-style manner can ask people to engage in domestic tasks that benefit the entire group and increase the functional skills of the people living in the home.

To be safe, staff should institute an active instructional program to ensure that people are taught housekeeping and personal management skills correctly. No one person should ever be solely responsible for one task; rather, the housekeeping jobs should be rotated among all the people living in the residence. In addition, tasks should benefit the group as a whole. Finally, residents should never be allowed to engage in labor that benefits only the staff, such as washing the staff’s car or babysitting the staff’s children.

Providing Appropriate and Active Treatment

When courts first addressed the issue of legal rights of people with developmental disabilities, the focus was on providing basic rights and protecting people from harm. In this beginning era, courts issued many guidelines for programs serving this

population. After basic rights were established, however, an issue arose as to whether programs serving individuals with disabilities were required to provide individuals with active treatment. Compounding this issue was disagreement among professionals as to whether active treatment should be required for individuals with developmental disabilities. Some special educators argued that people with disabilities should live in enriched environments where all of their rights were given to them, but they should not be required to engage in active treatment. Some also argued that many people with disabilities have difficulty learning and that requiring them to receive active treatment would bring unnecessary stress to their lives. Others, however, argued that all people with disabilities can learn, although at different rates, and thus people with developmental disabilities must be given opportunities to expand their skills. Experts advocating this position maintained that the more skills a person possesses, the more control he or she has over his or her life. Courts reviewed these arguments and held that clients have a right to active treatment and that this treatment should be provided to all individuals regardless of their level of disability.

In *O’Connor v. Donaldson*, the United States Supreme Court held that individuals with developmental disabilities have “a constitutional right to receive such individual treatment as will give [them] a reasonable opportunity to be cured or to improve [their] mental condition.” *O’Connor v. Donaldson*, 422 U.S. 563 (1975) (quoting *Donaldson v. O’Connor*, 493 F.2d 507 (5th Cir. 1974)). In addition, an early 1970s court found that “[t]he failure to provide suitable and adequate treatment to the mentally ill cannot be justified by lack of staff or facilities.” *Wyatt v. Stickney*, 325 F. Supp. 781 (M.D. Ala. 1971). Courts would later expand this right to treatment to include the right to active treatment.

In *Harvey v. Mohammed*, the United States District Court for the District of Columbia considered, among other things, whether a group home facility charged with caring for individuals with developmental disabilities negligently cared for a man with cognitive and adaptive profound mental retardation leading to his death.

The court determined that the institution “had an obligation to monitor the care being provided” to the client served and that they breached this duty to the detriment of him. In making this determination, the court specifically cited to the institution’s failure to “integrate, coordinate, and monitor the active treatment program” of the client. *Harvey v. Mohammed*, 841 F. Supp. 2d 164 (D.D.C. 2012).

Thus, to ensure that active treatment is appropriately provided, each person should have an individualized treatment plan that identifies goals for treatment that relate to the reason the person is in the program. Staff should also administer assessments not overly intrusive or invasive of a person’s right to privacy, upon an individual’s entry into the program and at regularly scheduled intervals each year. In addition, staff should document changes in behavior and if a person is not making progress, should reevaluate and modify the treatment program to ensure that progress is made. Finally, staff should provide all individuals with skills to allow the person to control and manipulate his or her environment.

Right to Refuse Treatment

Along with the right to treatment is the right to *refuse* treatment. This right was originally recognized for people with mental illness who did not want to receive chemical treatment with psychotropic medication or other forms of treatment that invaded their body or their right to privacy. The right was later extended to individuals with developmental disabilities. Although this right does not give a person the right to refuse all treatment, it does give the person the right to refuse a particular type of treatment. Thus, if a person objects to receiving a certain type of treatment, staff must offer another form of appropriate treatment.

Like a developmentally disabled individual’s right to safe conditions and freedom from bodily restraint, the Third Circuit has extended *Youngberg* to include the right to refuse treatment generally and the use of antipsychotic drugs specifically. *Rennie v. Klein*, 720 F.2d 266, 269 (3d Cir. 1983). In considering when the state may administer

antipsychotic drugs to a person against his or her will, the court stated that if a patient constitutes a danger to himself or to others, medical authorities may, in the exercise of professional judgment, administer drugs against the patient’s will. The exercise of professional judgment does not necessarily require administration of the “least restrictive” treatment, but neither does it free medical authorities to administer whatever treatment they prefer. Medical authorities may administer treatment only as “necessary to prevent the patient from endangering himself or others,” and “the exercise of professional judgment may require them to consider available alternatives in the context of such factors as the harmful side-effects that a patient may experience.” *Brandt v. Monte*, 626 F. Supp. 2d 469 (D.N.J. 2009).

Other courts have similarly limited the right of individuals with developmental disabilities to refuse treatment. In *In re Branning*, the Illinois Appellate Court considered a statute authorizing the “unusual, hazardous, or experimental” treatment of individuals with mental incompetencies upon court approval of the guardian’s consent. In its decision, the court found that an individual has a significant liberty interest in refusing unwanted electroconvulsive therapy, similar to the significant interest one has in refusing psychotropic medication. The court also found, however, that the state has a compelling interest in providing for individuals “who are without the capacity to make reasoned decisions regarding their need for treatment due to a serious mental illness or developmental disability.” Weighing these two interests, the court concluded that the state’s interest was sufficient to overcome the individual’s right to refuse unwanted treatment but only if the individual to whom the treatment was to be provided was “unable to make a rational decision for himself regarding treatment.” *In re Branning*, 285 Ill. App. 3d 405 (Ill. App. Ct. 1996).

Balancing the right to treatment with the right to refuse treatment may pose difficulties for administrators and treatment staff. An individual has a right to refuse a particular type of treatment, in which case program staff should propose another treatment intervention to accomplish the same goal. This treatment intervention should address

the concerns of the client and the reasons why the client is refusing the first type of treatment. It is important to have the guardian's and client's input in developing programs, so that they will have a vested interest in the success of the program.

Opportunity for Choice, Self-Management, and Active and Meaningful Participation in Decisions Regarding One's Life

For years, it was believed that professionals knew best what individuals with disabilities should do, what activities they should engage in, and what behaviors were appropriate or inappropriate. Bannerman and her colleagues, in a seminal article in 1990, argued that people with disabilities should be given the opportunity to participate in decisions regarding their lives. Thus, staff should allow people to have input on decisions regarding their daily life. This might include what clothes to wear, what to eat, when to take a shower, and when to go to bed. Congress recognized this right by incorporating it into regulations governing Intermediate Care Facilities for the Mentally Retarded. 42 C.F.R. Part 483 et seq. This recognized the importance of participant involvement and participation in daily life activities and teaching people how to make informed decisions.

The opportunity for choice and self-management is commonly considered in statutes and court decisions interpreting an individual's right to choose his or her course of treatment. The Illinois Mental Health and Developmental Disabilities Code, for example, provides that physicians must provide patients with written notification regarding the side effects, risks and benefits of treatment, and the availability of alternative treatments in certain situations, for example, when the State petitions for involuntary administration of psychotropic medication or electroconvulsive therapy. Mental Health and Developmental Disabilities Code, 405 ILCS 5/2-102(a-5). In *In re Nicholas L.*, the court held that a patient cannot waive this right to notification. *In re Nicholas L.*, 407 Ill. App. 3d 1061 (Ill. App. Ct. 2011).

Thus, to ensure that people have an opportunity for choice, self-management, and active and meaningful participation in life decisions, individuals with disabilities should be taught both how to make informed decisions regarding their personal life and also how to engage in group decision-making. For example, staff may want to have a "family meeting" each night after dinner where the residents discuss their day and decide on any activities that they might want to engage in as a group. During this process, people learn to propose ideas, express opinions, and vote on decisions. They also learn that the majority's decision controls and that although they voted for something, that may not be what the group decides to do.

Least Restrictive Alternative

The principle of the least restrictive alternative involves ensuring that any treatment environment or treatment modality is the least restrictive of a person's freedom while at the same time providing appropriate treatment. While the rights of individuals with developmental disabilities to live in the least restrictive environment are not limitless, the Supreme Court has held that "States are required to provide community-based treatment for persons with mental disabilities when the State's treatment professionals determine that such placement is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities." *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 587 (1999). Additionally, many state statutes mandate placement for individuals with disabilities in the least restrictive environment, and courts will often refuse to order placements of individuals in overly restrictive settings.

In making a determination of which commitment facility provides the least restrictive alternative, a court may rely on the opinions of experts. *In re Miner*, 424 N.W.2d 810, 815 (Minn. App. 1988). A court, however, may not place an individual in a restrictive facility if there is no

evidence regarding the possibility of alternative placements. In *In re Lance H.*, an Illinois appellate court found that an order involuntarily committing a man to a mental health center for 180 days violated his rights to treatment in the least restrictive setting because there was no evidence that the mental health center was the least restrictive alternative available for treatment. While the particular case involved a man with a mental illness, not a developmental disability, in reaching its decision, the court interpreted an Illinois statute that applied to the least restrictive alternative for individuals with mental illness and individuals with developmental disabilities. The court gave no indication that the result would be any different for an individual with a developmental disability. *In re Lance*, 402 Ill. App. 3d 382 (Ill. App. 2010).

In many cases, providers will find that the least restrictive environment for an individual with a disability is in a home or community care setting. When this is the case, courts will generally uphold this decision. In *Lynch v. Maher*, the Connecticut District Court considered the least restrictive alternative requirement and held that a state could be enjoined to continue paying for home care services for an individual with developmental disabilities even though alternative services might be available in a less expensive, yet more restrictive institutional setting. The court also held that under the DDA, an individual with a disability could forego the medical advantages of an institution in favor of the less restrictive environment of a home care facility with an appropriate level of care. *Lynch v. Maher*, 507 F. Supp. 1268 (D. Conn. 1981).

Still, courts do not always give priority to community-based or home placements over institutional settings. In fact, the United States Court of Appeals for the Sixth Circuit has rejected the conclusion that community-based services are the constitutionally required least restrictive environment for people with developmental disabilities. In *Kentucky Association for Retarded Citizens v. Conn.*, the Sixth Circuit concluded that the least restrictive alternative for some individuals with severe and profound developmental disabilities may in fact be in an

institution and, therefore, refused to prevent Kentucky from building a new and more modern institutional facility. *Kentucky Association for Retarded Citizens v. Conn.*, 674 F.2d 582 (6th Cir. 1982).

When placing individuals in programs, staff should ensure that the program is not overly restrictive of the person's freedom. For example, a person who could live semi-independently in an apartment should not be required to live in an institution or even a group home. Likewise, all treatment programs should be ones that restrict the person's freedom to the least extent possible. Most importantly, a program should not restrict basic rights if a less intrusive program would be as successful.

Confidentiality and Right to Privacy

People have the right to confidentiality and privacy in their lives. This requires that service providers respect clients' right to privacy in their daily living activities and also safeguard clients' medical, financial, and personal files from disclosure to third parties. Respecting privacy concerns in daily life includes allowing individuals the ability to keep personal belongings private, have alone time free from supervision, and interact with friends and family without intrusion from staff and other residents. These concerns go directly to an individual's dignity and, although not often legally mandated, are core components of successful community-based programs for people with developmental disabilities. The other aspect of privacy, protecting clients' confidential records including medical, financial, and personal information, is highly regulated by law and enforced by the courts.

The first area of privacy granted to individuals with disabilities is the right to confidential communications with a therapist or social worker for the purposes of treatment. In *Jaffee v. Redmond*, the Supreme Court held that "confidential communications between a licensed psychotherapist and his or her patients in the course of diagnosis or treatment are protected from compelled disclosure" under the federal rules of evidence.

The Court also extended the privilege “to confidential communications made to licensed social workers in the course of psychotherapy.” Thus, as the privilege now stands, confidential communications between a patient and a licensed psychotherapist or social worker, including “the notes taken during their counseling sessions,” are “protected from compelled disclosure.” *Jaffee v. Redmond*, 518 U.S. 1, 15 (1996). In addition, this privilege cannot yield even if a court determines that waiving the privilege would serve “the interests of justice.” *In re Sealed Case (Medical Records)*, 381 F.3d 1205 (D.C. Cir. 2004).

The next area of privacy regards individuals’ personal records and files including medical, financial, and personal information. Although most states limit the individuals who have access to this information, prohibiting disclosure to anyone but those involved with the treatment and oversight of the individual, there is an open question as to whether a developmentally disabled individual may withhold these records from state protection and advocacy systems established by the DDA. Many courts have held that state protection and advocacy systems are entitled to access the records of an individual with developmental disabilities. These courts have found that records must be shared even over the good faith objections of the individual’s guardian, even where the individual resides in a private institution not receiving federal funds, and even when a state law is more restrictive or explicitly prohibits the sharing of records. *Disability Law Center, Inc. v. Riel*, 130 F. Supp. 2d 294 (D. Mass. 2001); *Wisconsin Coalition for Advocacy, Inc. v. Czaplewski*, 131 F. Supp. 2d 1039 (E.D. Wis. 2001). However, some courts have also found that state protection and advocacy systems should not be given access to records of individuals with developmentally disabled individuals, specifically where the advocacy system has not received a complaint regarding abuse or neglect. *Pennsylvania Protection & Advocacy, Inc. v. Royer-Greaves School for Blind*, No. CIV. A. 98–3995, 1999 WL 179797 (E.D. Pa. Mar. 25, 1999).

Overall, assessment procedures and treatment interventions should not be overly intrusive.

All interventions should relate to the goal of treatment and the reason why the person is being served. Staff must also strictly protect the right to an individual’s confidentiality. All treatment information and records are confidential and should not be shared with anyone outside the program. When discussing individuals, staff should refrain from using the person’s entire name or giving any personally identifiable information regarding the person. Staff should also obtain consent before any information is shared with anyone outside the program. When developing a program, administrators should be cognizant of these various areas of concern where legal issues can arise and should develop procedures that specify the appropriate practice in each area. Administrators should also train staff in each area and should conduct periodic monitoring to ensure that all rights are protected.

Legal Liability

The following sections focus on the operation of the program in a legally safe manner. It is critical that staff are aware of the various areas of concern and that they behave in a manner that is appropriate and provides a safe environment for all involved.

Liability generally focuses on a person’s obligation to another person; legal liability involves an obligation that is enforceable by law. To understand legal liability, one must understand the concept of *negligence*. Negligence refers to careless conduct that results in harm to another person. Negligence is the failure to act as a reasonable and careful or prudent person would under similar circumstances. Four elements must be proved for liability to be imposed:

1. There must be a duty or obligation recognized by law that requires a person to act in a manner that protects others from unreasonable risks or harms.
2. There must be a failure on the part of the person to conform his or her conduct to the standard required.
3. A close causal connection must exist between the conduct and the resulting injury.

4. There must be actual loss or damage to another person.

William L. Prosser, *Handbook of the Law of Torts* 143 (West 4th ed. 1971).

As a general rule, individuals owe a duty not to cause harm to others. In the realm of disability services, there is often a special duty imposed on caretakers by law. When considering staff conduct in a program serving individuals with developmental disabilities and whether such conduct conforms to a reasonable duty of care, courts consider how a reasonable person under similar circumstances would behave. Liability will be imposed if a court finds that program staff were negligent in conforming their conduct to this standard of care and carrying out their duties accordingly. Liability can also be imposed if staff fail to conduct the program in a way that meets regulatory, legislative, judicial, or constitutional mandates.

In addition to staff liability, organizations or institutions overseeing staff behavior may also be liable for negligence committed by staff if the court finds the staff member was acting within the course of his or her employment. The following are areas where liability commonly has been imposed on treatment staff who work with people with disabilities. See Van Biervliet and Sheldon-Wildgen (1981).

Failure to Supervise Properly

A major area of potential liability involves failure to adequately supervise. This is of great concern in programs serving people with developmental disabilities. The belief is that even when staff themselves are not the cause of harm to individuals, staff should act prudently to avoid any foreseeable harm caused by others. In general, there is no duty to control the conduct of another or to warn a third person or potential victim of danger. However, there are five exceptions to this rule: (1) where one has a special relationship to the victim; (2) where one has a special relationship to the injurer; (3) where one voluntarily undertakes a duty; (4) where one negligently or intentionally creates the risk that leads to the injury; and (5) where a statute imposes such a duty. *Madison*

ex rel. Bryant v. Babcock Center, Inc., 371 S.C. 123 (S.C. 2006). Individuals working with people with developmental disabilities almost always meet some, if not all, of these requirements. Because of their cognitive limitations, individuals with developmental disabilities often do not perceive a situation as potentially dangerous. As a result, they do not respond appropriately to protect themselves. Staff are responsible for understanding these situations and providing the appropriate care and supervision.

There are many situations in which a court might find that caretakers provided a lack of proper supervision to the consumers they serve. If clients are involved in an activity that is potentially dangerous and staff do not intervene to stop the activity or protect the clients, liability may be imposed. Staff may also be liable if there are too few staff to properly supervise clients. Most programs require a certain number of staff to be present to care for clients. If, however, the clients are engaged in a potentially dangerous activity, for example, a field trip, programs may require additional staff.

Oftentimes, claims for failure to properly supervise will take the form of failure to protect and will be brought in conjunction with claims for abuse or neglect. For example, individuals will often allege that staff's failure to provide them with reasonable conditions of safety results in abuse and neglect by other staff or residents. As an initial matter, courts will not find a constitutional violation where the conduct complained of amounts to mere negligence. *Shaw by Strain v. Strackhouse*, 920 F.2d 1135 (3d Cir. 1990). However, the degree of fault, beyond mere negligence, required to give rise to a due process claim for failure to protect is not clearly established, although it appears to be the professional judgment standard articulated by the Court in *Youngberg*.

This is not to say that individuals can never be successful on failure to protect claims grounded in negligence. Even absent statutory requirements, care providers generally have a common law duty to exercise reasonable care in supervising and providing appropriate care to consumers. The Supreme Court of South Carolina's decision in *Madison ex rel. Bryant v. Babcock Center, Inc.*

is indicative of a court's approach in a negligence cases for failure to protect.

In 2006, Brenda Bryant, the mother of a young woman with mild mental retardation, brought claims against Babcock Center, a private nonprofit corporation providing housing and services for people with autism and other developmental disabilities, and the Department of Disabilities and Special Needs, the state organization responsible for overseeing private residential treatment facilities. In her complaint, Bryant alleged that Babcock Center failed to properly supervise Madison, who left the house early one morning and was later forced to have sex with two men from whom she contracted herpes. In determining that Babcock Center had a special relationship with Madison, the court considered the following factors: Madison was admitted for care and treatment at the center; Babcock Center voluntarily undertook the duty of supervising and caring for Madison; Babcock negligently created a risk of injury to Madison by failing to supervise; and Babcock had a statutory duty to exercise reasonable care under South Carolina law. Accordingly, the court held Babcock liable for negligence. *Madison ex rel. Bryant v. Babcock Center, Inc.*, 638 S.E.2d 650 (S.C. 2006).

Thus, staff must carefully supervise clients to prevent self-inflicted danger and danger from third parties. This duty is especially cogent when staff have knowledge of a client's propensity for engaging in dangerous behavior, either to self or others. Foreseeability of the harm is a critical issue in determining the staff and the program's legal liability. Therefore, if staff know, for example, that a client is likely to elope or harm another client, staff should impose stricter standards for supervision.

Failure to Maintain Facilities and Equipment Properly

Staff and administrators also have an affirmative duty to frequently inspect the facilities where individuals with developmental disabilities live and work and the equipment they use and to keep them in repair and safe working order. This duty

is especially important in home care settings where individuals with developmental disabilities can be unsupervised for extended periods of time throughout the day. Because individuals with developmental disabilities do not have the cognitive ability to perceive situations or objects as dangerous, ensuring that clients cannot come into contact with dangerous equipment or facilities is an important component of preventing crisis situations. When a dangerous or defective situation is observed, staff should notify their supervisor and address the problem immediately. Staff may want to keep a checklist of equipment and areas that should be regularly checked to ensure they are in proper working order. Staff should also teach clients how to use equipment safely because even typical household items can present safety risks if not used properly.

Fire Drills and Fire Safety

Fires can be devastating, resulting in significant property loss and, more seriously, significant injury and possibly death. Many residences serving individuals with disabilities do not have fully operational sprinkler systems, and thus fire safety is critically important. Staff should conduct fire drills on a regular basis and ensure that each person is able to exit the facility independently. Proper training for independence is critical, as fires present one of the most dangerous crisis situations staff and consumers face, and even small mishaps can result in significant damage. Staff should also ensure that all fire alarms are in good working order and are connected directly to the fire department. Homes should clearly indicate that people with disabilities reside in them so that fire fighters can quickly enter to protect people who may have difficulty exiting by themselves.

Failure to Treat Injuries or Provide Proper Medical Care

Injuries can occur in any program, especially in situations involving dependent populations. Thus, staff should be trained to deal with both serious

and nonserious injuries, using correct medical procedures. At a minimum, staff must be trained in nonemergency first aid procedures, including the Heimlich Maneuver, CPR, and other injury prevention techniques. Staff should also be trained in more advanced procedures as they are often the first individuals to come into contact with injuries during crisis situations. Although they must be able to provide proper emergency treatment before trained medical professionals arrive, staff should not attempt to provide treatment that requires the expertise of a medical professional. Before beginning any preliminary treatment, staff should notify medical personnel immediately.

To prevent serious injury before it occurs, programs should establish procedures to follow in case of accidents and emergencies. Emergency medical treatment authorization forms should be signed by each guardian to allow the program staff to obtain emergency treatment when necessary. Programs should also specify the steps to be taken in different types of emergencies, and staff should be trained on when emergency medical personnel should be contacted.

Residents in facilities for people with developmental disabilities may also experience frequent health problems, including client illness. Thus, staff should be trained in recognizing health problems and seeking appropriate care. Recognition of possible nonserious medical conditions can be critical in preventing the development of more serious medical issues. In addition, clients who are ill should be separated from others and given appropriate care and treatment. Many clients may have chronic diseases (e.g., hepatitis) that can be contagious. Staff need to use precaution when toileting, bathing, and feeding these individuals to ensure that the disease is not passed to others.

Transportation Accidents

Providing transportation is an integral component of any program serving people with developmental disabilities. Vehicle travel and transportation

from one place to another can be unsettling for some clients, and, therefore, appropriate procedures must be utilized to prevent crisis situations and provide safe and manageable travel. It is especially imperative that programs ensure that clients are safe when riding in program vehicles. The following procedures should be followed to best provide for client safety.

First, programs must provide safe drivers: all drivers must be properly licensed and insured, have a good driving record, and be safe and cautious motorists. Programs must also ensure the safety of their vehicles: all automobiles must be in good running order, have no known dangerous defects, and be regularly inspected and serviced. Additionally, staff should provide appropriate supervision for clients when they are riding in program vehicles, including ensuring that clients wear seatbelts and that they board and disembark from the vehicle in a safe manner. Some clients may engage in inappropriate, and even dangerous, behavior during travel from one place to another. Staff should anticipate this behavior and provide the necessary supervision to these clients so that they do not cause an accident. Finally, staff should not take personal excursions, for example stopping to pick up dry cleaning or going to the bank, with clients while using the program vehicle. Such detours can agitate clients and provide more opportunities for accidents and injuries. In addition, insurance covers staff only while they are acting in the scope of their employment; detours for personal errands are not covered.

Failure to Place or Discharge Clients Properly

Programs must maintain admissions criteria that are reasonable and related to the program's mission. These criteria should be used to evaluate all admissions without exception to provide for the safety of each client and the safety and cohesion of the group as a whole. Most importantly, admissions should be conducted in a nondiscriminatory manner without consideration to factors unrelated to the program's operation. Staff should also

conduct appropriate assessments upon intake to determine each individual's needs and to develop each individual's intervention program. Assessments should continue periodically to determine the progress that a person has made and if, and when, the person should be discharged.

Protective Mechanisms: Human Rights and Peer Review Committees

In *Wyatt v. Stickney*, the court suggested that programs should employ protective oversight mechanisms such as Human Rights Committees to ensure that individuals with developmental disabilities are properly served and treated. *Wyatt v. Stickney*, 325 F. Supp. 781 (M.D. Ala. 1971). In 1980, Risley and Sheldon described these committees and their functions (Risley & Sheldon-Wildgen, 1980a, 1980b). A Human Rights Committee serves to review any potential controversial program such as the deprivation of a basic right, the use of a restrictive procedure, or the administration of a psychotropic medication. This committee should be comprised of individuals who are not employed by the agency so that they may maintain an independent and unbiased perspective on proposed courses of treatment or procedures. Such a committee should meet at least monthly to review any proposed programs, at which time, staff should formally present the proposal and its justification. In making a determination, the committee should consider whether the proposal is humane and ethical and whether the individual in question will be adequately protected. The committee can then approve, disapprove, or suggest changes for any proposed programs. In this way, the committee ensures that community values and standards are considered in program implementation and that the program maintains the highest level of care for the consumers it serves.

Peer Review Committees are another mechanism to ensure adequate treatment for individuals with developmental disabilities. Peer Review Committees offer an outside evaluation of treatment programs and procedures by professionals

who can offer insight into whether the program is meeting professional standards. Programs should ask outside professionals to periodically conduct these reviews to determine whether the program and its implementation are appropriate.

Anticipating Crisis Situations

Perhaps the most important component of preventing crisis situations in programs that serve individuals with severe disabilities and behavior problems is anticipating what will trigger a crisis situation and properly preparing for it. Anticipating crisis situations requires that program staff know the individuals with whom they work and the problems that they display. For example, if a person has a problem with elopement, staff should be aware of the immediate and eventual consequences this problem poses and the means for addressing these outcomes. With this knowledge, staff should develop a protocol for intervention, staff should document this protocol, staff should be trained on this intervention, and staff should document this training. Additionally, staff should determine when and where problem behaviors might occur and should arrange the environment to decrease the opportunity for or the probability of these behaviors. In practice, this may mean that additional staff are needed at certain times and in certain places to help transition individuals between activities or to ensure that clients are not harmed in situations that might provoke conflict. Proactive planning is the best way to avert minor problems and to ensure that these do not escalate into major issues.

If a problem does occur, staff should utilize the set protocol without modification. After the problem has been addressed, staff should evaluate the procedure's success in mitigating the problem. If the procedure was not successful, staff should revise the protocol to properly address the problem in the future. Even in the absence of problems, staff should periodically review interventions to ensure that they meet clients' needs and are adequate at addressing potential problems.

Parents and Guardians Versus Program Staff

The final component to consider in working with individuals in crisis situations is the role of parents and guardians. Parents and guardians have much greater freedom in working with their children than program staff. Parents and guardians, for example, are not bound by the confines of federal or state regulations in working with individuals with disabilities in institutional settings, and, thus, have more choice and control in the mechanisms they employ for working with these individuals.

Although parents and guardians may be able to restrict basic rights more easily than program staff and implement restrictive procedures more often and with less oversight, parents and guardians should still be aware that their actions, like those of program staff, may be reviewed by the state agency responsible for overseeing the care and treatment of individuals with developmental disabilities. Laws addressing abuse and neglect of children and dependent populations do govern parents and guardians, and these individuals have been charged with abuse and neglect for actions such as locking children in a room for an extended period of time, using excessive force in disciplining children, and restricting food intake. Thus, parents and guardians should be aware that although they have greater freedom, they too need to refrain from using abusive or neglectful procedures in treating or working with individuals with disabilities.

Conclusion

Serving clients with severe behavior disorders can be difficult, and programs need to be aware of the potential problems that may arise. Nonetheless, these problems need not prohibit programs from adequately treating individuals with developmental disabilities in the least restrictive environment. With thoughtful planning, comprehensive assessment, and proper execution, programs can anticipate crisis situations and avert them.

In developing programs, it is important for administrators to develop a policy and procedures manual to specify procedures that should be carried out daily and procedures that should be implemented in a crisis situation. Staff should be well-versed in these procedures and should practice carrying them out, so that if a crisis situation arises, they can handle it effectively and in an ethical and legal manner. Administrators should periodically observe staff and give feedback to ensure that staff are aware of the procedures and are implementing them appropriately. Providing effective and legally safe environments will reduce the number of crisis situations that arise and help ensure that when a crisis does occur, it is managed in the best possible way. This creates a positive environment for everyone involved.

Acknowledgments The authors gratefully acknowledge Jamie Price, James Sherman, and Michael Strouse for their valuable contributions to this chapter.

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Less to More Restrictive Settings: Policy and Planning Considerations

16

Mitchell L. Yell and Erik Drasgow

The Education for All Handicapped Children Act (EAHCA) was enacted in 1975 to ensure that students with disabilities would have access to appropriate special and general education services. When the law was passed, approximately five to six million children and youth with disabilities were not receiving an education that was appropriate for their needs, and more than one million children with disabilities were excluded from education all together (Ballard, Ramirez, & Weintraub, 1982). When considering all disability categories, children and youth with developmental disabilities and with emotional disorders were most likely to be totally excluded from schools (Huefner & Herr, 2012).

The purpose of the EAHCA was to:

Assure that all children with disabilities have available to them ... a free appropriate education (FAPE) which emphasizes special education and related services designed to meet their unique needs, to assure that the rights of children and their parents or guardians are protected, to assist states and localities to provide for the education of all children with disabilities, and to assess and assure the effectiveness of efforts to educate children with disabilities (IDEA, 20 U.S.C. §1400(c)).

In 1990 the EAHCA was renamed the Individuals with Disabilities Education Act (IDEA).

The Congressional writers of the EAHCA and IDEA were and continue to be very concerned about the tendency of school officials to educate students with disabilities in segregated settings, away from their peers who were not disabled. To address these problems, Congressional writers included the requirement that students with disabilities receive their education in the least restrictive environment (LRE) that would meet their educational needs. According to this principle, students with disabilities who can benefit from placement in a general education setting are entitled to be educated there and, if they cannot benefit from such a placement, they should be educated in the setting that most closely resembles the general education setting. An important component of a student's FAPE, therefore, is his or her educational placement.

If a student with disabilities is not placed in an appropriate setting, he or she will not receive a FAPE, which is the fundamental guarantee of the IDEA (Pitasky, 2002). Issues surrounding the educational placement of students with disabilities, especially those students with developmental disabilities, have proven to be very controversial (Yell, 2012). In fact, placement issues have led to more litigation than virtually all other IDEA-related disputes (Huefner & Herr, 2012).

In this chapter we examine policy and planning decisions for placing students with developmental disabilities in less to more restrictive settings. First, we examine the fundamental requirements regarding special education placement decisions.

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The IDEA contains procedural requirements that must be followed when students with disabilities are placed in educational settings. One of the most serious procedural errors that school district personnel make when making placement decisions is failing to include a student's parents in the process. It is important that school district personnel adhere to these procedural requirements because in some cases failing to adhere to them can lead to depriving a student of a FAPE, and thus violate the IDEA. Second, we consider relevant factors in making legally correct placements in the LRE. Since the enactment of the EAHCA, disputes have arisen between parents and school district personnel regarding the placement of students with disabilities. In fact, questions of LRE have been a dominant factor in many disputes that have been litigated in state and federal courts. In this section we will review the most important litigation regarding LRE in the past two decades. Interestingly enough, these decisions have most often involved the placement of students with developmental disabilities. These court cases address basic misunderstandings of the IDEA's LRE principle and can be instructive to school district officials for making planning and policy issues regarding placements. Finally, we offer a model to assist teams for making educationally appropriate and legally correct decisions about least restrictive appropriate placements for children and youth with developmental disabilities.

The Fundamental Requirements of Placement

Procedural requirements refer to the process that the IDEA mandates that school personnel adhere to when developing a student's special education program or placement. There are a number of procedural requirements that placement teams must adhere to when determining a student's placement. Because the placement process has remained procedurally unchanged since the passage of the EAHCA, one would think that determining the placement of a student in special education should be a relatively straightforward process. Nonetheless, these procedural requirements have posed a

challenge to school districts (Pitasky, 2002). We now review the fundamental procedural requirements that school district personnel must follow when determining a student's special education placement. Understanding and adhering to these requirements are the foundation of the placement process.

The Placement Process

The IDEA requires that a placement decision be made for all students in special education. Although placement is often thought of in terms of the physical location where a student's IEP will be delivered, in actuality placement also involves consideration of facilities, personnel, and equipment that will be provided in the setting where the IEP services will be delivered (Huefner & Herr, 2012; Pitasky, 2002; Yell, 2012). Thus, it is important that a student's unique educational needs inform and drive the placement decision.

Although the placement decision is not actually a part of the IEP process, usually the IEP team determines a student's placement during the meeting in which a student's IEP is developed. The IDEA requires that a placement team, consisting of a student's parents, persons knowledgeable about the child, the meaning of the evaluation data, and the placement options, determines a student's placement. Bateman (2011) asserted that IEP teams almost always make placement decisions and this practice, although not legally required by federal law, is acceptable because parents are participating members of both the placement and the IEP team. In this chapter, we refer to the IEP meeting as the forum for discussing placement.

The four most important requirements in determining students' placement are as follows:

- Parents must play a meaningful role in the placement decision.

The IDEA requires that school districts must ensure that a student's parents must be a part of the group that makes the placement decision (IDEA Regulations, 34 C.F.R. §300.327). Moreover, the role that parents play in the placement decision must be meaningful. Although the IDEA does not

elaborate on what constitutes parental participation, due process and judicial decisions have shown that parental participation means more than mere physical presence in a meeting; rather, it means that a student's parents must be included in the decision-making process and to be allowed to ask questions and share their opinions and concerns (Slater, 2010). It is not enough, however, to give parents an opportunity to talk if district personnel have already decided a student's placement. The school-based members of the IEP or placement team must actually consider the parents' input (Lake, 2007; Slater, 2010). Although the school district is not required to adopt the placement requested by a student's parents, the parents must have the opportunity to discuss their preferences in the meeting and that school-based team members must consider and discuss the parental placement preferences.

One of the most serious procedural errors that school district personnel can make is to determine a student's placement before the placement or IEP meeting. Predetermining a student's educational placement has often led court rulings that school district personnel had denied a student a free appropriate public education (FAPE) and thus violated the IDEA. Perhaps the surest way for a school district to incur liability for predetermining a student's placement is to hold a placement meeting in which parents are told something like (a) "this placement is the only option available," (b) "all our students with ____ (fill in the blank) disability are served in this placement," (c) "we have placement in the general education setting because we only do full inclusion," or (d) "this is our offer, take it or leave it." Any of the situations would clearly constitute predetermination. On the other hand, one of the best defenses against a predetermination complaint is to offer proof that the team discussed and considered several placement options, including any options proposed by the parents (Slater, 2010). A way in which school district personnel can avoid predetermination claims is to assign a team member to keep notes during the placement discussion and then read and have the team approve the notes after the meeting (Lake, 2007).

- The placement decision can be made only after a student's IEP is written.

Placement decisions must be based on a student's IEP (IDEA Regulations, 34 C.F.R. §300.116(b) (2006)). The purpose of this requirement is to provide the placement team a basis for determining how and where a student's unique educational needs can best be met. According to Yell, Thomas, and Katsiyannis (2012), the litigation has been abundantly clear on this point: A school district cannot assign placement before the education program is developed. A student's placement decision must follow and be based on his or her IEP. Determining placement before the IEP is developed, if challenged in a due process hearing or court, will most likely be a violation of the IDEA. In fact, some legal authorities have used the term "shoehorning" to describe the clearly illegal practice of placing a student in a program and then developing his or her IEP to fit the program (Bateman, 2011; Lake, 2007; Slater, 2010).

Neither should school district personnel develop an IEP that is to be implemented in a pre-selected placement. For example, if a school district has a program for students with autism and it writes an IEP for a student that is designed to be delivered in the predetermined setting, that placement would likely constitute predetermination. This is not to say that the particular program is not the most appropriate setting for a student; the point is that the IEP must be written to address the needs of a student, and only then can the placement be determined.

Slater (2010) asserted that if a student's parents wish to discuss placement at the start of an IEP meeting, then school district members on the IEP team should explain that their child's placement will depend on the contents of the IEP. They should further explain that if placement is determined first, then the IEP will need to be shaped to fit that placement, a practice that is illegal and may deprive a student of needed services. She further advised that the parents be reassured that the team will have a thorough discussion about their child's placement after the IEP is complete.

- A student's placement must be individually determined based on his or her needs.

IEP teams cannot place students in programs based on such factors as the students' category of disability, severity of disability, the availability of

special education or related services, availability of space, or administrative convenience (71 Federal Register 2006, 46,588). Although these factors may be considered, they cannot be the sole determining factor in deciding on a student's placement (Lake, 2007). This requirement is clearly related to the obligation that a student's IEP must be developed before making the placement decision. Again, a student's needs must drive the placement decision.

- Students' placements must be made in accordance with the IDEA's principle of LRE. According to the IDEA:

To the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are not disabled, and special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only when the nature or severity of the disability of a child is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily (IDEA, 20 U.S.C. §1412(a)(5)(A)).

The IDEA, therefore, prefers general education placement but allows for more restrictive placements when attempts to maintain a student in general education by providing supplementary services have not been successful.

There are two parts to the LRE requirement of the IDEA. The first part addresses the presumptive right of all students with disabilities to be educated with students without disabilities. Schools must make good-faith efforts to place and maintain students in less restrictive settings. This presumptive right, however, is rebuttable; that is, the LRE principle sets forth a general rule of conduct (i.e., students with disabilities should be educated with students who are not disabled) but allows it to be rebutted or overcome when total integration in a general education setting is not appropriate for a student (Turnbull, Stowe, and Huerta, 2007). Thus, the IDEA favors integration, but recognizes that for some students more restrictive or segregated settings may be appropriate. Clearly, the law anticipates that placements in more restrictive settings may sometimes be necessary to provide an appropriate education. The US

Supreme Court, in *Board of Education of the Hendrick Hudson School District v. Rowley* (1982), interpreted the LRE principle similarly:

Despite this preference for "mainstreaming" handicapped children—educating them with nonhandicapped children—Congress recognized that regular education simply would not be a suitable setting for the education of many handicapped children... the act thus provides for the education of some handicapped children in separate classes or institutional settings (p. 192).

To ensure that students with disabilities are educated in the LRE that is most appropriate for their individual needs, the regulations to the IDEA require that school districts have a range or continuum of alternative placement options to meet the student's needs. The continuum represents an entire spectrum of placements where a student's special education program can be implemented. Regulations require that:

1. Each [school district] shall ensure that a continuum of alternative placements is available to meet the needs of children with disabilities for special education and related services.
2. The continuum required ... must:
 - (a) Include the alternative placements ... (instruction in regular classes, special classes, special schools, home instruction, and instruction in hospitals and institutions).
 - (b) Make provision for supplementary services (such as resource room or itinerant instruction) to be provided in conjunction with regular class placement (IDEA Regulations, 34 C.F.R. §300.551).

The purpose of the continuum is to allow school personnel to choose from a number of options when determining the most appropriate placement for a student. Champagne (1993) defined restrictiveness as "a gauge of the degree of opportunity a person has for proximity to, and communication with, the ordinary flow of persons in our society" (p. 5). In special education, this ordinary flow of persons means that a student with disabilities has the right to be educated with students in the general education environment when the general education setting is appropriate. The general education environment is considered the least restrictive setting because it is the placement in which there is

the greatest measure of opportunity for proximity and communication with the “ordinary flow” of students in schools. From this perspective, the less a placement resembles the general education environment, the more restrictive it is considered (Norlin, 2009). Students with disabilities, therefore, have the right to be educated in a setting that is not overly restrictive considering what is appropriate for an individual student.

Thus, IEP team members must make and document good-faith efforts to educate a student in the LRE with supplementary aids and services before proposing a more restrictive placement. When it is apparent that a student is not making educational progress in a particular placement, it is important the IEP team considers a placement in which a student will make progress.

Meeting the IDEA’s Procedural Requirements for Placement

The educational placement of students with disabilities has been an issue that has engendered a considerable amount of litigation. Determining students’ placements has been problematic because school districts often make procedural errors when determining a student’s placement. Yell et al. (2012) offered the following suggestions to assist school district teams and parents to ensure that their IEP teams correctly determine appropriate placements for students with disabilities:

- Ensure that IEP team members develop students’ IEPs prior to determining placement.
- Ensure that a student’s parents are on the team that determines their son or daughter’s educational placement and that they have meaningful input into the placement decision.
- Ensure that a student’s IEP or placement team determines his or her placement based on the student’s individual needs and not on the student’s category of disability or severity of disability. Do not substitute either a policy of full inclusion or special program placement for the consideration of a student’s individual needs.
- Ensure that IEP teams make diligent, good-faith efforts to educate students with disabilities in

general education settings with supplementary aids and services. Do not remove a student with a disability from a general education placement unless he or she will not receive an appropriate education in that setting even with the use of supplementary aids and services. Monitor and document a student’s progress, and if a student is not succeeding in a placement, the IEP team should meet to consider placement in a more appropriate, and sometimes more restrictive, setting.

- Ensure that when a decision is made to place a student in a more restrictive setting, the team thoroughly documents the decision-making process, including that they followed the continuum of alternative placements in a step-by-step manner. Additionally, in such situations, the team should make all efforts to include opportunities for students with disabilities to be included in integrated settings.
- Ensure that placement and IEP teams avoid predetermining a student’s placement.

In summary, placement decisions are team decisions that must be based on a completed IEP. The IDEA makes parental participation central in all decisions regarding a student’s placement, and when full and equal parent participation is abridged or denied, a denial of FAPE will most likely be found. Moreover, the placement decision must be made in accordance with the principle of the LRE. LRE has been the subject of much litigation in state and federal courts. We next turn to a discussion of the most significant federal court cases and what they tell us about placing students in less to most restrictive settings.

Relevant Factors in Making LRE Decisions

The placement requirements of the IDEA and the law’s principle of least restrictive requirement are inextricably intertwined. That is, the placement and LRE must be considered in tandem. Whether an education in the general education environment constitutes the LRE for a given student with disabilities, however, has proven to be a thorny legal issue (Huefner & Herr, 2012). LRE disputes

have led to numerous due process hearings, state level hearings, and cases in federal court. Although the US Supreme Court has never heard a case on LRE, a number of US Circuit Courts of Appeals have interpreted the LRE mandate. Because the high court has not heard an LRE case, the LRE interpretations by the circuit courts are the highest authority available. In this section we will review the three most influential LRE cases and extrapolate principles that are important for IEP teams in choosing less to most restrictive settings for students with developmental disabilities. Although these decisions are old by litigation standards, they are still good authority because LRE has been a settled area of law since these rulings were announced (Readers should note that the courts in all three cases referred to the LRE requirement of the IDEA as “mainstreaming.”).

The Roncker Portability Test

The earliest LRE decision at the circuit court level was *Roncker v. Walter* (1983). The decision was out of the 6th Circuit and is still controlling authority in that circuit, which covers Kentucky, Ohio, Michigan, and Tennessee. Additionally, the US Courts of Appeals for the 4th and 8th Circuits subsequently followed the standard developed in the 6th Circuit ruling. Thus, the standard would likely be applied to LRE cases in states in these circuits (i.e., Maryland, North Carolina, South Carolina, Virginia, and West Virginia in the 4th Circuit and Arkansas, Iowa, Minnesota, Missouri, Nebraska, North Dakota, and South Dakota in the 8th Circuit).

Neill Roncker was a 9-year-old child classified as “trainable mentally retarded” by a school district in Ohio. School district personnel believed that the most appropriate placement for Neill was in a special school for children with disabilities. The parents contended believed that Neill would benefit from contact with his peers in a general education setting, and brought suit against the school district, challenging the placement. Both the parents and school district personnel agreed that Neill required special education. The Ronckers

contended, however, that Neill should receive the special education services in a setting that would allow greater integration and contact with students without disabilities.

A due process hearing officer ruled against the school district holding that the district personnel had failed to prove that the proposed placement afforded Neill the maximum appropriate contact with children who did not have disabilities. The school district appealed to the Ohio State Board of Education who reversed the hearing officer’s decision holding that the district had proposed an appropriate program. Nevertheless, the Ohio State Board did require that the school district should provide opportunities for Neill to receive contact with non-disabled children. The Ronckers appealed to the US District Court for the Southern District of Ohio.

The US District Court ruled in favor of the school district. The court held that the LRE requirement allowed schools broad discretion in the placement of students with disabilities. The court ruled that the school district had acted properly in determining Neill’s placement. The Ronckers then appealed to the US Court of Appeals for the 6th Circuit.

The circuit court reversed the decision of the district court and returned the case to the district court requiring that the court reexamine the facts of the case and determine whether the services that made the segregated setting appropriate could feasibly be provided in an integrated setting, and if they could, then the segregated placement would be inappropriate. The standard adopted by the 6th Circuit court has been called the Roncker portability test.

Courts in the 6th Circuit using this test must determine if the services that make the segregated setting more appropriate can be transported to the nonsegregated setting. If the services can be transported, the modification is required by the LRE mandate. According to the court:

Framing the issue in this manner accords the proper respect for the strong preference in favor of mainstreaming while still realizing the possibility that some handicapped children simply must be educated in segregated facilities either because the handicapped child would not benefit from mainstreaming, because any marginal benefit from

mainstreaming are far outweighed by the benefits gained from services which could not feasibly be provided in the non-segregated setting, or because the handicapped child is a disruptive force in the non-segregated setting (p. 1064).

In *Devries v. Fairfax County School Board* (1989), the US Court of Appeals for the 4th Circuit cited the Roncker portability standard in ruling that the general education setting with supplementary aids and services was not appropriate for a student with autism. The Devries court agreed that the Roncker portability standard recognized the strong Congressional preference for educating students with disabilities while allowing for the possibility of students being educated in more restrictive settings because a student:

would not benefit from mainstreaming, because any marginal benefits received from mainstreaming are far outweighed by the benefits gained from services which could not feasibly be provided in the non-segregated setting, or because the handicapped child is a disruptive force in the non-segregated setting (p. 878).

Michael Devries was a 17-year-old student with autism. Michael's parents wanted him placed at a local high school. School personnel in the Fairfax Public School System, however, believed that Michael would only receive an appropriate education if he were educated in a special class at a nearby vocational school. The court agreed that Michael would not receive an appropriate education at the local high school even if he were provided with supplementary aids and services. Additionally, the court noted that the special class placement in the public vocation school provided Michael with a structured academic program that he needed as well as vocational and social skills training, community-based work experiences, and access to all the programs and facilities of the public high school.

In 1997, the US Circuit Court of Appeals for the 4th Circuit ruled on another LRE case, *Hartmann v. Loudoun County Board of Education* (1997). Mark Hartmann was an 11-year-old child with autism. His family lived in Loudoun County, Virginia, where he attended Ashburn Elementary School. Based on Mark's previous IEP, school officials decided to place him in a general education classroom. School

officials hired a full-time aide, provided specialized training for his teacher and aide, provided 3 h per week of instruction with a special education teacher (who also served as a consultant to Mark's teacher and aide), and provided 5 h per week of speech therapy. Additionally, the entire staff at Ashburn Elementary received in-service training on autism and inclusion. The IEP team also included the supervisor of the Loudoun County program for children with autism. Finally, the IEP team received assistance from two consultants.

Despite these measures, the IEP team determined that Mark was making no academic or behavioral progress in the general education setting. Moreover, his behavior problems were extremely disruptive in class. Because of his aggression toward others (e.g., kicking, biting, punching), five families asked to have their children transferred to another classroom. The IEP team proposed that Mark be moved to a program for children with autism in a regular elementary school where he would receive academic instruction and speech therapy in the special class and attend a general education classroom for art, music, physical education, library, and recess. The parents disagreed with the IEP, asserting that it violated the mainstreaming provision of the IDEA. The school district initiated a due process hearing. The due process hearing officer upheld the school district's IEP, and the state review officer affirmed the decision. The Hartmanns challenged the hearing officer's decision in federal district court. The district court reversed the due process decision, specifically rejecting the administrative findings and ruling that the school had not taken appropriate steps to include Mark in the general education classroom. The school district filed an appeal with the US Court of Appeals for the 4th Circuit.

The circuit court reversed the district court's ruling again stating that the IDEA's mainstreaming provision established a presumption, not an inflexible mandate. The circuit court also admonished the district court for substituting its own judgment for that of educators. Additionally, the court reaffirmed their ruling in *Devries* in holding that mainstreaming is not required when (a) a student

with a disability would not receive educational benefit from mainstreaming in a general education class; (b) any marginal benefit from mainstreaming would be significantly outweighed by benefits that could feasibly be obtained only in a separate instructional setting; or (c) the student is a disruptive force in the general education classroom.

In the *Devries* and *Hartmann* decisions, the US Court of Appeals for the 4th Circuit cited the *Roncker* standards as the appropriate test for determining a court's compliance with the LRE mandate of the IDEA. Nonetheless, the 4th Circuit court seemingly paid greater deference to educational decisions of school district personnel than did the 6th Circuit. Additionally, the *Devries* and *Hartmann* decisions focused on when the portability standard would be overcome.

The *Daniel* Two-Part Test

Perhaps the most influential, case regarding the LRE mandate came from the US Court of Appeals for the 5th Circuit in *Daniel R.R. v. State Board of Education* (1989; hereafter *Daniel*). The *Daniel* decision is the legal authority on LRE in the states that comprise the 5th Circuit: Louisiana, Mississippi, and Texas. It has proven to be a persuasive decision and has subsequently been adopted by the US Court of Appeals for the 3rd Circuit, which is the legal authority in Delaware, New Jersey, and Pennsylvania, and by the US Court of Appeals for the 11th Circuit, which is the legal authority in Alabama, Georgia, and Florida.

Daniel was a 6-year-old boy with Down syndrome enrolled in the El Paso, Texas Independent School District. Daniel was placed in a prekindergarten class for half of the school day and an early childhood special education class for the other half. Shortly after the beginning of the school year, Daniel's teacher informed the school placement committee that Daniel was not participating in class and was failing to master any of the skills taught, even with almost-constant attention and instruction from the teacher and aide. The committee met and decided that the prekindergarten class was inappropriate for Daniel so he was removed from the prekindergarten class

and attended only the early childhood special education class. Daniel did interact with children from the prekindergarten class at recess and lunch. The parents filed for a due process hearing. The hearing officer ruled for the school district. The officer concluded that Daniel could not participate in the prekindergarten class without almost-constant supervision from the teacher, that he was receiving little educational benefit, and that he was disrupting the class because his needs absorbed most of the teacher's time. The officer also noted that the teacher would have to modify the curriculum totally to meet Daniel's needs. The parents filed an action in the US District Court. The district court affirmed the hearing officer's ruling, and Daniel's parents appealed to the US Court of Appeals for the 5th Circuit.

The circuit court asserted that Congress had been imprecise in defining the IDEA's mandates and had deliberately chosen to leave the selection of educational policy and methods in the hands of local school officials. The court further noted that Congress had created a statutory preference for mainstreaming while at the same time creating a tension between the appropriate education and LRE mandates of the law. By creating this tension, Congressional writers had recognized that the general education environment would not be suitable for all students with disabilities and, at times, a special setting or school may be necessary to provide an appropriate education. Essentially, the *Daniel* court held that when the provisions of FAPE and mainstreaming are in conflict, the mainstreaming mandate becomes secondary to the appropriate education mandate.

The *Daniel* court declined to follow the 6th Circuit's analysis in *Roncker*. In fact the court wrote that the *Roncker* test necessitated "too intrusive an inquiry into educational policy choices that Congress deliberately left to state and local school districts" (p. 1046). Congress, according to the court, had left the choice of educational methods and policies to the schools. The court's task, therefore, was to determine if the school had complied with the IDEA's requirements.

The court noted that the statutory language of the LRE mandate provided an appropriate test for

determining a school's compliance with the LRE requirement. Relying on this language, the court developed a two-part test for determining compliance with the LRE requirement.

First, the court must ask whether education in the general education classroom, with the use of supplementary aids and services, could be satisfactorily achieved. To make this determination, a court must decide whether the school has taken steps to accommodate a student with disabilities in the general education classroom. Such attempts should include supplying supplementary aids and services and modifying the curriculum.

When determining whether the school complied with the first part of the test, the court must also decide if the student will receive benefit from the general education classroom and if the mainstreamed student will negatively affect the education of classroom peers. If the school has not attempted to mainstream the student to the maximum extent appropriate, the school will fail the first part of the test. The inquiry will thus end because the school district will have violated the LRE mandate of the IDEA.

If the court determines that a school district has passed the first part of the test, the court then moves to part two. Here, the court asks whether the school has mainstreamed the student to the maximum extent appropriate by relying on the continuum of placements. In situations in which a student was placed in a more restrictive placement, the court must determine whether the school district has provided the student with as much exposure to students without disabilities as possible. The *Daniel* court suggested that students who are educated primarily in segregated settings should be placed in integrated settings outside the special education classroom when feasible (e.g., nonacademic classes, lunch, recess).

If the school meets both parts of the two-part test, then its obligation under the IDEA is fulfilled. After applying the two-part test in *Daniel*, the 5th Circuit determined that Daniel's needs were so great and that he required so much of the teacher's time that it was affecting the education of the other students negatively. The court, finding that the school district had met the requirements of the two-part test, affirmed the decision of the

district court that the school district has satisfied the LRE requirement of the IDEA. In addition to the test, the *Daniel* court provided further direction for lower courts to follow in LRE cases in noting that the court's "task is not to second-guess state and local school officials; rather, it is the narrow one of determining whether state and local school officials have complied with the Act" (p. 1048).

The *Rachel H.* Four-Factor Test

On January 24, 1994, the US Court of Appeals for the 9th Circuit affirmed a district court's decision in *Sacramento City Unified School District Board of Education v. Rachel H.* (1994; hereafter *Rachel H.*). This case is the legal authority for the 9th Circuit, which covers Alaska, Arizona, California, Hawaii, Idaho, Montana, Nevada, Oregon, and Washington. The test developed by the 9th Circuit, which was very similar to the *Daniel* two-part test, has not been adopted by any other circuit.

The case involved Rachel Holland, an 11-year-old girl with moderate mental retardation. From 1985 to 1989, Rachel attended a number of special education programs in the Sacramento School District. In the fall of 1989, Rachel's parents requested that she be placed in a general education classroom during the entire school day. The district contended that Rachel's disability was too severe for her to benefit from being in a general education class and proposed that she be placed in special education for academic subjects, attending the general education class only for nonacademic activities (e.g., art, music, lunch, recess). The parents removed Rachel from the school and placed her in a private school. The parents also requested a due process hearing. The hearing officer held for the parents, ruling that the school district had failed to make an adequate effort to educate Rachel in the general education classroom. The school appealed the decision to the district court. The court, relying on the decisions in *Daniel* and *Greer v. Rome City School District*, considered four factors in making its decision (see Fig. 12.4 for the *Rachel H.* four-factor test).

The first factor concerned the educational benefits available to Rachel in the general education classroom with supplementary aids and services as compared with the educational benefits of the special education classroom. The court found that the district, in presenting evidence, had failed to establish that the educational benefits of the special education classroom were better than or even equal to the benefits of the general education classroom.

The second factor the court considered was the nonacademic benefits of each classroom. The court decided that the Hollands' testimony, that Rachel was developing social and communication skills as well as self-esteem, was more credible than the district's testimony that Rachel was not learning from exposure to other children and that she was becoming isolated from her peers. The second factor, therefore, was decided in favor of the Hollands.

Third, the court examined the impact of Rachel's presence on others in the general education classroom, attempting to determine whether Rachel's presence was a detriment to others because she was disruptive or distracting and if she would take up so much of the teacher's time that the other students would suffer. Both parties agreed that Rachel followed directions and was not disruptive. Also, the court found that Rachel did not interfere with the teacher's ability to teach the other children. The court ruled that the third factor was in favor of placement in the general education class.

Interestingly enough, in 1994, the 9th Circuit court also applied its four-factor test in an LRE case involving a student with serious problem behavior (*Clyde K. v. Puyallup School District*, 1994). This case is important because it addresses an issue that the other LRE courts did not need to address directly: What is the school's duty with respect to LRE when a student's behavior has a negative effect on other students? When applying the third factor regarding the student's behavior, the court noted the negative effect of the student's problem behavior on his classmates. In their opinion the judges asserted that school officials are required to ensure that all students with disabilities are not required to ignore problem

behavior when making placement decisions because the officials have an obligation to ensure that students are educated in a safe environment.

The fourth factor the court evaluated was the cost of placement in the general education classroom. The court found that the school district had not offered persuasive evidence to support its claim that educating Rachel in the general education class would be far more expensive than educating her in the combined general education and special education placement. Thus, the cost factor did not provide an impediment to educating Rachel in general education. Weighing the four factors, the district court determined that the appropriate placement for Rachel was full time in the general education classroom with supplemental aids and services.

An appeal to the 9th Circuit was heard on August 12, 1993, and the court delivered its opinion on January 24, 1994. The circuit court affirmed the decision of the district court. The higher court stated that the school district had the burden of demonstrating that its proposed placement provided mainstreaming to the maximum extent appropriate. The circuit court adopted the district court's four-factor test in determining that the school district had not met the burden of proof that Rachel could not be educated in the general education classroom. The court found the Hollands' position for inclusion to be more persuasive. Although the case was appealed to the US Supreme Court, the high court declined to hear it.

Applying Judicial Standards to Placement Requirements

The decisions in *Rocker*, *Daniel*, and *Rachel H.* are very important, especially in the states covered by these respective circuits. This is because hearing officers, state review boards, and lower courts are required to adhere to the standards developed by the higher courts in their jurisdictions, which, in the absence of a decision by the US Supreme Court rulings, are the US Court of Appeals. Thus, hearing officers, state hearing officials, and judges in the 4th, 6th, and 8th Circuits will likely adhere to the *Roncker* portability test. Hearing officer,

state hearing officials, and judges who reside in states in the 3rd, 5th, and 11th Circuit will adhere to the Daniel two-part test, and those in the 9th Circuit will follow the Rachel H. four-factor test. There are no LRE decisions from the US Courts of Appeals for the 1st Circuit (Maine, Massachusetts, New Hampshire, and Rhode Island), 7th Circuit (Illinois, Indiana, and Wisconsin), or the District of Columbia Circuit.

It is important to understand that the tests in these cases will guide the decisions in litigation within a given circuit; however, these standards will be applied to the specific set of facts in a case. Therefore the standards by themselves will not determine the outcome in a particular case. Nevertheless, these rulings in these can be very useful in planning and policy decisions because the principles in the cases provide information on the actions school district personnel need to take when determining placements in the LRE. We next extrapolate important principles for determining placements in the LRE derived from these cases.

Principles from the LRE Case Law

Appropriateness

The keystone principle in the IDEA is that a student's educational program must confer meaningful educational benefit. As the US Circuit Court of Appeals for the 5th Circuit noted in *Daniel R. R.*, Congress created a tension between the FAPE and LRE provisions of the IDEA. This tension, according to the court, was due to the requirement that a student's special education program must be tailored to his or her specific needs and must confer educational benefit and the requirement that whenever possible the student should be educated in the general education classroom. The court also noted that:

regular classes, however, will not provide an education that accounts for each child's particular needs in every case ... For these children, mainstreaming does not provide an education designed to meet their unique needs and, thus, does not provide a free appropriate public education. As a result, we cannot evaluate in the abstract whether a challenged placement meets the (law's) mainstreaming

requirement. Rather, that laudable policy objective must be weighted in tandem with the (law's) principle goal of ensuring that the public schools provide handicapped children with a free appropriate public education ... In short, the (law's) mandate for a free appropriate public education qualifies and limited its mandate for education in the regular classroom (p. 1042).

Therefore, whenever a court is confronted with a LRE case, the court must consider whether a school district has (a) tailored a student's special education program to his or her unique educational needs and (b) whether the special education has provided meaningful educational benefit. Only then can a court judge the adequacy of a school placement with respect to the LRE, and if the general education classroom does not provide an appropriate program, then that setting is not the LRE. In other words, as always is the case with the IDEA, the student's needs drive programming and placement.

Individualization

The IEP team (or placement team) is the forum for determining the placement for students with disabilities in the LRE. The IDEA and the implementing regulations clearly require that these decisions must be individualized. According to the comments to the IDEA regulations, "the overriding rule ... is that placement decisions must be made on an individual basis" (IDEA Regulations, 34 C.F.R. §300.552, comment). Similarly, the Office of Special Education and Rehabilitation Services (OSERS) in the US Department of Education has interpreted the LRE mandate as follows: "Children with disabilities should be educated with nondisabled children to the maximum extent appropriate; however, the determination of whether to place a child with disabilities in an integrated setting must be made on a case-by-case basis" (*Letter to Stutler and McCoy*, 1991, p. 308).

Because all placement decisions must be individualized, certain actions are never appropriate. Thus, school districts should never develop blanket policies regarding LRE decisions. For example, it would be clearly illegal for school

district personnel to deny a student a placement in an appropriate, but more restrictive, setting because “we do full inclusion.” Similarly, it would be as illegal if a student were denied placement in a general education setting because “we have special class placements for all students with Autism.”

Integration

When the EAHCA was first passed in 1975, the Congressional authors evinced a clear preference for educating students with disabilities alongside their nondisabled peers in general education classes. The law, and this preference, has not been changed with respect to LRE in the almost 40 years of the laws’ existence. To ensure that integration occurs whenever possible, Congress required that school district personnel made good-faith efforts to educate students with disabilities in the general education classroom, which includes providing supplementary aids and services. Supplementary are supports that are provided in a general education classroom to enable student with disabilities to be educated with their nondisabled peers to the maximum extent appropriate. Such aids and services may include, but are not limited to, resource room, itinerant teachers, aides, behavioral supports, adaptive equipment, curriculum adaptations, consultation, and assistive technology. The IDEA’s preference for integration extends beyond academic activities to nonacademic activities (e.g., physical education, meals, recess, special interest groups, clubs) and extracurricular activities (athletics, transportation, recreational activities). If needed to support a student’s engagement in academic, nonacademic, and extracurricular activities, supplementary aids and services should be considered. If the IEP team determines that supplementary aids and services are required, then they must be provided to a student and included in his or her IEP (Pitasky, 2002).

Prior to 1997, the IEDA required that IEP teams have to include a statement in a student’s IEP of the extent to which a student would be able to participate in regular education programs. In the IDEA reauthorization of 1997 Congress

required that if a student was not participating with nondisabled students and in extracurricular and nonacademic activities with students who do not have disabilities, the IEP had to include a statement of the extent to which the student would not participate. According to Huefner and Herr (2012), this small change enhanced the legal support for integrating students with disabilities in general education classrooms. Huefner and Herr (2012) also asserted that if a dispute arises with respect to an IEP placement, the school district will bear the burden of showing evidence that a student cannot participate in the general education setting.

Options

All school districts must ensure that a continuum of alternative placements is available to meet the placement needs of students with disabilities. The continuum consists of (a) general education classroom, (b) general classroom with supplementary aids and services, (c) special classes, (d) special schools, (e) home instruction, and (f) instruction in hospitals and institutions. The purpose of the continuum is to ensure that students are served in settings where they will receive an appropriate education in the LRE (Federal Register 2006). Although this list is not exhaustive, the least restrictive placement on the continuum always begins in the general education setting, and placements become more progressively more restrictive as students move along the continuum (Pitasky, 2002). The IDEA’s continuum of alternative placements is essential to the provision of special education in the LRE so when students are placed in more restrictive settings, the decisions are more likely to be based on an individual student’s needs rather than administrative convenience or the lack of availability of placement options (Yell, 2012).

When school district personnel determine that a more restrictive setting is necessary, they should move lockstep through the continuum. That is, begin with education in the general education classroom, including providing supplementary

aids and services, and if that setting will not provide an appropriate education, move the student to more restrictive settings. Weatherly (2007) suggested that the Congressional presumption for education in the general education setting is so strong that school district should always consider placing students in general education setting with supplementary aids and services, prior to moving students to more restrictive placements.

Court decisions in LRE cases from the US Court of Appeals for the 3rd Circuit (*Oberti v. Board of Education*, 1993) and another from the US Court of Appeals for the 11th Circuit (*Greer v. Rome City School District*, 1991) were decided against school districts. In both these cases school district lost when courts would not accept the more restrictive settings chosen by the school district when there was no evidence that the district's placement team had made good-faith efforts to provide an appropriate education in a less restrictive setting and the school district had skipped steps in the continuum.

Implications for School Districts

School district personnel often find that making placement determinations for students with developmental disabilities is a difficult undertaking. Although placement has been a highly litigated area in special education, the issue of determining placement in the LRE is now a relatively settled area of law. In the final sections of this chapter, we (a) present a sequential model for making placement decisions that meet the letter of the law and (b) end with our thoughts on making placement decisions that complement a student's educational program.

Placement Decisions that Meet the Letter of the Law

The IDEA clearly specifies the procedures that school district personnel must follow when deciding on a student's placement. Table 16.1 depicts the requirements of the IDEA.

To make placement decisions that meet the requirements of the IDEA, school district personnel must first develop a student's IEPs, including the present levels of academic achievement and functional performance, measurable annual goals, special education services, and a progress-monitoring system. Only when a student's FAPE has been finalized may the student's placement in the LRE be considered. To assist IEP teams with placement decisions, Fig. 16.1 is a flow chart that depicts the important decisions that a team must make and the order in which these decisions must be made.

Placement Decisions that Complement a Student's Program

The IDEA requires that a student's IEP team develops a program of special education services that are calculated to provide meaningful educational benefit. IEP development requires that teams assess a student's needs and develop a program, which includes measurable goals, research-based special education services, and a system for monitoring student progress. Additionally, after the student's IEP is developed, the team determines the student's placement. Although educational placement and educational programming are often considered separate tasks to be completed by the team, they are not isolated components. Rather, placement and programming should complement each other in ways that lead to improved results for a student.

For students with developmental disabilities, programming and placement should not only complement each other, but also should be highly related (Drasgow, Wolery, Halle, & Hajiaghamseni, 2011). That is, the content of a student's IEP should determine the context and location of instruction. For example, if an IEP goal for a student includes social skills, then the context of instruction would be environments where these skills are needed and where other peers and potential social partners are available. Fortunately, the structure of IEP goals and objectives contains the components that school districts can follow to make good decisions about

Table 16.1 Placement requirements of the IDEA

Requirement	Citation
The IEP must be developed before the placement decision is made because the placement must “be based on the child’s IEP”	IDEA Regulations, 34 C.F.R. §300.116(b)(2)
A student’s parents must be members of the team that makes the decisions regarding the student’s educational placement	IDEA Regulations, 34 C.F.R. §300.327
The placement decisions must be by a group of persons, including a student’s parents, and other persons knowledgeable about the student, the meaning of the evaluation data, and the placement options	IDEA Regulations, 34 C.F.R. §300.116
The IEP team can serve as the placement team	Appendix A to Part 300 of IDEA Regulations, Notice of interpretation, Question No. 37 (1999 regulations)
A student’s placement must (a) be determined at least annually, (b) be as close as possible to the student’s home, and (c) be based on the student’s IEP	IDEA Regulations, 34 C.F.R. §300.116
To the maximum extent appropriate students with disabilities are to be educated with students who are not disabled	IDEA Regulations, 34 C.F.R. §300.114(a)(2)
Special classes, separate schooling or other removal of students with disabilities from the general education environment occurs only if the nature or severity of the disability is such that education in general education classes with supplementary aids and services cannot be achieved satisfactorily	IDEA Regulations, 34 C.F.R. §300.114(a)(2)
School district must ensure that a continuum of alternative placements is available to meet the needs of students with disabilities	IDEA Regulations, 34 C.F.R. §300.115(a)
In selected the LRE, school district personnel must give consideration to any potential harmful effect on the student or on the quality of services that he or she needs	IDEA Regulations, 34 C.F.R. §300.116(d)
School districts must take steps, including the use of supplementary aids and services, to provide an equal opportunity to participate in nonacademic and extracurricular services and activities	IDEA Regulations, 34 C.F.R. §300.107(a)
Nonacademic and extracurricular services and activities include counseling, athletics, transportation, health services, recreational activities, special interest groups or clubs	IDEA Regulations, 34 C.F.R. §300.107(b)
A student with a disability cannot be removed from education in age-appropriate regular classrooms solely because of needed modifications in the general education curriculum	IDEA Regulations, 34 C.F.R. §300.116(e)
Unless the IEP of a student with a disability requires some other arrangement, the student should be educated in the school he or she should attend if they did not have a disability	IDEA Regulations, 34 C.F.R. §300.116

the proper context for instruction and, thus, make the best placement decision.

In order to be individualized and measurable, a goal or objective statement should contain four components: the student, the behavior, the condition, and the criterion for acceptable performance (Alberto & Troutman, 2013; Westling & Fox, 2009). Consider the following goal:

Student	Behavior	Condition	Criteria
Bobby	Will identify coins	When prompted by his teacher	With 100 % accuracy for 10 consecutive opportunities

Although this goal has all four components, both the behavior and the condition are flawed. The behavior is flawed because it is a *splinter skill* and, by itself, does not produce a meaningful outcome. Identifying coins is a splinter skill because it is extracted from the cluster of skills (e.g., making a purchase) that would make it useful and functional. The condition is also flawed because “prompted by his teacher” (a) does not specify a corresponding context in which money skills are naturally and normally useful and (b) is not a condition that has independence as the outcome. Because of these flaws, the IEP team

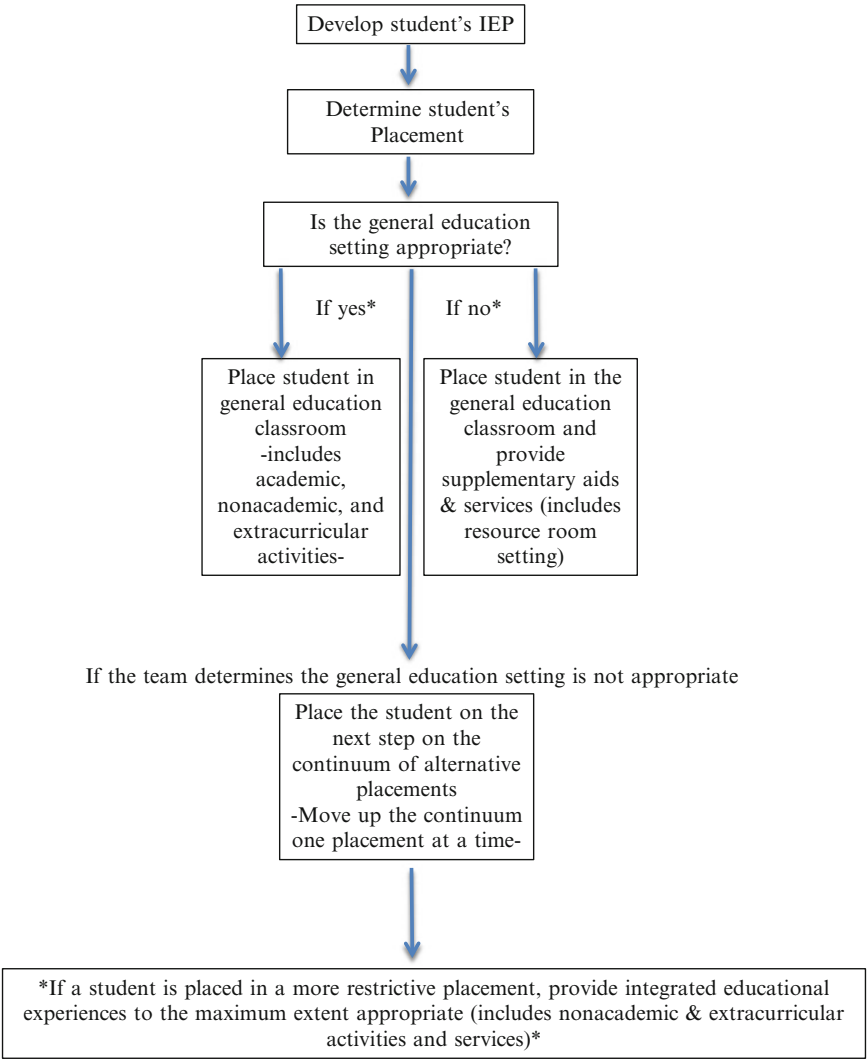


Fig. 16.1 Placement decision-making sequence

would be challenged to make a decision about placement because this goal is disconnected from any real world or instructional setting. It is devoid of context and could be taught in a segregated setting as easily as it could be taught anywhere else.

Consider this goal:

Student	Behavior	Condition	Criteria
Bobby	Will independently greet his typically developing peers	When they arrive to the regular education classroom	With 100 % accuracy for 10 consecutive opportunities

This goal is much better formed for at least two reasons. First, the skill is one that has a functional outcome because it fosters meaningful interaction with typical peers and has independence as the outcome. Second, the behavior (i.e., greeting typically developing peers) is related to a context (i.e., the regular education classroom) and thus makes the IEP team decision about placement much easier. The process for making placement decisions begins with a comprehensive assessment of the skills necessary for a student to become more independent in current and future environments so that IEP skills can have a corresponding natural

content (Renzaglia, Karvonen, Drasgow, & Stoxen, 2003). Placement decisions then are based on maximizing instruction in environments where the skill can be taught in its most natural context.

Curricular assessment leading to IEP goals for students with developmental disabilities, including autism, should include such areas as, for example, academics or functional academics, leisure skills, social skills, communication skills, and self-help skills (Snell & Brown, 2011). This assessment may lead to a variety of IEP goals that may not fit neatly into any one placement. Consider a young student with autism who is reading at or near grade level but has substantial deficits in self-care skills and communication skills. This situation presents a particular thorny problem for school districts when discussing placement. The best way to address this situation is to (a) consider the unique needs of the student, (b) determine the placement in which his or her needs will best be met, and (c) ensure that the student is served in the LRE that will meet his or her needs. In the situation cited above, multiple placements may be needed to confer meaningful educational benefit. In areas in which the student does well (i.e., reading), the general education setting may be most appropriate. In the areas in which the student has substantial deficits (i.e., self-help skills), a placement that offers more intensive educational programming may be necessary. Finally, when determining a placement where the student's communication needs can best be met, the team must consider the effects of his or her exposure to students with well-developed skills, which may serve as a model for the student. Thus, a more integrated setting may be appropriate.

Summary

Individualized program planning teams often have difficulty in determining appropriate educational placements for students with developmental disabilities. In this chapter we have discussed (a) fundamental legal requirements regarding placement, (b) rulings in federal courts regarding placement decisions made by IEP teams, and (c) a model to assist IEP teams in making legally

correct placement decisions. We have noted that the law regarding placing students with developmental disabilities in educational settings, including determination of students' LRE, is a well-settled area. Nonetheless, such placement decisions may be controversial. Such controversy, however, does not override two basic facts. First, such decisions must be made in accordance with a student's educational and functional needs. Thus, the most important consideration is in what placement will a student receive an appropriate education. Second, students with developmental disabilities must be educated with students who do not have disabilities to the maximum extent appropriate. It is critical that IEP team members understand the importance of educating students with developmental disabilities in the least restrictive placement, which will include the provision of supplementary aids and services to allow the student to receive a meaningful education in whatever setting is ultimately chosen.

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How to Make Effective Evaluation of Psychotropic Drug Effects in People with Developmental Disabilities and Self-Injurious Behavior

17

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Introduction

The purpose of this chapter is to give clinicians, especially behavior analysts, guidelines for evaluating the literature and making effective clinical decisions about the use of psychotropic medication for treatment of people with developmental disabilities (DD) who also have serious self-injurious behavior (SIB). We review only the literature relevant to the topic at hand. There are several conflicting reviews of the broader literature on psychotropic drugs and intellectual disabilities, from different countries, that are of varying quality and exhaustiveness. Different countries may not have the same practice guidelines for their use. We will restrict our discussion mostly to use in the USA, where the prevalence of behavioral intervention is common in the treatment of SIB and where most states already have guidelines for behavioral and pharmacological intervention in DD and a history of laws governing their use (see Valdovinos, Schroeder, & Kim, 2003 for review). Much of our discussion may also be applicable to other settings in other countries as well.

Significance and Background

SIB refers to acts directed toward one's self that may result in tissue damage (see Rojahn, Schroeder, & Hoch, 2008; Schroeder, Oster-Granite, & Thompson, 2002; Schroeder, Loupe, & Tessel, 2008 for comprehensive reviews of both the human and the animal literature). It occurs most frequently among persons who have severe or profound intellectual developmental disabilities (IDD) and/or autism. It is a cardinal symptom of over 15 genetically linked syndromes (e.g., Lesch-Nyhan Syndrome) which involves a genetic disorder of purine metabolism (Lesch & Nyhan, 1964). Prevalence estimates of SIB among people with IDD range widely from 2 to 90 %, depending on a variety of variables and the population sampled, but they average from 10 to 25 % (Rojahn & Esbensen, 2002). Thus, people with severe or profound DD, who live in residential facilities and who have serious often life-threatening SIB in the USA, number at least 35,000. The total prevalence, including milder forms of SIB among higher functioning people, is unknown, but it is likely much higher (over 600,000+ in the USA).

SIB is a devastating chronic condition for which there is no known cure. A Consensus Development Conference by the National

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Institute of Child Health and Human Development (National Institute of Health, 1991) on destructive behavior estimated that the annual cost of services to people with DD who injure themselves or harm others or damage property in the USA exceeds \$3.5 billion dollars per year. Thus, destructive behavior is a significant problem, often leading to life-threatening crises among families and other caregivers. Thus far, few preventative efforts have been made. There is good agreement on the behavioral and environmental risk factors related to its occurrence, but not on its genetic and neurobiological bases.

There have been at least ten different hypotheses as to the etiology of SIB over the past 30 years (Rojahn et al., 2008). About half of them are based upon the premise that much of SIB is learned, since behavioral intervention procedures can change it in many cases. Only about 10 % of studies in this area, however, have experimented with generalization and maintenance of their interventions (Kahng, Iwata, & Lewin, 2002).

Unfortunately, most of these behavioral changes achieved do not generalize well and are not maintained in the long term without surveillance and continued intervention. Early studies (Schroeder et al., 1982; Schroeder, Schroeder, Smith, & Dalldorf, 1978), in which we followed up 208 individuals with SIB after behavioral and/or psychopharmacological interventions, showed that while approximately 20 % remitted spontaneously without treatment, 94 % improved while on behavioral and/or psychopharmacological programs, but 2 years after the program ended, all of the chronic severe cases (24) had relapsed. An even poorer outcome was described in a recent 20-year follow-up of a large total population study of SIB in the United Kingdom (UK) by Taylor, Oliver, and Murphy (2011). They found that 84 % of their cases continued their SIB topography and severity. Although these individuals had moved from institutions into the community, they were receiving even more anticonvulsant and psychotropic medications and were accessing fewer daily activities than previously. The authors advocated a stronger emphasis on early identification and

intervention for SIB, as we also have (Mayo et al., 2012; Schroeder & Courtemanche, 2012).

Psychopharmacological interventions for SIB, especially those guided by neurobiological animal and human research on modulators of dopamine, serotonin, and opioid peptide hormones, have shown some success in managing subsets of the SIB population who have disorders in these neurotransmitter systems, but there remains a large number of individuals for whom results are mixed or negative. These treatment failures have led researchers to take a closer and more experimental look at the gene-brain-behavior (GBB) antecedents of SIB, which affect the probability of development and occurrence of SIB in all of its forms and functions (see Chap. 12 of this volume).

A 1999 NIHCD conference on SIB spurred considerable research in the past 10 years on the multiple causes and effects of this likely polygenic disorder. SIB is likely not a single disorder with one primary deficit. It is multiply caused and multiply affected. It is manifested in at least 38 different topographies (Rojahn, 1994) at selected locations on the surface of the body, although the most frequent ones are headbanging with a body part, headbanging with objects, self-biting, self-scratching, self-pinch-ing, and hairpulling. It overlaps heavily, although not completely, with the occurrence of aggression and stereotyped behavior (Rojahn et al., 2008). Three biobehavioral animal and human models reflect GBB risk factors for SIB: (1) disruption of the endorphin system and HPA axis (Sandman, Hetrick, Taylor, & Chicz-Demet, 1997; Sandman, Touchette, Marion, & Chicz-Demet, 2008), (2) elevated brain serotonin and its effects on the HPA axis (Chen et al., 2010; Tiefenbacher, Novak, Lutz, & Meyer, 2005), and (3) dopamine depletion and related elevation of serotonin in the basal ganglia (Lewis & Kim, 2009). This chapter will focus on these three models in evaluating psychotropic drug effects because they have the most SIB-related genetic and neurobiological research published on them to date. We recognize that many of these SIB models are inter-related (Schroeder et al., 2008).

Common Methodological Problems

Designing and carrying out a credible clinical trial of psychotropic and behavioral intervention is a complex matter requiring consideration of many issues. It is very difficult to address them all well in a clinical trial. We will divide them into theoretical issues, design and analysis issues, common design problems in DD populations, common pharmacological issues, common side effects issues, common behavioral issues, consumer satisfaction issues, and political and funding issues.

Theoretical Issues

One's theoretical approach to the use of psychotropic drugs is likely to affect the choice of drug, the method of evaluation, the measures to be used, and the conclusions as to its effects. To many behaviorists, "drug" is a word with negative connotations for ineffective treatment, while to many psychiatrists and biomedical professionals, it is a major treatment for severe behavior disorders in DD, like SIB. Psychiatrists are trained to prescribe medications using DSM IV-TR diagnoses. A national survey by Rush and Frances (2000) revealed that most physicians are not trained to, nor do they readily use such DSM diagnoses for people with DD. Most of them infer some diagnosis from psychopathological symptoms apparently similar to those in the non-DD population.

Most physicians and psychologists in this survey by Rush and Frances (2000) responded that they only used drugs after behavioral programs had failed to be effective. This practice, however, does not appear to be the case everywhere, for example, in the UK (Unwin & Deb, 2008). In the USA, one author (SRS) has even recently done reviews for the Department of Justice, where the consulting psychiatrist came to the facility monthly to review cases and to adjust doses without even seeing the clients. This practice is clearly unethical and illegal.

There are now several psychometric instruments validated for people with DD which take a dimensional approach to psychopathology, but these instruments do not correlate well with DSM categories (see Chap. 8 of this volume). While several of these instruments are sensitive to drug effects, the bottom line is that severe behavior problems like SIB, aggression, and stereotypy of persons with DD are not well studied or placed into context in relation to current DSM diagnoses. Unfortunately, aggression and SIB have been the main reasons for their use. Very few drug studies have been aimed also at changes in symptoms of schizophrenia or depression among people with DD. Usually people with DD have been excluded from such studies.

Most psychiatrists who specialize in the population with DD tend to use the rationale underlying the genetic and neural substrates of the symptoms they are targeting with a certain medication. Many other physicians, who may have little training in DD or psychopharmacology, however, still use the trial-and-error method. Behaviorists also should inform themselves about the basic neuropsychopharmacology underlying behavior problems such as SIB so as to be able to contribute to the interdisciplinary team when making decisions about drugs (see Chap. 12). We have listed some basic papers and textbooks, where appropriate, throughout this chapter that may be helpful to them.

Although the rate of use of psychotropic drugs has decreased over the years from 1970 to 2000, it remains substantial (Valdovinos et al., 2003), and it is likely to continue. A recent survey from a national registry of over 5,181 children and adolescents with autism (Rosenberg et al. (2010) showed that 35 % of these children and adolescents received at least one psychotropic medication. We need to work as an interdisciplinary team with our colleagues in other disciplines (Zarcone, Napolitano, & Valdovinos, 2008) to keep the use of drugs to the minimum necessary.

Another theoretical issue is the research methodology for efficacy of a drug. According to McCannell and Duff (1995), the clinical development and evaluation of a drug by the Food and

Drug Administration (FDA) usually involves four phases: *Phase I*, i.e., testing of the basic pharmacokinetics, pharmacodynamics, and toxicology of the drug in a small number of normal male volunteers in a controlled setting, like a hospital clinical drug metabolism research unit; *Phase II*, i.e., testing larger numbers of patient volunteers selected for the disease under investigation in a hospital, using an open design; and *Phase III*, i.e., testing a broader selection of outpatients in a double-blind, placebo-controlled trial. Randomized assignment to groups or treatments is highly desired in Phase III trials because that is the only way to assure freedom from bias due to placebo effects. Such randomized controlled trials (RCTs) are considered the gold standard by many researchers and clinicians (Higgins & Green, 2006), but there are several pros and cons to such trials, as we will discuss below; *Phase IV* trials are testing with open studies for surveillance in large broader populations with fewer and less restrictive inclusion or exclusion criteria than Phase III trials. Phase IV trials also test the breadth of applicability and the adverse reactions to drugs after long-term use. These are the types of trials most commonly used for clinical decision making discussed in this chapter. Each of the above four phases yields complementary valuable information in the evaluation of a drug. All are necessary, as has been recognized in a widely cited proposed framework for categorizing five levels of evidence of efficacy of an intervention by Nathan and Gorman (2003). Direct drug comparisons are also warranted in large clinical trials to inform the evidence base regarding efficacy and side effects (Tamminga, 2011).

Design and Analysis Issues

We recently published a detailed position paper on designs and analyses of psychotropic and behavioral interventions in DD (Courtemanche, Schroeder, & Sheldon, 2011), which can be used as a companion to this chapter. We will summarize the main points relevant to the evaluation of Phase IV open and single-blind clinical drug and behavioral trials. It is unlikely that most clinicians

would attempt a Phase III randomized double-blind placebo-controlled trial in their practice. These are very time-consuming, labor-intensive, and expensive. Nevertheless, clinicians' awareness of the research in this area and of the accepted criteria for a drug's efficacy is important in matching appropriate drugs in the right dose range for the right client, given that there is a wide variation of behavior phenotypes in a relatively small percentage of the DD population engaging in severe SIB.

The modern era of psychopharmacology for people with DD dates back to a classic review by Sprague and Werry (1971), although its history goes back to the early 1800s. Sprague and Werry (1971) recommended six methodological criteria for drug studies: (1) double-blind, (2) placebo control, (3) random assignment to treatment groups or to the order of treatments, (4) multiple standardized doses, (5) standardized evaluations, and (6) appropriate statistical analyses. These remain the major criteria today for group studies.

Interestingly, Sprague and Werry (1971) also noted the advent of behavior modification techniques, and they recommended their potential utility in evaluating drug and behavior effects. Ironically, their criteria excluded most single-subject behavioral research designs, as we show below. It is possible to test a large group of cases using a single-subject design and then to aggregate them into a group for statistical analysis (e.g., Hellings et al., 2006; Sandman et al., 1993; Thompson, Hackenberg, Cerutti, Baker, & Axtell, 1994), but these designs are the exception more than the rule. They are very expensive, labor-intensive, and may often be limited to smaller numbers of study participants than larger parallel-dose group-designed studies.

It is useful to independently compare the Sprague and Werry (1971) criteria for psychopharmacological trials and behavioral intervention trials, as we do below:

1. *Double-blind conditions* in drug trials require that the caregivers, participants, and prescribing and evaluating team be unaware of the drug condition until after the trial is over. In most behavior intervention studies, this criterion is

- nearly impossible. Single-blind conditions may be achieved if videos are taken and coded by blinded coders not informed of the purpose and the treatment conditions in the study.
2. *Placebo conditions* in drug studies are recommended when possible. Because of ethical concerns, such procedures must be reviewed and approved regularly by a human rights committee. Some clinical facilities ban placebos as a matter of policy. In medical centers and outpatient clinics, placebos are more likely to be approved, but with the restriction that treatment not be withheld from a person who needs it. This situation can often be avoided by using wait-list groups in a cross-over design in which all participants eventually receive treatment or if participants receive the “next best” treatment (O’Leary & Borkovec, 1978). These restrictions, however, often result in excluding crisis cases from a trial, the very people who need treatment the most. In behavioral intervention studies, a similar dilemma exists. Scahill et al. (2009) have suggested that placebo conditions can be avoided if the treatment has been proven effective previously in similar cases.
 3. *Random assignment* in group-designed studies can rarely be done in either single-subject drug or behavior intervention trials used in a clinical setting, especially with crisis cases. Sometimes, order of treatments can be randomized or counterbalanced. In clinical drug trials, a baseline washout condition, then a placebo condition, if circumstances permit, and then a careful titration are usually done. The general rule with drug dosing is “Start low and go slow.” In the case of clinical tapering off a drug or changing to another drug, it usually is done by add-on of the new drug in small steps, then cautious tapering, clinically, of the other drug. Abrupt changes are likely to increase side effects or serious relapse in behavior problems. Such a procedure usually precludes double-blind conditions. In most cases of behavioral interventions, double-blind conditions are inappropriate since success of the procedure usually depends on teaching clients and caregivers to change their behavior. Single-blind conditions for coding of behavior observations are sometimes possible, however, and are recommended.
 4. *Multiple standardized doses* are useful for Phase III clinical trials using group designs to discover the average effective dose range, but they are rarely used in Phase IV open trials. Even in Phase III trials, a preliminary titration under open conditions often is done to find an individual’s optimal dose range for the problem, and then this dose is used in a subsequent double-blind trial. In most behavioral intervention studies, different doses of the behavioral intervention are rarely used (Schroeder, Lewis & Lipton, 1983). We are only familiar with one group study comparing different doses of methylphenidate in combination with different doses of a behavioral intervention for typically developing children with ADHD (Fabiano, Aman, McCracken, McDougle & Vitiello, 2007). While desirable, it is unlikely that these dose-ranging, drug-behavior interaction studies will be done with crisis cases in DD. Napolitano et al. (1995) were able to find nine drug-behavior action studies using single-subject and group designs, five of which used multiple standardized drug doses, but none of which used multiple doses of behavioral intervention. In fact, in most of these drug studies, the therapist held behavioral interventions constant during the drug trial to avoid confounding their effects. A recent study by Aman et al. (2009) appears to be a true drug-behavior interaction study in children with autism using risperidone and a parent-training program. This appears to be one of the few published controlled studies of this type in a population with DD since the study by Campbell et al. (1978), which studied the effects of haloperidol alone and in combination with a Lovaas-type intervention program for children with autism.
 5. *Standardized evaluations* with drug-sensitive psychometric instruments, validated with the DD population, are now available for use since the advent of the Aberrant Behavior Checklist (ABC) (Aman, Singh, Stewart, & Field, 1985). Used in over 300 studies, this 58-item rating scale has proven validity for assessment of drug

effects. Unfortunately, only 3 of the 58 items address the problem of SIB. The Behavior Problem Inventory (BPI-01) (Rojahn, Matson, Lott, Esbensen, & Smalls, 2001) is a 49-item scale that rates both the frequency and severity of SIB, aggression, and stereotypy. It has also proven valid in over 30 studies. Rojahn et al. (2012) have recently published norms across the entire age range based on a large sample from five countries. They also have developed a short form (BPI-S) with 30 items, which is briefer but well validated against the BPI-01. It should prove very useful for clinical purposes in assessing SIB and its overlap with aggression and stereotyped behavior. Other instruments aimed specifically at assessing SIB include the Self-Injurious Behavior Trauma Scale (SIT) (Iwata, Pace, Kissel, Nau, & Farber, 1990), which may also be useful for clinical purposes of rating intensity of SIB crisis cases. Behavioral studies rely on direct observations, clear operational definitions, and quantitative measures of frequency, duration, and their derivative measures. Usually, these are customized for the individual being treated, although some standard procedures have proven very useful. Analogue Functional Analysis (FA) (Iwata, Dorsey, Slifer, Bauman, & Richman, 1982) is such a procedure. A recent derivative of FA adapted for clinical drug trials by Johnson et al. (2007) is the Standard Observation Analogue Procedure (SOAP). These methods are useful in making comparisons across studies more possible. Some human rights committees, however, object to exposing an individual with SIB to further self-injury during these FA assessments. Safeguards, such as rules for halting the assessment due to potential tissues damage, should be instated. Our experience is that parents usually do not object to such procedures once the purpose and importance are explained. It is more likely that service providers will object in order to protect themselves against liability. In such a case, informant questionnaires, such as Questions About Behavior Function (QABF) (Vollmer & Matson, 1995), may be helpful. Consider, however, that ques-

tionnaires often do not provide the same conclusions as traditional FA.

6. *Appropriate statistical analyses* are relevant to larger group-designed studies and, in some cases, to smaller individual clinical trials. Single-subject statistics usually require copious trials per treatment (100+) and are therefore of limited use in crisis cases. Single-subject designs usually eschew statistics. The rationale for this practice has been explained in many papers (e.g., Birnbrauer, Peterson, & Solnick, 1974) and textbooks, (e.g., Barlow, Nock, & Hersen, 2008; Johnston & Pennypacker, 2009; Sidman, 1960). Single-subject trials receive their strength and internal validity from repeated measurements of each treatment, and they get their external validity (generalizability) from repeated replication. FA analysis is a good example; it has yielded valid information in over 450 studies (Kahng et al., 2002). Another example is that in drug studies for treating SIB, naltrexone has proven effective for subsets of SIB cases in 27 of 48 studies, most of which were single-subject but controlled, clinical trials (Symons, Thompson, & Rodriguez, 2004). This result lends to naltrexone's external validity as a potential candidate for use with SIB, although it is currently rarely used by psychiatrists in the USA.

In summary, Phase III clinical trials are an important step in demonstrating efficacy, but they are not the only step. Some have advocated only Phase III studies as evidence of efficacy (Higgins & Green, 2006). The psychopharmacology literature in DD contains mostly open clinical trials. For instance, Cheng-Shannon, McGough, Pataki, and McCracken (2004) reviewed 176 studies of atypical antipsychotics from 1974 to 2003 for all indications among children and adolescents with and without DD, aged 5–28 years, and found 15 double-blind controlled trials, 58 open-label trials, 18 retrospective chart reviews, and 85 case-series reports. While open studies are useful for reporting new drugs whose efficacy may justify more study with in-depth intensive Phase III trials, such as for SIB, where there are ethical concerns related to use of a placebo, or for reporting unusual or idiosyncratic adverse effects, or

drug-drug interactions, they tend to overestimate the effectiveness of a drug. At the same time, Phase III trials are not always useful in clinical decision making in a given case of SIB because they use narrow inclusion and exclusion criteria, which eliminate outlier cases (e.g., participants with multiple diagnoses, seizures, or mild cases). Doing so might increase the likelihood of demonstrating a larger effect, but such a sample also may actually fail to represent a large proportion of the population of interest.

Tunis, Stryer, and Clancy (2003) have argued for Practical Clinical Trials (PCTs), which would include a broader selection of participants more representative of the population under study and conducted in manner more closely aligned with clinical practice, as in the case of Phase IV trials. Few of these studies have been funded by the NIH or promoted by the FDA as yet for individuals with DD. Only two psychotropic drugs, risperidone and aripiprazole, have even been approved by the FDA for use in the DD population. This approval is restricted to aggression in children aged 6 years or older with autism. There is little evidence, however, that SIB, aggression, or stereotyped behavior in autism is any different from other forms of DD. Most physicians, working with the DD population, prescribe psychotropic medications “off-label.” This is deemed a legitimate use of such drugs if there is a clear rationale for using them in a given case (Mayhew, 2005; Unwin & Deb, 2010; Ventola, 2009), and it applies to all branches of medicine, including neonatology.

Common Validity Problems in Clinical Trials with DD Populations

A book on design and statistical analysis of clinical drug trials, with both group and single-subject designs, which we have found very helpful, is by Chassan (1976), who was employed in the Intramural Program at NIMH at the time. He identified several threats to the validity of clinical drug trials that we have also found to be the case in the DD population over the last 45 years. Most of these are appropriate for research studies and not to clinical trials per se, but they help to explain potential biases in some research studies.

Lack of adequate sample size is often the bane of clinical group drug studies in DD. In order to have sufficient statistical power to detect a reliably significant effect, a sufficient number of participants of sufficient homogeneity, using instruments with sufficient sensitivity and specificity, are all required. Often it is difficult to recruit enough participants within a single clinic or facility. In such a case, multisite studies have been employed, involving many sites such as the studies by the Research Units for Pediatric Psychopharmacology (RUPP). As one might suspect, this strategy involves additional administrative, logistic, and statistical problems, in that all sites need to conduct the trials using the same inclusion/exclusion criteria in the same way, the same procedures, the same training on the same instruments, and the same reliability checks for procedural drift. If these criteria are not followed, the study may fail to find an effect of the drug. This was one of several criticisms of a recent widely cited large negative multisite study of risperidone and haloperidol among adults with DD in the UK (Tyrer et al., 2008). Trying to prove the null hypothesis from this study was problematic (Scahill, Aman, McCracken, McDougle & Vitiello, 2008; Scahill et al., 2009).

Single-subject trials do not have sample-size problems in interpreting their results, because they rely mostly on large visually apparent effects. Unfortunately, large unambiguous visually apparent effects are not always the result, and larger multimodal assessments from a variety of sources (e.g., parents, teachers, caregivers) are required to make a confident clinical decision about the drug’s clinically significant effect. Interdisciplinary teams are central to this process.

Extreme heterogeneity of participants is common in this population of persons with DD and SIB, aggression, and stereotypy. Individuals with SIB often have genetic behavioral phenotypes, neurological impairments, physical handicaps, and behavioral difficulties, as well as impaired cognition, communication, and social skills that may affect the statistical and clinical outcome of a study. In ordinary clinical trials, however, this is the variability we must live with. It challenges us to be aware of these sources of variability and to

strive for more robust drug and behavioral treatments.

Participant attrition is another serious problem. Because of their many difficulties, individuals with SIB are often ill and unable to participate in programmed activities. In larger group drug studies, the dropout rate may be high.

Idiosyncratic all-or-none response is another problem for drug studies. Often such variability in response may be due to the way a person metabolizes a drug. If the route of administration is oral, the drug is absorbed by the gut and processed first by the liver. A large proportion of the drug may simply be excreted in the urine (i.e., first-pass effect) until it reaches a sufficient level to enter the blood stream. At this point, the next few elevations in dose may result in an unexpectedly large psychotropic effect or negative side effects like sedation or lethargy. The knowledge of the pharmacokinetics of the drug is very important in titrating it appropriately.

Lack of specificity of drug effects is a common complaint of critics, especially behavioral critics, of drug trials. Some of this criticism apparently comes from a lack of awareness of how psychotropic drugs in general work in the body. Their action is only relatively selective at best. They usually have multiple effects on interconnected neural target sites. It is often believed, for instance, that serotonin reuptake inhibitors should be restricted to treating affective disorders, yet they often also affect aggressive behaviors among certain cases. Antipsychotic drugs allegedly should be restricted to treating schizophrenia, yet they also often affect aggression, stereotyped behavior, and/or SIB. All of these drugs are prescribed for people with mental illness, based upon their symptomatology. These same symptoms overlap considerably with the behavioral symptoms observed in the DD population, although their expression may differ somewhat. By the same token, there is considerable overlap in symptomatology of affective disorders and schizophrenia among people with mental illness (Van Praag et al., 1990). Thus, the sensitivity and specificity of their symptomatology are also limited. By contrast, most behavioral descriptions of aberrant behavior are highly

specific, often to a certain setting, stimulus, and consequence. Generalization and maintenance of behavioral treatments in other settings is often the main problem.

These specificity and sensitivity issues require some give-and-take by the interdisciplinary team. Often the psychiatrist, needing to make a decision about raising or lowering the dose of a drug, will look at all of the behaviorist's graphs of observations of SIB and ask, "Well, is he or she improving or not?" By the same token, the behaviorist will say, "Why are you relying on the Clinical Global Impressions Scale (Guy, 1976) as a valid measure, since it is only your clinical impression?" Meanwhile, the psychometrically oriented clinician will say, "You need to use my rating scale of the parents,' teachers,' and/or caregivers' impressions." Each of these is a different sample estimate of the behavior in question, and each is valuable. None alone is usually sufficient to make an effective consensus clinical decision about the efficacy of a drug treatment for a particular individual.

Ethics of placebo groups or wait lists is another issue that needs to be addressed, especially for crisis cases, such as severe SIB. As mentioned before, these people are often excluded from Phase III clinical trials and treated individually in open Phase IV trials. The use of wait-list and placebo groups with such cases is problematic. Nevertheless, the need to neutralize false expectations about an intervention is still important. Participants and their caregivers are often stressed and desperate for a treatment that will work (Lloyd & Hastings, 2008). Drug studies in this population usually have shown a large placebo effect. Therefore, baseline conditions, comparison of dose effects, and brief treatment reversals under controlled conditions are important whenever possible. Also, single-blinding of observers who code the behaviors may be helpful.

Difficulty in maintaining blinded conditions is another problem in drug and in behavioral studies. If either treatment has a large, immediate effect or serious side effects, it will be apparent (Barlow et al., 2008). If there is little effect, the longer the placebo condition is in effect, the more it will become clear that the treatment is

either working or not working. This outcome has been found several times in recent drug studies in the DD population (McAdam, Zarcone, Hellings, Napolitano, & Schroeder, 2002; Rickels, Lipman, Fisher, Park, & Uhlenhuth, 1970; Vitiello et al., 2005).

Common Pharmacological Issues

Dose Response. Achieving the optimal dose of a medication is one the most important factors in a successful psychopharmacological trial. All psychotropic drugs have side effects that usually increase with higher doses. A typical dose-ranging procedure is to titrate the dosage up slowly until a therapeutic window is found. This dose needs to be checked periodically, to see whether it is still effective. For most psychotropic drugs for SIB, it takes 2–6 weeks to reach steady state. The exception is stimulant drugs for hyperactivity, which are rarely used for individuals with SIB. During the acute phase of a clinical trial (e.g., the first 6 months), this checking should occur monthly or quarterly. After the patient has adjusted to the dose, psychiatrist visits should occur at least every 6 months. If side effects become unacceptable, the drug should be titrated down in small doses as appropriate. No client should be on a psychotropic drug longer than necessary. Even if the drug remains effective, many states have guidelines that call for annual drug holidays when the drug is not used for a short period of time. These dose-ranging trials are important because some individuals respond and some do not. Thus far, it is very difficult to predict who will be a responder. Also, a small number of clients may adversely respond to a medication, e.g., behavioral worsening. In this case, the drug trial is stopped immediately and the adverse response is recorded. In some cases, the drug may be retried later, perhaps in combination with another drug, and it might demonstrate efficacy. Most of these dosing procedures are rather straight forward, but surveys have shown that they often are not followed in practice (Unwin & Deb, 2008). Greater understanding of pharmacodynamics, how drug metabolizing

genes affect efficacy and side effects, shows promise for a more evidence-based selection of a drug and dosing in an individual patient.

In our experience, the optimal dosage of many psychotropic drugs is lower for people with DD than in the non-DD population. There is no consensus guideline for optimal dose ranges, however, in the DD population. For instance, a recently proposed guideline for the use of atypical antipsychotics in DD (De Leon, Greenlee, Sabaawi, & Singh, 2009) recommends upper dose limits twice as high as we have found effective. In some cases (e.g., risperidone), it is even much higher than recommended doses by the pharmaceutical company marketing the drug.

The most comprehensive resource guide for psychopharmacology in DD available has been the *International Consensus Handbook on Psychotropic Medications and Developmental Disabilities* (Reiss & Aman, 1998), which covers each class of medication in terms of main effects, side effects, drug-drug interactions, and clinical indications. Consensus involved 113 expert members from several countries. Unfortunately, it is over 15 years out of date, and many of the more controlled studies have been published since then. Nevertheless, it still contains much useful information. It would be helpful to have an updated edition of this handbook or a comparable up-to-date authoritative information source.

Behavioral interventions should not be changed while a drug change has occurred, to avoid confounding the treatment effect. The general rule in clinical practice is to change only one treatment, drug or behavioral, at a time. This means that most dose titrations may take several weeks, depending on the pharmacokinetics and pharmacodynamics of a given drug. Caregivers should be informed of this issue. However, in extremely serious and health-threatening cases, it may be clinically necessary and justified to make drug and behavioral changes simultaneously.

Drug-Drug Interactions. The best single resource to find drug-drug interactions for different drugs used for SIB is still Reiss and Aman (1998). Drug-drug interactions should be avoided and

monitored carefully when more than one drug at a time is used.

Many individuals with SIB have multiple disorders. Only a minority of individuals requiring psychotropic medication treatment respond adequately to one drug, especially if their behavioral problems have been severe enough to result in placement in a residential treatment or in a state hospital. This applies also to the population without developmental disabilities. In addition, a drug combination may achieve better outcomes with fewer side effects. Individuals require drug combinations selected based on their presentation and DSM IV-TR comorbid diagnosis if one can be honed in on. For example, individuals with severe hyperactivity, impulsivity, aggression, and SIB may require low doses of risperidone together with low-dose atomoxetine. Likewise, individuals presenting with bipolar-like illness, aggression, and SIB may benefit from a combination of low-dose antipsychotic, divalproex and gabapentin (Hellings, 1999).

Common drug interactions in individuals with seizures and DD result from induction of liver enzymes to more rapidly metabolize drugs, as occurs with phenytoin, phenobarbital, carbamazepine, oxcarbazepine, and zonisamide. Another class of drugs commonly producing inhibition of cytochrome enzymes that metabolize many psychotropics is the SSRIs. Paroxetine, fluoxetine, and sertraline inhibit cytochrome P4502D6, which metabolizes many psychoactive medications as well as non-psychotropics. Paroxetine, for example, can increase the effective dose of an antipsychotic to more than tenfold of that prescribed. Drugs used in combination, if metabolized by the same CYP enzymes, will increase the effective doses of each other. For example, divalproex increases the effective dose of the tricyclic antidepressant amitriptyline by 30 %. Lithium toxicity may result if other drugs acting on the kidney are added for hypertension, including ACE inhibitors and diuretics, such as hydrochlorothiazide and furosemide.

Drugs Frequently Used for SIB and Their Side Effects. Every psychotropic drug may have positive and negative side effects, as do most behavior interventions (Williams & Saunders, 1997). In the

literature on drugs for SIB in the population with DD, this is also true, although the most attention has been given to the negative side effects of drugs (Matson, 1998; Matson & Neal, 2009). Few studies have reported positive side effects. For example, some studies have reported increased attention and learning (Sandman et al., 1993), cooperation (Symons et al., 2004), and improved sleep (Thompson et al., 1994) in response to naltrexone and improved sleep and no decline in attention and cognition in response to a low dose of risperidone (Aman et al., 2008; Yoo et al., 2003). Williams and Saunders (1997) have provided a thorough critical review of the many tests and procedures, both cognitive and behavioral, which have been used. It is a good resource guide for the behavior analyst on these issues.

We have provided a detailed review of the psychopharmacological research in Chap. 4 of our recent book on SIB (Rojahn et al., 2008), which is a comprehensive review of the epidemiology; assessment; treatment, both behavioral and pharmacological; and the prevention of SIB, which we have not repeated but only updated in Table 17.1. We report optimum daily doses for adults found in the best-controlled drug studies. Most of these drugs are prescribed for a variety of neuropsychiatric conditions or for aggression, in which SIB may be a secondary target. While there is considerable overlap among these symptoms and SIB (Rojahn et al.), there may also be very different neural substrates for them (Schroeder et al., 2008). Thus, they should not be treated as if based upon the same underlying rationales. Only two drugs have been studied extensively, in which the rationale for SIB was the primary target (i.e., naltrexone and clozapine).

Table 17.1 also reports only side effects that were found in 3 % or more of cases in the drug studies reviewed by Rojahn et al. (2008). There is a much longer list of less common side effects that can usually be averted by lowering the drug dose. Some are very rare side effects (e.g., agranulocytosis), which may occur in less than 1 % of people receiving clozapine or carbamazepine, but which can be fatal if the white cell count is not monitored frequently with blood tests. In such cases, the drug is lowered or stopped if the white cell count continues to drop.

Table 17.1 Optimum effective adult daily dose ranges and adverse side effects of psychotropic medications used most for people with SIB and DD

Drug class	Name Generic	Brand	Daily Dose (mg)	Side Effects
Atypical anti-psychotics	Clozapine	Clozaril	200–300	1,2,3,4,11
	Risperidone	Risperdal	0.5–4	2,3,4,6,8,11
	Olanzapine	Zyprexa	6–16	2,3,
	Quetiapine	Seroquel	75–600	1,2,3
	Aripiprazole	Abilify	10–15	2,3,12 13
Serotonin uptake inhibitors	Clomipramine	Anafranil	100–250	1,2,3,7,10,14
Selective serotonin	Fluoxetine	Prozac	20–80	10,12,13,14,15
Reuptake inhibitors	Sertraline	Zoloft	50–200	10,12,13,14,15
	Paroxetine	Paxil	20–50	1,2,10,12,13,14,15
	Fluvoxamine	Luvox	50–300	2,10,12,13,14,15
Mood stabilizers	Valproic Acid	Divalproex (DVP)	750–3,000	2,3,9,16
		Depakote (tablet)	Same	
		Depakene (liquid)	Same	
	Carbamazepine	Tegretol	200–1,200	3,9,14
	Gabapentin	Neurontin	900–3,600	3,9,12,14,17
	Lamotrigine	Lamictal	100–500	3,9,14
	Topiramate	Topamax	50–400	3,9,12,14,17
	Tiagabine	Gabitril	12–56	3,9,14,17
	Lithium carbonate	Eskalith	600–1,800	1,2,3,11,13,16,17
	Lithium citrate	Cibalith-S	Same	
Narcotic analgesics	Naltrexone	Naltrexone	50–200	10,11,13,14,15
	Naloxone			
Atypical anxiolytics	Buspirone	Buspar	200–450	12,14,15
Beta-adrenergic blocker	Propanolol	Inderal	80–120	1,3,15,17

1-cardiovascular, 2-weight gain, 3-fatigue/sedation, 4-EPS/akathisia, 5-dystonia, 6-tardive dyskinesia, 7-seizures, 8-hyperprolactinemia, 9-elevated liver enzymes, 10-bowel control, 11-enuresis, 12-nausea, 13-headache, 14-agitation, 15-sleep disturbance, 16-tremor, 17-impaired cognition. Sources: Reiss and Aman (1998), Cheng-Shannon et al. (2004), and Hellings (1999)

Drug history is important because behavioral interventions and clinical drug trials with SIB cases often turn out negative and sometimes worsen the behavior. There may be adverse drug reactions (ADRs) or drug-drug interactions that should not be repeated. It is important to have a detailed history of these trials so as not to put SIB clients through the same negative trials. Our experience has been that this circumstance is most likely to occur when there is staff turnover or the physician prescribing the drug changes. Burnout rate of service personnel providing services to SIB cases is high (Noone & Hastings, 2011) because the work is so stressful (Hastings, 2002). *Drug metabolism* is also a key factor in prescribing the dosage and the drug regimen (e.g., times of day, rules for drug monitoring blood levels, wash-

out periods when changing to another drug, avoiding drug-drug interactions). For instance, the peak pharmacokinetic effect for a stimulant, like methylphenidate, may be 15–90 min after administration, and it may clear the system within 4 h after withdrawal, while the pharmacokinetic curves of an antipsychotic may be very different (it may take 2–6 weeks for the peak effective dose to reach steady state). The clearance of some antipsychotics may be on the order of weeks, with small doses remaining in the blood for up to a year or more (Gualtieri, Schroeder, Hicks, & Quade, 1986).

Pharmacodynamic effects, like drug tolerance, may result in loss of therapeutic effects and in the raising of the dose to achieve them again. This is a slippery slope that often is responsible for the overdoses one sees in pharmacy records of some

facilities. Thus, drug monitoring for risk of extrapyramidal movement disorders after chronic antipsychotics should continue much longer than for other drugs.

Drug monitoring needs to be done for all psychotropic drugs as well as annual reviews for drug holidays. Many states have such guidelines in place. Valdovinos et al. (2003) have reviewed these state guidelines and various drug- and side effects-monitoring systems available and their relative utility. De Leon et al. (2009) have recently published a useful set of practical guidelines for administration and monitoring of atypical antipsychotics, the most frequently used psychotropic medication for people with DD and aggression and SIB. Careful drug monitoring is usually the job of the pharmacist, caregivers, and the prescribing physician with the help of the interdisciplinary team.

Pharmacogenetics (i.e., genetic influences on the efficacy and adverse effects of drugs) is a relatively new development in the DD literature on drugs, but it is growing in importance. A good example is a recent paper by Sleister and Valdovinos (2011) demonstrating that several gene polymorphisms or variants may be related to weight gain resulting from the use of atypical antipsychotic drugs. Pharmacogenetics may eventually be able to predict who is likely, and who is not likely, to show important side effects of psychotropic medications.

Common Behavioral Issues

Weeden, Ehrhardt, and Poling (2010) give a good primer for the behavior analyst on psychopharmacological treatments for people with autism that are also relevant for people with SIB. We also have treated these topics in a recent position paper (Courtemanche et al., 2011). We will only summarize the main relevant points below.

Types of Measures

The types of measures most used are psychometric rating scales and checklists and direct

observations. Preference should be given to properly standardized measures for the DD population under study. Matson's *Handbook on Assessing the Persons with Intellectual Disabilities* (2007) is a good guide for the full range of available instruments. Most behavior analysts are familiar with using direct observation measures, so we will not review those specialized for SIB here. Instead, the reader is referred to our book on SIB (Rojahn et al., 2008).

Monitoring Drug-Behavior Interactions. Monitoring drug-behavior interactions is important. Behavior pharmacology is the fundamental field of the study of such interactions as *rate dependency* (Branch, 1984). This phenomenon also can occur in drug studies on SIB. For instance, if the SIB rate of a crisis case is very high, any drug he/she receives is likely to lower the SIB. The use of PRNs (i.e., prescribed as needed) is likely based upon this rationale. On the other hand, the habitual use of PRNs is likely to result in habituation to their effect. Some guidelines prohibit the use of PRNs because they could be used excessively. Similarly, if the SIB rate is very low, any drug administered suffers the risk of increasing it. In our studies (e.g., Hellings et al., 2006; Zarcone et al., 2001), the dose response curves of people who were receiving risperidone for SIB varied greatly. Similarly, increased appetite resulting from receiving atypical antipsychotics may be a motivating operation (MO) for increased SIB.

Analogue Functional Analysis. It is also another method for examining drug-behavior interactions in the DD population. Several studies have shown that the functions of the aberrant behavior may change as a result of receiving medications (Crosland et al., 2003; Dicesare, McAdam, Toner, & Varell, 2005; Valdovinos, Nelson, Kuhle, & Dierks, 2009; Zarcone et al., 2004).

Monitoring Compliance with Drug Regimens. Compliance with drug regimens is another critical behavioral issue. In residential facilities, this problem may not be as prevalent, because

of ICF-MR (Intermediate Care Facility for the Mentally Retarded) regulations. In outpatient programs, however, drug compliance in some cases has been as low as 50 % (Rasaratnam, Crouch, & Regan, 2004). Such a compliance failure may result in an adverse effect of a usually effective drug for SIB, many of which depend upon strict compliance over an extended period of time to achieve steady state. To counter noncompliance, bubble packaging of capsules or monitoring the amount of elixir form of the drug consumed at clinic follow-up visits can help to detect noncompliance.

Reactivity of Evaluators of the Drug's Effect. The ratings of parents, teachers, and caregivers often differ, and these ratings correlate poorly with behavior observers' data in drug studies of SIB (Schroeder, Rojahn, & Reese, 1997). This result is not surprising since each is a sample based upon their respective roles, experience, and interests in achieving outcomes, which also may differ markedly. Parents and teachers may also have very different observations of a drug effect. At some molar level, however, they should agree (Valdovinos et al., 2002), and differences should be reconciled. Singh et al. (2002) have shown that training staff on how to integrate behavioral and pharmacological treatments can improve them. Aman, Bensen, Farmer, Hall, and Malone (2007) have produced Project MED, which is a series of eight brief training manuals, in English and Spanish, on the major psychotropic drugs used in DD, written in simple language for consumers and caregivers, which we have found very helpful. Consensus development by an interdisciplinary team is key to a successful outcome.

Consumer Satisfaction. Social validity study was invented by behaviorists (Kazdin, 1977; Wolf, 1978), to assess the acceptability of treatments by caregivers and consumers that might affect their long-term maintenance and generalization. Poling and LaSage (1995) called for social validity studies in psychotropic drug studies, especially for individuals with DD. Because people with SIB often have impaired ability to consent or assent to

procedures, caregiver acceptability measures by people who know the client well are most frequently used (e.g., Aman & Wolford, 1995; McAdam et al., 2002; Tierney et al., 2007).

Consumer measures of satisfaction in drug studies of SIB have been difficult, although we have often observed positive and negative behavioral side effects (e.g., reduced stress and signs of pain, more smiling and cooperation with parents and caregivers, symptom substitution). More research in this area should be done. For instance, Courtemanche, Schroeder, Sheldon, Sherman, and Fowler (2012) demonstrated a method for coding videos of signs of pain and distress among chronic SIB cases. Symons, Harper, McGrath, Breau, and Bodfish (2009) have shown how a rating scale for noncommunicating persons can be used similarly for this purpose.

Political and Funding Issues

Most drug studies approved by the FDA are large group RCT studies that may cost hundreds of thousands of dollars to conduct. The main funding mechanism is the National Institute of Mental Health, which has the same bias toward large RCT studies. These practices make it difficult to win the funds necessary for research on large-scale PCTs, which may also involve single-subject designs of the type used by behavior analysts. Less than 10 % of all clinical trials approved or funded by the FDA are PCTs (Getz & Sisson, 2003). Less than 2 % of all NIH funding was allocated to research on all DD topics. Psychopharmacology studies of SIB are only a small fraction of that 2 %. Yet these people are some of the most overmedicated groups in our society.

The other major funders of drug research for people with DD are the pharmaceutical companies, who need to make enough profit. For a drug to be brought to market to enable further drugs to be developed, the average cost is \$2,000,000,000. Researchers who receive pharmaceutical-company money are expected to disclose all of their potential conflicts of interest when publishing their research. It is impor-

tant for the clinician to check these footnotes in published papers because conflicts of interest may affect the outcomes and interpretations of such studies. Indeed, some investigators refuse to accept pharmaceutical company funding for this reason.

Research on naltrexone and SIB is a good example of drug company politics. Recently, there has been a dearth of research on naltrexone for SIB in the past decade, while over 50 studies were published from 1980 to 2000. Why? The answer likely has little to do with its effectiveness. It is more likely the case that the patent on the drug has expired and it is now sold more cheaply as a generic drug. Also, the company that originally developed the drug for treatment of alcohol abuse was bought by another pharmaceutical company, that now produces naltrexone, but has no interest in cooperating with investigators to submit an Investigative New Drug (IND) application permit to the FDA for treating SIB. An IND is necessary to conduct a research study on an off-label use of a drug. Thus, future research funding for naltrexone and SIB remains unlikely.

Summary and Conclusions

Since the Sprague and Werry (1971) review, much research effort has been expended on psychopharmacology in DD. We have tried to focus on drugs for persons with DD and SIB and to share some of our personal experiences and opinions gathered over these past four decades. We feel that we have learned much about what is necessary to conduct and analyze an effective clinical drug and behavioral trial. We have outlined these issues briefly in this chapter. For the clinician, performing an effective clinical trial for an individual case is a complex process, with the clinical arts as well as the sciences at its base. In clinical drug trials, one often hears the aphorism, "KISS. Keep it simple, stupid!" Unfortunately, it's not simple.

Acknowledgements NIH grants Nos. HD 060500, HD02528, HD 026927.

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Federal legislation mandates a free and appropriate public education for students with disabilities within a least restrictive environment (e.g., P.L. 99–142; P.L. 99–457) and provides assurance that individuals with severe challenging behavior will have access to appropriate educational services (P.L. 105–117). While these educational reforms have the potential to advance the equity and quality of services offered to students with disabilities, they also place increased demands on educators to meet the needs of an increasingly diverse group of students with unique needs (Putnam, Handler, Rey, & McCarty, 2005). As a result of these and other mandates, consultation within public school settings has become a stand-alone service available to educators by a team of professionals (Luiselli & Diamant, 2002; Martens & DiGennaro, 2008).

Although there are several philosophical approaches to consultation, those based on the principles of behavior analysis (i.e., behavioral consultation) are the most common (e.g., Medway, 1982; Sheridan, Welch, & Orme, 1996) and have been shown to produce positive outcomes in both case studies and experimental investigations (Fuchs, Fuchs, & Bahr, 1990; Gutkin, 1986; Medway, 1982; Sheridan et al., 1996).

Research suggests that the number of students referred for special education has decreased due to school-wide behavioral consultation (Fuchs et al., 1990; Graden, Casey, & Bonstrom, 1985; Gutkin, Henning-Stout, & Piersel, 1988; Rosenfield, 1992). Teachers also report that school consultation is highly effective and improves performance for a majority of students (e.g., MacLeod, Jones, Somers, & Havey, 2001). As such, school-based behavioral consultation has become an important service and is a valuable resource to educators and students in crisis. The purpose of this chapter is to describe behavioral consultation in public schools and the various roles comprising this service. In addition, the chapter will provide details about the range of activities commonly addressed during consultation and decisions concerning the transition of a student in crisis to a more restrictive service-delivery model.

What Is Consultation?

School consultation is an indirect process by which an expert provides support and assistance to an educator to improve student learning and engagement (Erchul & Martens, 2010; Putnam et al., 2005). In this model, the expert has little or no direct contact with the student, hence, an indirect service-delivery process; instead, the expert collaborates with the educator who is expected to be an active participant. Responsibilities of

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educators include participating in face-to-face interviews, providing relevant information about the conditions under which problem behavior occurs, collecting data, and implementing agreed-upon treatment plans (Kratochwill & Bergan, 1990; Luiselli, 2002; Martens, Erchul, & Witt, 1992). For the purposes of this chapter, we will rely on the definition offered by Erchul and Martens (2010) who defined consultation as:

a process for providing psychological and educational services in which a specialist (consultant) works cooperatively with a staff member (consultee) to improve the learning and adjustment of a student (client) or groups of students. During face-to-face interactions, the consultant helps the consultee through systematic problem solving, social influence, and professional support. In turn, the consultee helps the client(s) through selecting and implementing effective school-based interventions. In all cases, school consultation serves a remedial function and has the potential to serve a preventive function (pp. 12–13).

Consultation is designed around a systematic problem-solving process implemented through a series of face-to-face interviews (Erchul & Martens, 2010; Putnam et al., 2005) and consultation activities in order to identify and assess an academic or behavioral problem as well as to evaluate the effectiveness of an assessment-driven intervention. D’Zurilla and Goldfried (1971) originally conceptualized the four-stage process of behavioral consultation, which has since been described and expanded by Kratochwill and Bergan (1990) and Erchul and Martens (2010). The four-stage process includes several interviews requiring shared consultant-consultee responsibility (Martens & DiGennaro, 2008). The goal of the problem identification interview (PII) is to identify a particular target behavior that will be addressed through consultation, estimate how often and when it occurs, and determine baseline data collection that will take place before the next interview. During the second interview—termed the problem analysis interview (PAI)—the consultant and consultee use the gathered baseline data to identify behavior change goals, discuss the putative function of problem behavior based on hypothesized antecedents and consequences, and design an intervention to address

the target behavior. The problem evaluation interview (PEI) is arranged after the plan has been implemented for a period of time so that the consultant and consultee can determine whether the plan should be terminated, continued, or modified.

Because of the effectiveness of this model and federal mandates emphasizing prevention and early identification of school-related problems through the use of behavioral consultation (c.f. Individuals with Disabilities Education Improvement Act of 2004; IDEIA), public schools have adopted consultation in various formats over the past three decades. The way in which consultation is offered differs across states and even districts within the same state. For example, schools may hire an *internal* consultant as an employee to provide consultation to educators on an as-needed basis. School-based consultation may also be provided by an *external* consultant who has a contract with the district. In this model, consultants may function as independent practitioners under their own license, certification, or other credential and arrange the contract directly with the school. Alternatively, consultants might work as part of a team hired by a not-for-profit or for-profit organization who holds the contract with the school district.

Schools may also offer prereferral intervention services (McDougal, Clonan, & Martens, 2000) where a teacher can seek consultative assistance from a team of consultants or specialists often comprised of numerous disciplines (e.g., school psychologist, behavior analyst, speech therapist, reading specialist all of whom are school employees), to address a behavioral or academic concern in the classroom. Note that the terminology used for the prereferral intervention team varies widely, for example, school-based intervention and child study teams. Some schools or districts implement school-wide positive behavior support (SWPBS), a systemic and preventive approach derived from behavioral theory, whose goal is to eliminate problem behavior in favor of socially appropriate behaviors (Carr et al., 2002). In SWPBS, a continuum of support is available for educators within a three-tiered system (<http://www.pbis.org/>). Efforts toward

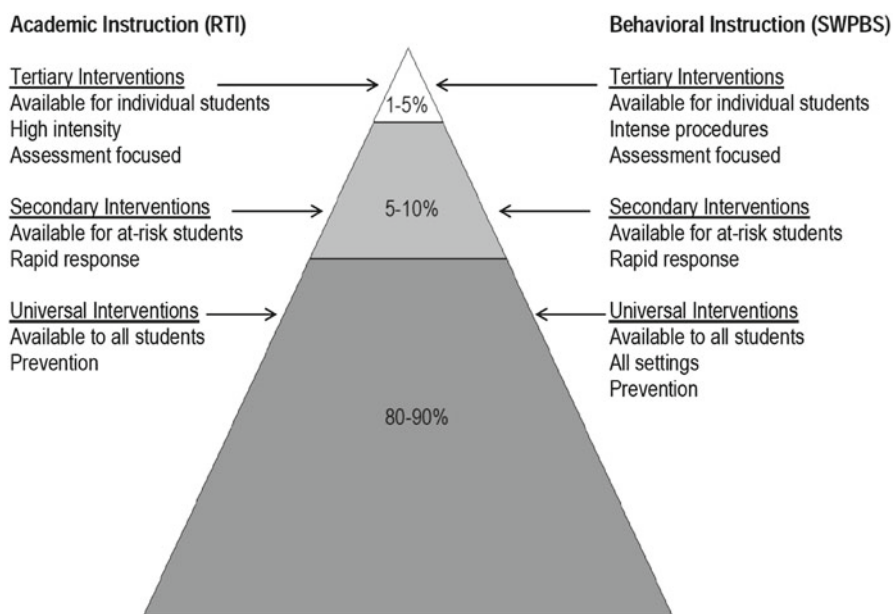


Fig. 18.1 RTI and SWPBS model. A pictorial display of the similarities and differences between RTI and SWPBS within school settings. The percentage of students who are served by each tier is represented within the pyramid.

A general description of each tier for each type of intervention is also provided (Adapted from Positive Behavioral Interventions and Supports, retrieved August 22, 2012, from <http://www.pbis.org/school/rti.aspx>)

primary prevention include making available a school-wide behavior management system using positive reinforcement procedures. Secondary prevention includes more specialized systems for at-risk students or students who continue to emit problem behavior despite the school-wide reinforcement system. In tertiary prevention, individualized and specialized systems are available for high-risk students (Fig. 18.1).

IDEIA also permits the use of Responsiveness-to-Intervention (RTI) practices within educational settings, and many schools have since adopted this model. Special education state department directors report that efforts are being made to train RTI and emphasize progress monitoring and data-based decision making in 90 % of states (Hoover, Baca, Wexler-Love, & Saenz, 2008). Like SWPBS, RTI includes three levels of prevention (<http://www.rti4success.org>) but focuses on instructional practices rather than problem behavior prevention, although the National Dissemination Center for Children with Disabilities indicates RTI can be used for both academic and behavioral problems. Primary

prevention efforts include adopting quality instruction for all classrooms in all grade levels. If a student experiences difficulty with the core content, secondary prevention including an evidence-based intervention is implemented. Tertiary prevention is offered to students who do not respond to previous efforts and includes individualized instruction and intervention (Fig. 18.1). Students who continue to struggle even after intense, individualized intervention are referred for a comprehensive evaluation and determination of eligibility for special education services. Interested readers may wish to refer to a blueprint specifying acceptable and best practices available at no charge on the internet (see Fuchs & Fuchs, 2005).

Roles Within School Consultation

As previously described, three primary roles exist within a consultative model including consultant, consultee, and client. A successful consultative relationship depends upon the actions each indi-

vidual takes toward meeting a set of shared and unique responsibilities. In the past, the consultant–consultee relationship was described as collaborative and nonhierarchical, suggesting that neither person had more power than the other. It was also considered a voluntary relationship, one in which the consultee was able to decline consultant assistance (Erchul, 1999). However, recent changes in legislative regulations outlined in IDEIA 2004 altered the consultative process dramatically. Because the regulation requires scientifically supported interventions for clients needing additional support and instruction (Yell & Drasgow, 2007), consultation is no longer considered a voluntary activity and educators have less flexibility to reject or decline assistance. Additionally, inclusion of RTI within IDEIA increased school-based educators' reliance on experts (consultants) to analyze outcomes of clients and provide an appropriate intervention when outcomes do not meet the legislative standards (Erchul, 2011).

Consultant

The consultant is hired by virtue of having particular expertise and/or specialization in the target problem area or referral issue (Martens & DiGennaro, 2008). Responsibility rests with the consultant to follow federal educational regulations and to spearhead the consultation process beginning with school entry and contract negotiations through ensuring that the goals of consultation are realized via intervention evaluation (Kratochwill & Bergan, 1990). To meet the target goals for change, it is necessary for the consultant to support and maintain the consultative relationship with the consultee. To this end, the consultant works directly with the consultee, rather than the client, and is responsible for generating *consultee* behavior change (Erchul & Martens, 2010) via training and support (Martens & DiGennaro, 2008; Wickstrom, Jones, LaFleur, & Witt, 1998). Changes in consultee behavior (e.g., intervention plan implementation, responding to problem behavior in a different manner) bring about changes in client behavior (e.g., less problem behavior).

To maximize effectiveness, a consultant should have coursework, training, and supervision in consultation, applied behavior analysis, functional behavior assessment, school-based interventions, and single-case research designs (Kratochwill & Bergan, 1978; Shriver & Watson, 1999). Consultants may be master's level or doctoral level certified school psychologists or board certified behavior analysts. In addition, licensed clinical or educational psychologists may serve as consultants. It is important to note that individuals with doctoral level training and experience within both school and behavioral consultation generally have the appropriate amount of experience and expertise to effectively use the problem-solving model and to evaluate outcomes (Putnam et al., 2005). Luiselli (2002) also pointed out that consultants should have exemplary interpersonal and time management skills to achieve success.

Consultee

Consultees have direct contact with the client and are charged with the responsibility of implementing designed interventions during consultation (Martens & DiGennaro, 2008). The consultee is typically a teacher or other educator who is responsible for the behavioral and academic progress of students. The consultee plays an important role in the consultative relationship by interacting with and providing important information to the consultant during the problem-solving process, collecting data, implementing the agreed-upon intervention, interacting directly with the client, and communicating with the consultant on all relevant matters. As an indirect service-delivery model, the consultant produces behavior change in the client through the consultee.

Client

The client is an individual who faces an obstacle that is not being sufficiently remedied or addressed and, in many cases, is a student (Erchul & Martens, 2010). Within the roles of consultation,

the client is charged with making the behavioral changes (e.g., increases in appropriate behavior and/or decreases in problem behavior) that serve as an end goal of consultation. Depending on the client's skills, she/he may help to define and assess the goals, which is an important step within the consultation process (Kratochwill & Bergan, 1990).

Professional Activities Within the Consultation Model

Functional Behavior Assessment and Analysis

The problem-solving process includes interview questions in the PII and PAI that evoke discussion about the environmental variables surrounding problem behavior. This philosophical approach to problem behavior remediation focuses on the events that occur before and after problem behavior, rather than on causes internal to the child (e.g., pathology, frustration, anger, self-esteem), and is consistent with a behavior analytic approach (Asmus, Vollmer, & Borrero, 2002). A behavioral consultant will conduct a functional behavior assessment (FBA) to identify the purpose that problem behavior serves for a client (or the function of problem behavior) by assessing the conditions under which clients emit problem behavior and the consequences that follow it.

FBA includes a continuum of assessment techniques including indirect assessment (e.g., rating scales or informant reports; e.g., Durand & Crimmins, 1988), direct assessment (i.e., observing clients in the natural environment and recording the environmental events surrounding problem behavior; e.g., Bijou, Peterson, & Ault, 1968; English & Anderson, 2006), and functional analysis (i.e., an experimental approach; Iwata, Dorsey, Slifer, Bauman, & Richman, 1994; Martens, Witt, Daly, & Vollmer, 1999). Readers are encouraged to see Chaps. 8 (assessment of problem behavior) and 9 (functional analysis) in this handbook for precise descriptions of these techniques. The 1997 amendments to the

Individuals with Disabilities Education Act mandated FBA in public schools under particular circumstances; however, the regulations lack the specificity to require a behavior-based and empirically supported approach to FBA (Asmus et al., 2002; Ingram, Lewis-Palmer, & Sugai, 2005). As a result, assessment is often restricted to indirect techniques in public school settings, which fall short of best practices (March & Horner, 2002; McIntosh, Brown, & Borgmeier, 2008).

Academic Assessment

Consultants may also be involved with assessment of academic skills for students experiencing performance problems in the classroom curriculum. Standardized, norm-referenced testing, such as cognitive and ability testing, is typically restricted to school psychologists who have the required training and certification to conduct assessments of this type. However, consultants may be involved with *direct academic assessment* by (1) sitting on a prereferral intervention team whose members determine assessment is necessary, (2) completing one as part of the consultation process, or (3) implementing RTI and conducting academic assessment for progress monitoring purposes (Luiselli, Reed, & Martens, 2010).

Direct academic assessment refers to practices that assess performance of students within the instructional curriculum. That is, the assessment itself has overlap with the curriculum materials used in the classroom. There are several types of direct academic assessment including curriculum-based assessment (e.g., Blankenship, 1985; Shapiro, 1990), curriculum-based evaluation (Howell & Nolet, 1999), and curriculum-based measurement (Deno & Mirkin, 1977). Although there are differences in scope and use (e.g., progress monitoring versus assessment to guide intervention), the shared purpose of all types of direct academic assessment is to “focus on the evaluation of student academic performance to examine student skills” and “to examine the instructional environment in which the student is being taught” (Shapiro, 2004, p. 19). Shapiro

(2004) recommends a four-step process informed by the empirical literature that includes assessment of the environment where instruction takes place, assessment of placement within the curriculum, modifications to instruction, and ongoing monitoring of progress. Students who experience difficulty with the instructional curriculum may engage in problem behavior to avoid or escape challenging tasks. As a result, direct academic assessment may be necessary if the FBA identifies the function of problem behavior as negative reinforcement in the form of escape from—or avoidance of—instruction.

We encourage readers to incorporate assessment procedures for academic difficulties in order to better understand the reasons a student is exhibiting low performance. In some instances, academic difficulties are due to a skill deficit (i.e., a *can't do* problem; Lentz, 1988). Skill deficits occur for several reasons including (a) not enough exposure to the curriculum, (b) a student requiring more help than is presently available, (c) lack of student mastery of the curriculum goals, or (d) the academic task exceeds the student's skill level (Daly, Witt, Martens, & Dool, 1997). Academic difficulties may also result from a performance deficit (i.e., a *won't do* problem) in which the student lacks interest and/or fails to interact with curricular materials because reinforcement contingencies do not support doing so (Lentz, 1988). Identifying the type of deficit is important because it directly informs the appropriate next steps in developing an intervention. Interventions addressing skill deficits aim to teach new skills and/or behavior, whereas performance deficit interventions create new contingencies within the environment in order to increase active participation in the curriculum (Daly et al., 1997).

Intervention Design

Determining the function or purpose of problem behavior helps the consultant design appropriate intervention procedures (Iwata, Pace, Kalsher, Edwards Cowdery, & Cataldo, 1990). An assessment-driven and function-based intervention must incorporate findings of the FBA and,

as appropriate, a direct academic assessment. In addition, identifying the purpose of problem behavior may aid in selecting the least intrusive intervention (Vollmer & Northup, 1996), which requires fewer resources and can be implemented quickly by teachers who are more likely to implement them across a longer span of time (Erchul & Martens, 2010). Recent clinical advances now consider a treatment analysis—an evaluation of the effects of a consultee-implemented intervention on client behavior or performance—an important component of comprehensive assessment. Although requiring resources up front, a treatment analysis will help preserve time in the long term by increasing the likelihood that an effective intervention will be recommended and adopted. To make the most efficient use of resources, a brief experimental analysis (BEA) of potential interventions can be conducted to quickly evaluate the effects of treatment before long-term implementation (Martens, Eckert, Bradley, & Ardoin, 1999).

Brief Experimental Analysis

BEA is an assessment tool used to determine which treatment or intervention is most appropriate and effective in addressing a given academic or behavioral problem (Martens et al., 1999). It is derived from the fields of school psychology and applied behavior analysis and allows consultants to base recommendations on methodologically sound assessment practices (Martens et al., 1999). BEA relies on the elements of single-case design (e.g., repeated measurement, replication of effects, and visual inspection; Martens & Gertz, 2009) to demonstrate the beneficial effects of one intervention over another. Thus, a consultant must have training and experience in behavior analytic research methods to conduct this analysis. Meta-analytic findings suggest that BEA has empirical support (Burns & Wagner, 2008). During BEA, client performance is measured during brief and rapidly alternating intervention sessions (Erchul & Martens, 2010). Clear behavior change in the desired direction during an intervention session helps the consultant make a recommendation to the consultee about which procedures should be implemented long term.

Harding, Wacker, Cooper, Millard, and Jensen-Kovalan (1994) used BEA to identify the least intrusive intervention package necessary to improve appropriate behavior for seven children in an outpatient clinic. Using a multielement design, Harding et al. (1994) rapidly alternated conditions in a hierarchy of least-to-most intrusive interventions beginning with those that were easiest to implement by parents. If improvements in on-task behavior were not observed with a less intrusive intervention (e.g., antecedent procedures), more intrusive components (e.g., reinforcement and/or mild punishment procedures) were added to the intervention package. This analytic technique allowed the researchers to individualize the interventions they designed for the clients. Three clients showed increases in on-task behavior when antecedent interventions were implemented (e.g., increased choice-making opportunities, delivery of clear instructions by caregivers). Other participants required the addition of consequence-based components, such as differential reinforcement of alternative behavior and access to preferred activities, in order to produce changes in behavior.

Intervention Components

Two categories of intervention components are typically embedded into behavioral interventions, both of which reduce the likelihood of problem behavior occurring in the future. A body of research supports the effective use of antecedent and consequence-based interventions to reduce problem behavior and teach appropriate behavior (Bregman, Zager, & Gerdtz, 2005). Both categories of intervention procedures and corresponding research examples are described below.

Antecedent Interventions

Antecedent interventions include procedures that prevent the occurrence of problem behavior and, as a result, increase the occurrence of appropriate behavior (Kern & Clemens, 2007; Reeve & Carr, 2000). The results of FBA should reveal the contexts under which problem behavior occurs as well as situations during which clients do not engage in problem behavior. This information allows consultants to identify slight modifications

to the environment which can produce dramatic reductions in problem behavior. Although FBA has not always been necessary to inform effective antecedent strategies (O'Reilly et al., 2012), we recommend its use to better understand why a particular strategy is effective. Common antecedent intervention practices are modifying the delivery (Matheson & Shriver, 2005), pace (Darch & Gersten, 1985), or difficulty of instruction (Kern, Gallagher, Starosta, Hickman, & George, 2006); establishing clear expectations (Johnson, Stoner, & Green, 1996); providing access to an enriched environment (Wilder, Zonneveld, Harris, Marcus, & Reagan, 2007), revising or developing routines (Bohn, Roehrig, & Pressley, 2004; O'Reilly, Sigafoos, Lancioni, Edrisinha, & Andrews, 2005), and many others (e.g., providing choices; Cannella, O'Reilly, & Lancioni, 2005).

Haley, Heick, and Luiselli (2010) evaluated the effects of colored cards—meant to signal the appropriate times to engage in vocal stereotypy—on the occurrence of stereotypy emitted by a second grade boy with autism in a general education classroom. During training, the student was taught to discriminate when it was appropriate or inappropriate to engage in stereotypy. In the presence of a green card bearing the statement “Sean, okay to speak out,” vocal stereotypy received no programmed consequences (i.e., the student was allowed to engage in stereotypy). In the presence of a red card bearing the statement “Sean, quiet,” the student received a prompt when he engaged in vocal stereotypy (i.e., the red card was held approximately 6 in. in front of Sean's face). Decreases in stereotypy were observed in the presence of the red card even when the size of the card was reduced and the text was removed. Stereotypy occurrence in the presence of the green card was similar to baseline levels. In a study by Butler and Luiselli (2007), escape-maintained problem behavior involving self-injury, aggression, and tantrum decreased to near-zero levels when an intervention package consisting of a noncontingent break and instructional fading (eliminating and gradually introducing instruction) was implemented. As the schedule of noncontingent breaks

decreased and the rate of instructional requests increased during the study, problem behavior remained low.

Consequence-Based Interventions

Consequence-based interventions refer to procedures that take place after the occurrence of behavior and involve modifying the behavior's consequences (Bregman et al., 2005). Reinforcement, extinction, and punishment are common consequence-based procedures (Lanovaz & Sladeczek, 2011). Reinforcement refers to the presentation (i.e., positive reinforcement) or removal (i.e., negative reinforcement) of a stimulus contingent on the occurrence of behavior, which increases the future probability of that behavior occurring (Catania, 2007). Differential reinforcement procedures are often incorporated into behavioral interventions and involve delivering reinforcement for some, but not all, behaviors (Catania, 2007). Several types of differential reinforcement procedures are available to consultants to use as a consequence-based intervention. Differential reinforcement of other behavior (DRO) is defined as the provision of reinforcement for behavior other than the target (problem) behavior (Thompson, Iwata, Hanley, Dozier, & Samaha, 2003). Differential reinforcement of alternative behavior (DRA) involves withholding reinforcement for target behavior and providing reinforcement contingent on the occurrence of an appropriate behavior (Petscher, Rey & Bailey, 2009). Differential reinforcement of incompatible behavior (DRI) is a type of DRA procedure where reinforcement is provided for an appropriate behavior physically incompatible with the target behavior (de Zubicaray & Clair, 1998). In a procedure involving differential reinforcement of low rates of behavior (DRL), reinforcement is provided for target behavior that occurs at a rate less than an established criterion (Dietz & Repp, 1973). Differential reinforcement of high rates of behavior (DRH) is defined as providing reinforcement for target behavior occurring at a rate higher than an established criterion (Catania, 2007). Durand and Carr (1991) used DRA and functional communication training to reduce problem behavior (tantrum, self-injury, disruption) displayed

by three boys with developmental disabilities. A functional analysis determined that problem behavior was maintained by escape from challenging tasks for all three boys and maintained by attention for one boy. To address the escape function, the boys were taught phrases to request help or convey that they did not understand the task. To address the attention function, one of the boys was taught to request attention while working on the tasks. Differential reinforcement consisted of delivering the requested reinforcer (e.g., help, attention) contingent on functional communication, such that problem behavior no longer produced the reinforcer. Problem behavior decreased for all three participants following the introduction of DRA and functional communication training. Follow-up data indicated that results were maintained over time and generalized to other classrooms for two of the three participants.

Extinction occurs when reinforcement is withheld for behaviors that previously contacted reinforcement (Catania, 2007) and is a component of differential reinforcement procedures involving the contingent delivery of reinforcement for some, but not all, responses. Presumably, when behaviors no longer produce reinforcement, their occurrence decreases (Simpson & Gagnon, 1999). Cote, Thompson, and McKerchar (2005) evaluated the effects of two antecedent interventions (a 2-min transition warning and access to a toy) and extinction alone and in various combinations on compliance and problem behavior for three typically developing toddlers during school transitions. Participants demonstrated increased compliance and lower problem behavior in conditions involving extinction. Specifically, the treatment package consisting of access to a toy and extinction produced the greatest improvements for two of three participants. A third participant responded positively to the extinction-only condition. Given that extinction does not teach appropriate alternative behaviors and is associated with a number of side effects (Bregman et al., 2005), we recommend that consultants evaluate the effects of extinction in a BEA before asking consultees to adopt this procedure for long-term use and consider packaging extinction with differential reinforcement.

Punishment procedures involve the presentation (i.e., positive punishment) or removal (i.e., negative punishment) of a stimulus contingent on the occurrence of behavior, which decreases the future probability of that behavior occurring (Catania, 2007). Gresham (1979) evaluated the effects of two punishment procedures (response cost alone and in combination with time-out) on the noncompliance of 11 children with intellectual disabilities. Response cost involved the loss of one earned token contingent on each instance of noncompliance with the teacher's request. During time-out, children were prompted to sit in a chair positioned away from other children and remained in time-out until appropriate behavior was displayed for one minute. Both procedures were effective in reducing noncompliance, suggesting that the response cost procedure was the necessary intervention component (i.e., controlling variable). Readers should note that the use of punishment is a source of much controversy in the fields of behavior analysis, psychology, and education so much so that many professional organizations have developed position statements on its use (e.g., Association for Behavior Analysis International, 2010). In addition, consequence-based punishment procedures are viewed as less acceptable than reinforcement procedures (Michaels, Brown, & Mirabella, 2005).

Consultee Training

Effective consultation requires consultants to train consultees to appropriately implement the recommended intervention with the client. In addition, consultants are responsible for providing ongoing follow-up to ensure that the intervention is being implemented well in the applied classroom context and is effectively addressing the referral concern. Failure to provide sufficient training will likely result in poor intervention implementation or treatment integrity, which refers to the degree to which interventions are implemented as planned (Gresham, 1989; Yeaton & Sechrest, 1981). Studies have shown that behavioral interventions lack effectiveness when they are implemented with low treatment integrity

(DiGennaro, Martens, & Kleinmann, 2007; DiGennaro, Martens, & McIntyre, 2005; Wilder, Atwell, & Wine, 2006). Efforts directed toward consultation will be wasted if consultants do not provide the necessary training and follow-up to ensure consultees implement the assessment-based interventions with integrity.

Consultees may struggle with implementing agreed-upon classroom interventions even if they have received initial training consistent with best practices (i.e., behavioral skills training consisting of modeling, coaching, and performance feedback until criterion performance is achieved). For example, Mortenson and Witt (1998) reviewed agreed-upon intervention procedures and the rationale for each intervention step with teachers, provided out-of-classroom training, confirmed verbal understanding of the intervention, and provided in-class training consisting of prompting and feedback until criterion performance of 100% integrity was met by participating teachers. Three of four teachers showed reductions in treatment integrity following these training procedures when they were asked to independently implement the intervention without consultant assistance. This finding has been replicated across studies (DiGennaro et al. 2005, 2007; Noell, Duhon, Gatti, & Connell, 2002), treatment protocols (e.g., academic interventions versus behavior support plans), and classroom settings (e.g., special versus general education classrooms). As a result, consultants should be prepared to provide ongoing follow-up in the form of performance feedback and on-the-job coaching to be maximally effective (van Oorsouw, Embregts, Bosman, & Jahoda, 2009). Readers are encouraged to read the chapter about staff training for more information about empirically supported training techniques (see Chap. 5 in this handbook).

Crisis Management

Clients may display dangerous or intense problem behavior in public school settings despite having access to consultation services and the array of activities described in this chapter. In some

instances, a more restrictive placement within or outside the school will be necessary in order to ensure the student receives a free and appropriate education (Pitasky, 2002). We cannot emphasize enough the importance of consultants recognizing the boundaries of their competencies and when continued consultation in the current form poses a risk to the client, consultee, or other students. A consultant may assist with referrals to an alternative setting as part of a team of educators associated with the public school. Depending on the receiving placement, the school district will likely be responsible for paying for some or all of the services; thus, school representatives should be involved in any conversations or decisions about a change of placement. Families will also play an important role in placement decisions and should be actively encouraged to participate as a team member. A chapter in this handbook describes policy and planning considerations when a student transitions from a less to more restrictive educational setting (see Chap. 16) and provides rich and valuable information to guide readers.

Conclusion

This chapter provides a summary of relevant research regarding the various roles within public school consultation, assessment and intervention activities, consultee training, and abbreviated considerations regarding the transition of a student in crisis to a more restrictive service-delivery model. We recommend reliance on a behavioral consultation model that uses the principles of behavior analysis since this approach has been shown to produce beneficial outcomes for students. In our experience, consultation is most effective when (1) interventions are derived from the results of a functional behavior assessment, (2) the efficacy of interventions is tested in a brief experimental analysis, (3) consultees are provided behavioral skills training before intervention implementation, and (4) consultants provide ongoing follow-up and support to consultees to ensure interventions are implemented with high treatment integrity.

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Many effective services have been provided for individuals with developmental disabilities in the home setting. In making decisions about the best setting for treatment, several factors must be considered, not the least of which is the degree to which published research supports providing treatment in the various settings being considered. Because a comprehensive review and description of all home-based services is beyond the scope of this chapter, we describe the major forms of treatment that have been successfully implemented in the home-based setting as well as review the published research that supports each. In so doing, we discuss early intensive behavioral intervention (EIBI), parent training, and assessment and treatment of challenging behavior in the home setting. The latter half of the chapter is dedicated to a discussion of other factors that should be considered when evaluating the best possible setting for supporting an individual with a developmental disability experiencing crisis.

Comprehensive Early Intensive Behavioral Intervention

EIBI for children with autism spectrum disorders (ASD) is perhaps the application for which applied behavior analysis (ABA) is best known, and EIBI services are expanding rapidly in the USA and abroad. In addition, EIBI is the most-researched form of home-based treatment for individuals with developmental disabilities; therefore, a substantial portion of this chapter is dedicated to this form of treatment. Below, we describe the general characteristics of home-based EIBI, summarize its research, and discuss variables that are crucial to the effectiveness of home-based EIBI. Table 19.1 includes the EIBI outcome studies presented in this chapter, in addition to a summary of the number of participants, treatment intensity, treatment duration, treatment team composition, frequency of supervision and who delivered it, and overall outcomes.

EIBI for children with ASD has been described thoroughly elsewhere (e.g., Granpeesheh, Tarbox, & Dixon, 2009). Readers are encouraged to consult this and other resources since space does not permit a comprehensive description. The goal of home-based EIBI is to maximize the skill development of children with ASD across all developmental domains including language, play, independent living skills, academics, motor, and social skills. Comprehensive EIBI programs

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Table 19.1 Major components of EIBI outcomes studies described in the chapter

Study	Participants (n)	Hours per week	Duration (months)	Treatment team	Supervision (frequency)	Outcomes
<i>University-based outcome studies of home-based early intensive behavioral intervention</i>						
Lovaas (1987)	EIBI high: 19 EIBI low: 19	EIBI high: 40 EIBI low: 10	24+	Several trained therapists and parents	University-based researchers (NR)	EIBI high: 47 % achieved IQs > 85 and mainstream classroom placement EIBI low: No children achieved IQs > 85 or mainstream classroom placement
Smith, Groen, and Wynn (2000)	15	18–30	12–36	4–5 trained therapists and parents	University-based researchers (NR)	26.7 % achieved IQs > 85 and mainstream classroom placement
<i>Community-based outcome studies of home-based early intensive behavioral intervention</i>						
Anderson, Avery, Di Pietro, Edwards, and Christian (1987)	14	15–25	12+	One trained therapist per child and parents	NR	28.6 % achieved IQs > 80 and mainstream classroom placement (all requiring assistance)
Boyd and Corley (2001)	22	30–40	12–36	Trained therapists	Experienced coordinators (weekly)	44.4 % achieved IQs > 80; 40.9 % (9 children) had mainstream classroom placements
Howard, Sparkman, Cohen, Green, and Stanislaw (2005)	29	25–40	14	4–5 trained therapists per child and parents	Master's level supervisors, BCBA's, and authors (weekly)	44.8 % (13 children) achieved IQs > 85; classroom placement not reported
Sallows and Graupner (2005)	13	m = 38	24–48	Trained therapists and parents	Senior therapist and consultation from author (6–10 h/week)	38.5 % (5 children) achieved IQs > 85 and mainstream classroom placements
Cohen, Amerine-Dickens, and Smith (2006)	21	35–40	36+	Trained therapists and parents	Master's level BCBA supervisor (NR)	57 % (12 children) achieved IQs > 80; 81 % (17 children) had mainstream classroom placements
Magiati et al. (2007)	28	18–40	23–27	3–18 trained therapists per child and parents	Varied based on treatment provider	Normal range IQs not reported; 82 % (23 children) had mainstream placements (all requiring assistance)

Remington et al. (2007)	23	18–34	24	3–5 trained therapists per child and parents	Experienced supervisor and PhD consultant (every 2–12 weeks)	21.7 % (5 children) achieved IQs >80; 74 % (17 children) had mainstream placements
Perry et al. (2008)	332	20–40	4–47	Therapists trained by various agencies	Master's level BCBAs (weekly)	10.8 % (32 children) achieved IQs >85; classroom placement not reported
<i>Outcome studies of parent-directed home-based early intensive behavioral intervention</i>						
Sallows and Graupner (2005)	10	$m = 31$	12–48	Trained therapists and parents	Experienced senior therapist and consultation (6 h/month)	60 % (6 children) achieved IQs >85 and mainstream classroom placements
Bimbrauer and Leach (1993)	9	9–25	17–24	Therapist volunteers did on-the-job training with parents	Program coordinator with prior experience (1 day/week) and parents (weekly)	44.4 % (4 children) achieved IQs >80; classroom placement not reported
Smith, Buch, and Gamby (2000)	6	23–35	12–36	3–6 therapist volunteers and parents	First author conducted workshops (1–3 workshops per month)	No children achieved IQs >80; 50 % (3 children) had mainstream placements (all requiring assistance)
Bibby, Eikeseth, Martin, Mudford, and Reeves (2002)	66	$m = 31.6$	12	3–5 trained therapists and parents	Parent-hired consultant conducted workshops (4 per year)	15.1 % (10 children) achieved IQs >85; although 5 children had IQs >85 at intake; 4.5 % (3 children) had mainstream classroom placements

attempt to assess all possible skill deficits at intake and then provide skill acquisition in each area, with the goal of “catching up” the child’s development to the greatest extent possible. Comprehensive EIBI programs also use the full range of empirically supported behavioral intervention procedures including positive reinforcement, prompting, prompt fading, discrete trial training (DTT), naturalistic behavioral teaching procedures (e.g., incidental teaching and pivotal response training), shaping, and chaining. Conceptually, EIBI programs are based on behavioral principles of learning and motivation including reinforcement, extinction, stimulus control, motivating operations, and generalization (Cooper, Heron, & Heward, 2007). Intervention is primarily delivered in a one-to-one ratio by a trained educator and structured around measurable goals and outcomes. Moreover, treatment decisions are made by analyzing daily behavior data with respect to those goals.

University-Based EIBI Outcome Research

In 1987, Ivar Lovaas published a seminal study on the outcomes of EIBI for 19 children with ASD who received 40 h per week of treatment for 2 or more years. The results were encouraging and suggested that nearly half of the participants achieved IQ within the normal range (>85), were successfully placed within a regular education classroom without assistance, and were indistinguishable from their typically developing peers. A follow-up study showed that eight of nine participants who achieved typical functioning maintained their gains at 13 years of age (McEachin, Smith, & Lovaas, 1993).

Several partial replications of the Lovaas study have been published since 1987. In the only randomized controlled trial (RCT) of EIBI, Smith, Groen, et al. (2000) randomly assigned 28 children with autism or PDD-NOS to either an EIBI group or a parent-training group. The children in the EIBI group received an average of 25 h per week of one-to-one treatment for 2–3 years. A team of four to five therapists, supervised by the

authors of the study, implemented the treatment. In the parent-training group, parents received approximately 5 h per week for 3–9 months of training on the use of behavioral principles in skill acquisition and behavior reduction. The EIBI group made significantly greater improvements than the parent-training group in IQ, visual-spatial skills, language, and academic achievement. No difference was observed in adaptive behavior skills between the two groups at follow-up, but more individuals from the EIBI group had less restrictive school placements, with 27 % placed in mainstream classrooms with no assistance. Although the gains achieved in the EIBI group were substantial, they were not as robust as those observed in the original study conducted by Lovaas (1987). However, this was not surprising given that the participants in Smith, Groen, et al. (2000) received only 63 % of intensity of treatment compared to participants in the Lovaas (1987) study ($m=25$ h per week and 40 h per week, respectively).

The studies by Lovaas (1987) and Smith, Groen, et al. (2000) were conducted by researchers in university settings with a high degree of oversight and control over study procedures. Although substantial effects were produced in both studies, community-based research is necessary to determine the extent to which similar effects can be obtained in community settings in less-controlled contexts.

Community-Based EIBI Outcome Research

Below, we summarize the outcomes of research on home-based EIBI conducted outside of hospital and/or university settings. Sallows and Graupner (2005) conducted a community-based study comparing outcomes of children who received clinic-directed versus partially parent-directed EIBI. Participants included 23 children with ASD randomly assigned to two groups. The clinic-directed group received an average of 39 h per week of treatment for the first year and an average of 37 h per week during the second year. This group also included a treatment team of

therapists who received 30 h of training before intervention delivery as well as senior therapists with extensive training in EIBI. The first author or a clinic supervisor provided consultation to senior therapists who directly observed therapists for 6–10 h per week. In the parent-directed group, children received 32 and 31 h of treatment per week for the first and second year, respectively. The therapists working directly with the children were hired, trained, and employed by the same organization as those in the clinic-directed group. A senior therapist provided 6 h of monthly in-home supervision and the first author or clinic supervisor provided consultation every 2 months. No significant difference in outcomes was observed between the two groups, but as a whole, both groups made substantial gains in IQ scores, language ability, and adaptive functioning. After 4 years of treatment, 48 % of all children (11 of 23) achieved IQ scores within the average range and were fully included in mainstream settings.

Cohen et al. (2006) compared an EIBI group to a comparison group receiving services from local public schools. Children in the EIBI group ($n=21$) received treatment 35–40 h per week, for 3 or more years, from community-based EIBI providers. The comparison group ($n=21$) received “treatment as usual” services provided by public schools. The children in the EIBI group made significant gains in IQ and adaptive behavior compared to the comparison group. No significant group difference was found on measures of language comprehension or nonverbal skills. At the end of the study, 6 of 21 children (28.5 %) from the EIBI group were fully included in mainstream classrooms without an aide, compared to only one child from the comparison group (4.8 %). Ten children from the EIBI group (48 %) achieved scores within the normal range on measures of IQ, language, nonverbal skills, and adaptive behavior. No children in the comparison group scored in the average range on all measures.

In another evaluation of community-based EIBI, Remington et al. (2007) compared the effects of EIBI versus treatment as usual on outcomes of children with ASD in the United Kingdom. Based on parent preference, 44 children were placed in an EIBI group ($n=23$) or a

treatment as usual group ($n=21$) receiving various public school services. Children in the EIBI group received an average of 25.6 h per week of one-to-one behavioral therapy for 2 years. The treatment team included three to five therapists, a supervisor experienced in ABA, and a consultant with even greater experience in ABA; however, no details were provided regarding the degrees or years of experience these professionals held. Supervision was provided minimally every 2 weeks with additional support and consultation provided via direct observation, as needed. The EIBI group outperformed the comparison group in IQ, in mental age, and in daily living, motor, socialization, and communication skills. Twenty-six percent of children in the EIBI group achieved a statistically and clinically significant IQ score increase from baseline, whereas only 14 % of the comparison group showed these results. Only the children in the comparison group showed a statistically or clinically significant regression in IQ.

Howard et al. (2005) evaluated the effects of EIBI, high-intensity eclectic services, and low-intensity eclectic services on treatment outcomes for 61 children with ASD. The EIBI group included 29 children receiving 25–40 h per week ($m=32.5$ h per week) of behavioral services provided in the home, at school, or in community center-based programs. Treatment teams for the EIBI group included four to five therapists who were trained and supervised by master’s level individuals and the study authors. The children in the eclectic groups received a combination of services in public school settings with the high-intensity group ($n=16$) receiving 25–40 h per week of services and the low-intensity group ($n=16$) receiving 15 h per week. Pre- and post-treatment measures were collected for cognitive, language, and adaptive skills. The EIBI group achieved significantly greater gains in all domains measured with the exception of motor skills. The EIBI group also had higher learning rates during the follow-up assessment compared to the two eclectic groups. No significant differences were found between high- and low-intensity eclectic groups, suggesting that the type of service (EIBI vs. eclectic) is important for outcome, not merely the intensity.

Parent-Directed EIBI Interventions

The high prevalence of ASD and the lack of qualified behavioral treatment providers have resulted in a situation in which many families perceive that their only option is to learn how to implement EIBI and deliver services themselves. To our knowledge, no data exist to indicate how many families are creating and managing their own EIBI programs, but it has become common practice in virtually all rural areas of the USA that lack behavioral intervention providers. EIBI, like any other complex and difficult psychoeducational intervention, requires a high degree of experience and professional-quality training before proficiency is reached. Therefore, we do not recommend that families attempt to implement their own EIBI programs, unless all possible options for securing professional intervention have been exhausted. Still, given that it is a common practice, it would be beneficial to evaluate the effectiveness of parent-directed programs. Unfortunately, very few studies have attempted to evaluate parent-directed EIBI programs (McConachie & Diggle, 2005).

As discussed earlier, Sallows and Graupner (2005) showed that parent-directed treatment may produce effective results that are similar to those of children receiving clinic-directed treatment. Although the treatment was parent-directed, the therapists who directly implemented the treatment were professionals working for a top-quality EIBI service provider, run by the authors of the study, so it is expected that they were implementing therapy with a high degree of integrity. It should also be noted that the “parent-directed” group still received professional supervision by senior therapists, albeit at a significantly lower intensity (approximately 6 h per month, as opposed to 6 h per week in the clinic-directed group).

A university-based study led by Birnbrauer and Leach (1993) found similar results to Sallows and Graupner (2005) when parents directed their child’s therapy, in concert with university program coordinators. In this study, parents were responsible for recruiting and orienting approximately half of the volunteer therapists who provided

therapy, providing weekly trainings and leading team meetings every 3 weeks. Nine children received EIBI for an average of 19 h per week, for 17–24 months. Families that lived too far away from the study site or inquired about the study after the experimental group was full were asked to participate in the control group. Datasets from five children were collected as controls. No details about services for the control group were reported. Four of nine children receiving EIBI were reported to have made substantial gains, while only one of five children in the control group made similar gains.

In another study on partially parent-directed EIBI, Hayward, Eikeseth, Gale, and Morgan (2009) analyzed outcomes for 44 children who received 1 year of either clinic-directed or parent-directed EIBI. Children in the clinic-directed group ($n=23$) received an average of 37 h per week of one-to-one behavior therapy, based on the UCLA model (Lovaas, 1987), with weekly professional supervision. Each team was comprised of two to five tutors, a senior tutor with a minimum of 1-year experience working as a tutor, and a program consultant with a minimum of 3 years experience as a tutor and senior tutor. Supervision was provided by program consultants on a weekly basis in the form of team meetings and direct observation of therapy. Children in the parent-directed group ($n=21$) received an average of 34 h per week, with supervision from the same program consultants as the treatment group for 6 h every 6 weeks. All therapists implementing treatment in the clinic-directed group received extensive training, whereas a little over one third of the children in the parent-directed group had professional therapists on their therapy teams. The remainder of therapists in the parent-directed group was recruited by parents and received training during supervision meetings, i.e., 6 h every 6 weeks. No significant difference in outcomes was observed between groups, with both making significant progress. As a combined group, there were significant improvements in IQ, language, and adaptive behavior scores after 1 year of treatment. The results are comparable to Sallows and Graupner (2005) and Birnbrauer and Leach

(1993), demonstrating that children who receive EIBI with high levels of professional supervision had similar outcomes as children who received moderate levels of professional supervision when combined with a substantial amount of parent involvement.

The following studies investigated the effectiveness of parent-directed EIBI with far less professional supervision and without professional therapists providing the direct treatment—a model that more closely resembles that which commonly occurs in rural communities. Smith, Buch, et al. (2000) studied parent-directed EIBI treatment for six children with ASD. Children received treatment from three to six therapists with no previous experience and who were trained, with the parents, in workshops in the children's homes. A total of six, 6-h workshops occurred in the first 3 months of intervention and 2-h workshops monthly thereafter. Children received an average of 26 h per week of treatment. After 2–3 years, two children showed marked improvements on standardized tests, three children's scores remained fairly stable, and one child regressed. None of the children achieved IQ scores within the average range. Overall, treatment effects were significantly less substantial than those produced in studies of professionally delivered EIBI.

Bibby et al. (2002) analyzed 66 cases after 12 months of parent-managed EIBI treatment from various service providers. Children were already receiving intensive behavioral intervention prior to the beginning of the study and received an average of 30 h per week of one-to-one behavioral therapy throughout the course of the study. The 66 children were served by 25 different consultants from a large variety of organizations, who made four visits per year to provide supervision to parents and the treatment teams. Results were similar to Smith, Buch, et al. (2000) in that improvements were not robust. After 12 months of treatment, IQ scores did not change significantly. Ten children had IQs within the typical range (>85), but five of those already had IQ in the average range at intake.

Taken together, these findings suggest that parent involvement in EIBI can be beneficial;

however, outcomes are not maximized when the design and management of EIBI programs are left to families. That is, the design, management, and supervision of EIBI programs and therapists should be the responsibility of well-trained professionals. Like any other intensive, complex, long-term psychoeducational intervention, EIBI requires intensive direction by an expert in EIBI with years of experience in designing and managing EIBI programs for children with autism. However, it is interesting to note that the results of the Sallows and Graupner (2005) and Hayward et al. (2009) studies seem to suggest that it may be possible to replace some amount of professional supervision with parent direction, if parents are provided with intensive training and supervision in the process. However, it should be noted that the parent-directed group in the Hayward study still received 6 h of professional supervision every 6 weeks (an average of 1 h per week). In addition, the parent-directed group in Sallows and Graupner (2005) received 6 h per month of supervision from a professional senior therapist (an employee of the clinic who was not recruited nor trained by the parents) as well as consultation every 2 months from the study authors, which comes to an average of well over 1 h per week of professional supervision. Thus, the “parent-directed” groups still received what would likely be considered a significant amount of supervision and direction from expert EIBI professionals.

Treatment Intensity

Intensity of treatment generally refers to the number of hours of one-to-one therapy a child receives per week—this is the first “I” in “EIBI.” A small but significant amount of research has evaluated the effects of various degrees of intensity on EIBI outcome. Lovaas (1987) was the first study to directly address intensity when it compared outcomes for the treatment group who received 40 h per week to a control group who received 10 h per week. The high-intensity group clearly outperformed the low-intensity group in all outcomes.

Reed, Osborne, and Corness (2007) descriptively evaluated the effects of treatment intensity. A comparison was made between high-intensity (20–40 h per week) and low-intensity (10–20 h per week) behavioral intervention provided by community-based agencies. The high-intensity group made greater improvements in intellectual and educational functioning, but there was no difference between groups on adaptive functioning.

In another study of intensity, Granpeesheh, Dixon, Tarbox, Kaplan, and Wilke (2009) analyzed variables affecting learning for 245 children with ASD receiving EIBI services from a community-based provider. Regression analyses of the effects of the number of treatment hours per month on the number of behavioral objectives mastered per month showed a clear relation, wherein increased treatment intensity led to increased rates of learning.

A casual examination of the differences in treatment effects produced by the major EIBI outcome studies also supports the notion that increased intensity leads to improved outcome. Figure 19.1 depicts the number of hours of behavioral therapy per week and changes in IQ reported by all professionally directed EIBI outcome studies discussed in this chapter. Please note that (1) statistical analyses were not conducted on these data due to the small sample size and (2) the trend line on the graph simply shows the slope of the graphed data points. Casual visual inspection of the data suggests that, as studies provide a larger number of treatment hours per week, they produce larger gains in IQ. Figure 19.2 graphs the changes in Vineland Adaptive Behavior Composite scores in the same manner. Note that fewer outcome studies include Vineland data, so the graph includes fewer data points. Similar to IQ, visual inspection of the data suggest that greater numbers of treatment hours per week may lead to larger improvements in adaptive behavior.

The total duration of treatment (e.g., in hours, months, or years) is another way in which intensity can be quantified. Little research has directly addressed this variable, but Luiselli, Cannon, Ellis, and Sisson (2000) used regression analyses to evaluate predictors of outcome for children

with ASD who received behavioral intervention for less than 15 h per week and for less than 12 months. Results indicated that the total duration of treatment predicted changes in communication, cognition, and social-emotional functioning. The Sallows and Graupner (2005) study described earlier conducted outcome assessments at intake and yearly for a total of 4 years. Although the largest gains were made in the first year of treatment, most participants continued to make gains throughout 4 years of treatment. Taken together, these studies suggest that the total duration of EIBI matters and that longer duration may lead to greater treatment gains.

Age at Intake

Behavioral intervention for children with autism should begin as *early* as possible—this is the “E” in “EIBI.” No research studies, of which we are aware, have intentionally begun EIBI services earlier for some children than others for the purposes of evaluating the impact of age on outcome. Such research would clearly be unethical, given the documented effectiveness of EIBI, but a small number of studies have attempted to evaluate the effects of age on outcome by descriptively analyzing it. For example, Fenske, Zalsenski, Krantz, and McClannahan (1985) compared outcomes for nine children who entered EIBI before age 5 and nine children who entered after age 5. Services were provided in group homes and a center-based program. Young age at intake was found to be strongly related to the positive outcomes of successful placement in public school, as well as children residing with their natural parents. Similarly, Harris and Handleman (2000) evaluated outcomes for 27 children who received center-based EIBI services and found that a younger age at intake was predictive of eventual placement in a regular education classroom, whereas older age at intake was predictive of later placement in a special education classroom. Finally, the study by Bibby et al. (2002) described earlier analyzed their data separately for children who began treatment before 43 months of age versus those who began after 43 months of age and found a substantial difference

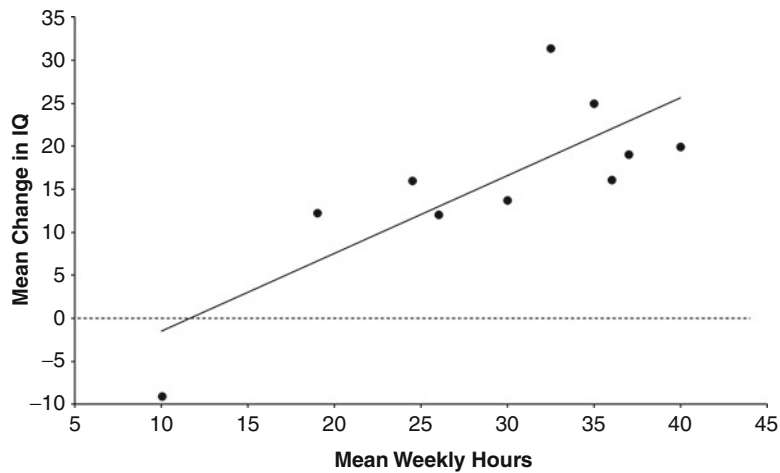


Fig. 19.1 Mean changes in IQ and mean weekly hours of behavioral therapy reported in outcome studies of home-based early intensive behavioral intervention described in this chapter

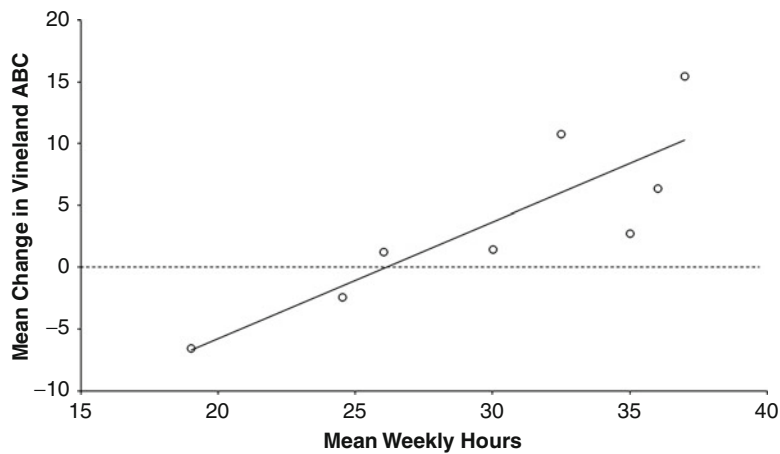


Fig. 19.2 Mean changes in Vineland Adaptive Behavior Composite scores and mean weekly hours of behavioral therapy reported in outcome studies of home-based early intensive behavioral intervention described in this chapter

in IQ gain (10.8 points vs. 2.4 points, respectively). Taken together, these findings suggest that early identification and treatment is predictive of better outcomes.

Parent Training

A large number of studies have demonstrated the effectiveness of behavioral home-based approaches to training parents of children with developmental disabilities across a variety of

diagnoses and behavioral challenges. In this form of intervention, the professional does not provide direct service to the child. Instead, the professional trains the parent(s) to deliver intervention with the goal of improving child outcomes. A comprehensive review is beyond the scope of this chapter; however, below we describe a small sample of parent-training studies. Readers may wish to consult Matson, Mahan, and Matson (2009) for an overview; Brookman-Frazee, Vismara, Drahota, Stahmer, and Openden (2010) for an in-depth review of training procedures for

parents of children with ASD; Kaminski, Valle, Filene, and Boyle (2008) for a meta-analysis of effective training procedures for parents of young children; Gabovitch and Curtin (2009) for a review of research on family-centered care in ASD; Patterson, Smith, and Mirenda (2012) for a review on parent-training procedures to enhance communication and social development in children with ASD; and Roberts and Kaiser (2011) for a review of research on parent-training interventions for improving receptive and expressive language in children with and without intellectual disabilities.

Training on EIBI Procedures

The research on parent-directed EIBI described earlier demonstrates fairly clearly that parents cannot and should not be expected to take the place of professional behavior interventionists. However, parental involvement in behavioral intervention is crucial, and for parents to be involved most effectively, they need to be trained in the procedures they are expected to implement. These procedures will vary, depending on the nature and scope of the behavioral intervention program. While not a replacement for professionally delivered therapy, research suggests that parent-implemented discrete trial and behavior management may be an important *supplement*. Below, we describe a small sample of studies demonstrating effective procedures for training parents to participate in EIBI.

Anderson et al. (1987) evaluated the effects of parent involvement and implementation on accuracy of EIBI implementation. In their study, they asked 14 families (11 mothers and 3 mother/father dyads) to initially act as observers of their child's therapy and then gradually transition into the role of primary therapist for their child. Before training, parents' performance ranged from 17 to 48 % accuracy, but increased to above 80 % accuracy post-training.

Lafasakis and Sturmey (2007) evaluated the effects of a behavior skills training (BST) procedure on parent-implemented DTT procedures. BST included instructions (written and vocal),

modeling, rehearsal, and feedback. Correct implementation of DTT was low during baseline and improved significantly for all three parents after BST was provided. Ward-Horner and Sturmey (2008) replicated and extended these findings in another evaluation of BST on parent-implemented DTT procedures. The study evaluated the degree to which parents could generalize the DTT skills to novel lessons for which they were not directly trained to implement. The results replicated Lafasakis and Sturmey (2007) and showed that correct implementation of DTT for all three parents improved following BST. In addition, the findings extended previous research by documenting generalization to untrained lessons. In general, research on training parents of children with ASD to supplement EIBI programs suggests that parents are highly trainable and the implications are that all EIBI programs should include a strong parent-training component.

Reduction of Behavior Problems

Parent training has been shown to be effective at reducing behavior problems for children with and without developmental disabilities by using in-home consultation to train parents to implement behavioral interventions. Kuhn, Lerman, and Vorndran (2003) used a pyramidal training model, wherein caregivers were trained, who then trained other caregivers to reduce a child's problem behaviors in the home. Three children and their caregivers participated in this study. Mothers acted as primary caregivers and conducted trainings with two secondary caregivers, including fathers, stepfathers, brothers, and grandmothers. One behavior was targeted for intervention for each participant and included stereotypic hand movements, spitting, and compliance with instructions. The primary caregiver was initially trained on implementation of the treatment over three, 1–2-h home visits. Trainers provided the primary caregiver with instructions (written and vocal), used role-play, and provided feedback on how to implement the treatment and how to train others. Primary caregivers were able to implement the treatment with high fidelity and

successfully trained two other caregivers to implement the treatment accurately in the home environment.

Tarbox, Wallace, Penrod, and Tarbox (2007) used BST (e.g., written description, modeling, role-play, and feedback) to train parents and teachers of children with ASD and attention deficit hyperactivity disorder to implement a three-step compliance protocol. The three-step compliance protocol consisted of caregivers first presenting tasks with a single verbal instruction. If children did not comply with the verbal request within 5 s, caregivers then modeled the correct response. If children did not comply within 5 s of the model prompt, caregivers implemented a physical guidance prompt to ensure compliance. Following training, caregivers reduced the number of prompts per trial to more acceptable levels, children displayed increased compliance to instructions, and generalization across tasks/instructions was observed for three caregiver-child dyads. A significant amount of research has demonstrated the utility of parent-training approaches to the reduction of challenging behaviors in general, emphasizing the importance of including training procedures for parents in any home-based behavioral intervention program for individuals who display challenging behavior.

Feeding Disorders

Feeding disorders are common among children with cognitive or major motor impairment, with prevalence estimated between 30 and 90 % (Schwarz, 2003). A substantial amount of research has documented the effectiveness of behavioral treatments for feeding disorders (see Chaps. 10 and 22 in this handbook). A small but significant amount of research has also documented treatment for feeding disorders in children with developmental disabilities via home-based parent training. Werle, Murphy, and Budd (1993) used verbal description, role-play, feedback, and videotape review to train parents to treat their children's feeding disorders. Parents learned to implement procedures well and consumption of new foods increased across all

children. Mueller et al. (2003) trained parents to implement feeding protocols to their young children through verbal instructions, modeling, and rehearsal. The study found that feeding difficulties could be effectively addressed via parent training and that modeling and rehearsal alone were sufficient to effectively train parents. Recently, Tarbox, Schiff, and Najdowski (2010) trained a mother of a child with autism to implement a modified escape prevention procedure for treating food selectivity. The mother implemented all treatment procedures in her home, initially with a consultant present, and the presence of the consultant was systematically faded. Consumption of healthy foods increased to 100 % and maintained.

In summary, a significant amount of research has shown that behavioral approaches to parent training can be effective in establishing a wide variety of parent skills. Just as important as establishing specific skills, effective parent training may also make parents feel empowered and improve their feelings of effectiveness. For example, Feldman and Werner (2002) evaluated the collateral effects of parent training and found that weekly behavioral parent training resulted in a reduction in stress levels and family life disruptions, as well as an increase in opportunities to engage in activities outside of the home. In addition, parents reported feeling better prepared to intervene and prevent future problem behaviors. The authors suggested that overall quality of life for families with children with developmental delays was enhanced through parent training.

Functional Assessment and Treatment of Severe Behavior

A large amount of research has documented the effectiveness of home-based models for the assessment and treatment of challenging behaviors. Generally speaking, consultants may visit an individual's home, conduct a functional assessment—generally with the involvement of caregivers—and design a behavior intervention plan (see Chaps. 8 and 9 in this handbook for a description of functional assessment and analysis

procedures). Initially, the behavior intervention plan may be implemented by the consultant, but the goal is to have the client's family take over responsibility for implementing the intervention plan as soon as possible. Space does not permit a comprehensive review of research literature on home-based assessment and treatment of challenging behavior, but a small sample of studies will be described.

Functional communication training (FCT) has been validated by a substantial body of research, showing its effectiveness in reducing challenging behaviors and increasing communication (Tiger, Hanley, & Bruzek, 2008). FCT involves teaching an individual to ask for what he/she wants instead of engaging in challenging behavior to get it. Wacker and colleagues have produced numerous studies in a program of research on the effectiveness of parent-implemented functional assessments and FCT on the long-term reduction of aberrant behaviors in children with developmental disabilities. For example, Derby et al. (1997) studied the long-term maintenance of FCT protocols for four young children enrolled in a home-based early intervention program. Initial assessments and parent interviews were conducted, followed by functional analyses to determine the operant function of each child's behaviors. Parents were then trained to implement an FCT protocol based on the results of the functional analyses. The results indicated that parents were able to effectively implement FCT interventions in the home, producing long-term reductions of aberrant behaviors and increases in communication. Long-term maintenance of communication may be the result of caregivers continuing to reinforce the behavior, resulting in positive interactions between parent and child. Parents have also reported satisfaction with these interventions (Wacker et al., 2005).

Generalization of overall reduction in aberrant behaviors across tasks, settings, and people has also been demonstrated through the use of in-home functional assessments and FCT treatments implemented by parents. Berg, Wacker, Harding, Ganzer, and Barretto (2007) evaluated generalization of behavior reductions across stimulus sets with four children, showing generalization to

70 % of untrained stimulus sets. FCT is one of many interventions for challenging behavior that have been shown to work in the home setting, but it is often preferred because it is effective and it ensures that appropriate communication is strengthened, an important goal in itself.

Discussion

Strengths of Home-Based Service Delivery

Home-based service delivery has several potential strengths, relative to other service delivery settings. One major advantage is that it is often easier to involve parents and other family members in treatment. Most home-based behavioral intervention service providers require that at least one family member or caregiver be present in the home while services are delivered. Since they are already home, it is often relatively straightforward to actively involve them in treatment. This convenience can be contrasted to clinic, school, or hospital-based services, where the transportation to the treatment site alone may present significant challenges for caregivers, particularly if they need to travel there on a regular basis.

A second potential strength of home-based services is the fact that, by definition, the treatment services are provided in the individual's natural environment. When behavior is successfully changed somewhere other than the individual's natural environment (e.g., hospital), then a major concern must be the generalization of that behavior change to the natural environment. Generalization of behavior change to an individual's daily life depends on a large number of variables (e.g., similarity between treatment setting and home), and many of these variables are simply eliminated by providing treatment in the home.

An additional potential advantage of providing services in the home is that it may decrease overhead costs to service providers. Renting or purchasing business space, obtaining certification or local licensure of space, and building maintenance fees are all likely to be far greater if services

are provided at a center. All other things being equal, it seems plausible that decreased overhead costs may lead to decreased fees for service, thereby potentially saving expense to families and/or funding providers. In an age of shrinking funds for human services, costs savings may be a significant advantage to home-based services.

Inclusion of siblings or similar-age peers is an important part of the treatment process, particularly for teaching reciprocal language and social skills. If an individual lives with siblings or has similar-age peers that live in the same neighborhood, it may be relatively easy for families to arrange for such individuals to be available during treatment sessions. Of course, school-based services probably excel in this regard, in that schools have a large pool of peers who already spend a significant amount of time with the student being served.

One rarely discussed potential advantage of home-based services is that the mere presence of the client's parents may help ensure that the design of the treatment remains grounded in real-life concerns. Sometimes, treatment providers (both behavioral and otherwise) stray too far from real-life considerations when designing and evaluating treatment procedures in overly controlled settings. For example, it may be possible to simply ignore potentially dangerous attention-maintained self-injurious behavior in a carefully controlled session room with padded walls and where doctors and nurses are on hand to administer treatment, if needed. This procedure may simply not be realistic in a family's normal everyday environment. The same may be said for treating aggression. If the same individual is being treated at home, it would be clear from the outset that a more preventive approach would likely be needed.

Potential Limitations to Home-Based Service Delivery

In addition to the significant strengths of providing behavioral treatment services in the home setting, there are several potential limitations that are worthy of discussion. The constant need for staff

to travel is a significant limitation of home-based services. Turnover is high at entry-level staff positions, and it is likely that the need for excessive driving contributes to the problem. Especially in metropolitan areas, where a behavioral therapist can spend up to 4 h per day sitting in traffic while driving between treatment sessions, the need for travel to the home setting can be considered a major drawback.

An additional limitation to home-based treatment is the difficulty that service providers may have with obtaining adequate control over the client's environment. Behavioral intervention procedures work by altering and controlling the individual's environment, so if adequate control is not possible, then treatment will not be effective. Sometimes barriers to controlling the environment are explicit and intentional, as when a parent refuses to allow their home environment to be altered sufficiently to allow for effective treatment. Far more often, however, are situations in which it is simply very difficult to adequately control the home environment. For example, many families reside in homes that are too small for the number of people living in them to allow for dedicated, uninterrupted space for behavioral treatment sessions. In addition, many families have other children in the home who also experience behavioral challenges and may disrupt the treatment environment. On very rare occasions, family members engage in clearly dangerous behaviors, such as hoarding, substance abuse, or domestic violence, which may make maintenance of a healthy therapeutic environment impossible. In such cases, treatment services simply cannot be provided in an ethical and safe manner in the home.

A third limitation to providing behavioral intervention services in the home setting is that supervision of the services is more logistically demanding and costly. For example, for a supervisor to observe the services being provided in the home, he/she must drive to and from the home. Consider a situation in which driving time is 1 h each way. It will require at least 3 h of the supervisor's time to accomplish only a single hour of supervision, assuming there are no traffic delays. In school or hospital settings, where the

supervisor may be physically present in the same building where services are provided, supervision may be significantly more efficient, occur more frequently, and be more cost-effective.

Some have concern over the potentially intrusive nature of home-based treatment. Specifically, the mere presence of someone who is not a member of the family on a regular basis may increase stress for the family. While this is certainly possible, it could also be that treatment reduces stress, relative to what the family endured before the child was being effectively treated. Little research has addressed this question empirically, but initial data seem to suggest that home-based services do not increase stress (Birnbrauer & Leach, 1993; Remington et al., 2007).

A major practical limitation to home-based service delivery is the requirement of having a caregiver present in the home while services are delivered. This may simply be impossible for families where all adults need to work full-time. If the intervention is intensive (i.e., 30 or 40 h per week), there may be no family members available who can stay home while treatment is delivered. Although it has not been evaluated empirically, it is possible that this requirement may make home-based services out of reach for some socioeconomically disadvantaged families.

Finally, home-based service delivery introduces the potential for boundary issues to arise between family members and service delivery staff. Dual relationships are always potential areas for concern in human services, but when the services are delivered in the family's home and often for a protracted period (up to 4 or more years), this seems especially so. Little published research has evaluated the problem, but there are numerous anecdotal reports of family members sharing alcoholic beverages with staff, making sexual advances toward them, and otherwise engaging in behavior that can create harmful dual relationships. It seems plausible that family members may be more inclined to engage in these behaviors in the context of home-based service delivery (relative to other formats such as schools and hospitals) because they are in their own homes, where their behavior may be less restricted.

Low-Quality Home-Based Behavioral Intervention Services

The demand from families for home-based behavioral services, as well as the funding for these services, has expanded dramatically over the past two decades. The large demand and the availability of funding have resulted in significant business opportunities for professionals to start new service provision agencies. This is a great development for the field of ABA because it has facilitated expansion of the discipline and a great development for individuals with ASD because it has increased access to EIBI services. However, some undesirable developments have come to pass as well. Some service provision agencies have been started by individuals who lack the appropriate training and expertise. If these individuals continue to oversee the services provided by their organization, then the quality of the services may never be adequate. In some cases, organizations are started by individuals who have experience at a top-quality service provision agency, but only at the entry level, and so they have not received adequate training for program supervision, design, and management. In other cases, organizations are started by individuals with no clinical experience, primarily for a business investment. There is, of course, no reason why a treatment provision organization cannot be founded and owned by a business person, but great care must be taken to ensure that the quality of the clinical services is overseen by an expert clinician and that clinical imperatives are not overruled by business interests. Still, other service provision organizations have been founded by parents of individuals with autism and other developmental disabilities, often in response to a lack of qualified providers available in their area. This development automatically introduces dual relationships into the organization. However, it seems likely that this development helps the field of ABA remain anchored in real-life concerns of the families it serves. There should be no reason why a service provision organization cannot be founded and governed by parents of individuals with disabilities, so long as an expert clinician is in charge of

ensuring quality and so long as any potential dual relationships are not allowed to unduly influence decisions of clinical importance.

Due to the vast range of quality that is present among EIBI programs, many of the existing studies of community-based EIBI may actually amount to studies of mixed or low-quality EIBI. In other words, existing studies of community-based home-based intervention may not be evaluating community-based intervention, per se, as opposed to evaluating the effectiveness of behavioral intervention delivered at a low level of quality. For example, an uncontrolled retrospective case review by Boyd and Corley (2001) assessed outcomes for 22 children who had received 1–3 years of in-home EIBI services from community service providers for 30–40 h per week. Treatment was provided by a wide variety of service providers, with no attempt to control or standardize treatment fidelity. No validated measures of client outcome were assessed, but it was noted that none of the 22 children were able to be transitioned to regular education without specialized supports after treatment was finished.

In the largest study of community-based EIBI to date, Perry et al. (2008) conducted a retrospective analysis of 332 children receiving community-based services for 20–40 h per week and for 4–47 months. Numerous agencies provided one-to-one behavioral services, and it was not possible to standardize quality of care to any great degree. Supervision of individualized services was conducted weekly by individuals with Board Certification in Behavior Analysis (BCBA) and/or master's degree. Statistically significant improvements from pre- to posttreatment were seen in the categories of IQ, mental age, and adaptive behavior, and 34 % of the total sample scored in the non-autistic range, as measured by the Childhood Autism Rating Scale (Schopler, Reichler, & Rothen Renner, 1988). As a group, the average rate of development doubled from pretreatment rates. Developmental rate was determined by using each participant's ABC Age Equivalent score on the *Vineland Adaptive Behavior Scales* (VABS; Sparrow, Balla, & Cicchetti, 1984) and dividing it by the participant's current age. Although 75 % of all

participants made at least some gains from baseline, only 11 % of the sample achieved functioning in the average range, a percentage significantly lower than that seen in the studies by Lovaas (1987), Sallows and Graupner (2005), and Cohen et al. (2006).

Researchers and practitioners who are involved in the provision of top-quality behavioral intervention services may decry studies such as Boyd and Corley (2001) and Perry et al. (2008) because they may not be a fair evaluation of top-quality services. Furthermore, if such studies find less robust effects than studies of university-based behavioral intervention programs, then the findings may be misinterpreted to imply that behavioral intervention cannot be effectively implemented in the community setting. A more appropriate interpretation of such findings might be that low-quality services produce a less robust effect, regardless of setting. This general relationship would be expected in any field—top-quality hospitals that implement best practices surely produce better outcomes than poor-quality hospitals, regardless of university affiliation.

At the current time, no accepted measures of intervention quality exist. This fact makes it difficult for research studies to assess the extent to which they are evaluating good-quality intervention. It also highlights the need for the development of tools that can validly measure intervention quality. Further complicating this problem is the fact that there are hundreds of variations in how behavioral intervention procedures can be combined for any one child (e.g., least-to-most vs. most-to-least prompting mass trials vs. interspersed trials), and there is no validated algorithm to guide decisions about which procedures to implement for which particular child. Indeed, the very nature of applied behavior analytic treatment is such that a high degree of *analysis* is needed at the level of each individual child. Some measure of the ability of the clinician to make appropriate analyses across children would be useful. Again, no such measure exists at the current time, but this would be a potentially fruitful area for future research.

Assessing the quality of outcomes for treatment providers may be a potentially viable

alternative to assessing the quality of their procedures. As the published data on EIBI outcomes grows, more and more evidence amasses that should provide a reasonable expectation of the range of outcomes for children of a given age (e.g., 3 years) who receive a given treatment (e.g., 30 h per week). For example, as a group, one might expect clients to demonstrate changes in IQ, language scores, or daily living scores, within a particular range, over the course of 3 years. Providers who produce results at the top end of the range may be considered higher quality, while providers who produce outcomes at the lower end, or entirely below the range, may be implementing treatment of lower quality. Of course, many factors affect outcome, including parental involvement, IQ at entry, behavioral repertoire at intake, comorbid medical illnesses, and socioeconomic status. But all of these variables should be measurable, and eventually the influence of many or all should be amenable to research. Eventually, given all of these variables, it should be possible to predict at the group level a reasonable range of outcomes that should be expected of a provider who is implementing treatment of a given intensity and for a given period of time. Naturally, the current state of outcome research and research on predictor variables is nowhere near the level of sophistication that will be required for calculations of this sort, so much future research in this area is still needed.

Choosing Between Home-Based and Other Service Delivery Settings

Many treatment providers, educators, parents, funding agencies, and administrators maintain dearly held beliefs about the superiority of one setting for service delivery over another. Often, individuals believe the setting in which they work or fund treatment to be the superior setting. Usually, such beliefs come more from one's personal history than anything else. In actuality, there is very little research to support one service delivery setting over another. However, if evidence-based, effective procedures are implemented with good fidelity, and if the proper

supports are implemented across an individual's daily life, then it should not matter too much in which setting treatment is primarily based.

When choosing which setting is most appropriate for an individual's treatment, the critical question should be *What setting has the most qualified clinicians, with the greatest amount of resources to implement treatment with the appropriate intensity, consistency, integrity, and system supports?* When participating in multidisciplinary decision-making processes, it is important to acknowledge the potential sources of motivation that may be relevant. Is the public school official recommending a public school placement primarily because it will save cost to the school district? Is the university-based researcher recommending treatment in their university clinic because it will contribute to the researcher's ongoing studies? Is the clinician from the for-profit service provision agency recommending their own home-based services because they have a financial stake in the recommendation? Is the parent objecting to home-based services because they do not desire the inconvenience of having therapists in their home? All of these examples are caricatures, and real-life decisions are rarely this simplistic, but all are also very real potential sources of influence on decisions regarding the setting in which treatment should be implemented. The individual being treated will likely benefit most if all possible sources of bias are at least considered and made transparent.

Choosing Among Home-Based Treatment Models

There is currently a large degree of variety among the various options for home-based behavioral intervention, even among top-quality programs. Some of these differences amount to differences in emphasis within ABA. For example, very traditional behavioral programs place a heavy emphasis on DTT (e.g., the Lovaas model), while some programs are focused more heavily on naturalistic teaching strategies (e.g., pivotal response training), while others focus heavily on B. F.

Skinner's analysis of verbal behavior as the basis for language intervention. Still, others explicitly reject narrowing their focus and emphasize the need for a *comprehensive* application of behavioral teaching strategies. Generally speaking, very little research has compared these different models. One exception is the descriptive study reviewed earlier, in our discussion of treatment intensity (Reed et al. 2007). In addition to evaluating the effects of intensity, the study compared outcomes for children who received different models of EIBI, including the following: (1) Comprehensive Application of Behavior Analysis to Schooling (CABAS), (2) EIBI emphasizing Skinner's verbal behavior, and (3) a traditional Lovaas model. All models produced significant treatment gains, but the Lovaas and CABAS groups made the greatest gains in IQ, and the CABAS group made the greatest gains overall. Caution must be taken in interpreting the results of this study because of the following reasons: (1) they have not been replicated; (2) the analysis is retrospective; (3) there was no random assignment to groups, so it is likely the participants could have fared differently for other reasons; and (4) there was no objective measure of whether treatment was actually implemented according to the reported model. Much more research is still needed to compare these models.

Another potentially relevant difference between various home-based behavioral intervention programs is the particular organization or brand behind the treatment. The brand or name, per se, is irrelevant, but different organizations do indeed have different practices and different clinical traditions. Since these practices involve differences in the ways in which services are delivered, they may well impact client outcome. For this reason, comparative research on the outcomes of various organizations would be valuable. There would of course be conflicts of interest (e.g., financial interests, reputation) in research of this sort, but it should be possible to conduct research of this kind in a sufficiently objective manner, perhaps by independent groups. Independent third-party comparative research is common in the automotive and higher education industries, among others.

Conclusion

A large amount of research supports the effectiveness of home-based behavioral intervention for solving a diverse array of behavioral challenges for individuals with developmental disabilities and their families. Proven areas of effectiveness include EIBI for children with ASD, assessment and treatment of challenging behavior, and parent training. The home as a setting for behavioral intervention has many potential strengths, including convenient inclusion of family members in treatment, the fact that intervention occurs in the individual's natural environment, decreased overhead costs to treatment providers, and the potential that treatment decisions remain grounded in real-life family considerations. Home-based treatment is not without its limitations, however. Potential challenges inherent in home-based intervention include the amount of travel that is required of treatment providers, the potential difficulty with maintaining adequate control of the environment, the logistical difficulty of providing adequate supervision of services, the potential financial demands of requiring a family member to be home during treatment, and the potential for dual relationships and boundaries issues that can arise while providing treatment in the home. Finally, it should be noted that there is little research guiding consumers and funding providers about the best choice regarding the setting for service delivery. However, the choice between settings should be made, to the greatest extent possible, on a rational decision-making process around what is most likely to provide the highest quality of service to the individual, with the maximum amount of systems and family support.

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Components of a Private School Program Serving Children and Adolescents with Severe Problem Behavior

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A guiding principle of school placement for students with disabilities is the provision of educational services within a least restrictive environment, which refers to the opportunity to be educated with nondisabled peers to the greatest extent appropriate (Individuals with Disabilities Education Improvement Act (IDEIA), 2004). Although placement within a general education classroom is often considered the goal of this principle, some students with disabilities and severe problem behavior require intensive behavioral, psychological, and/or educational services that cannot be provided in general education classrooms or public schools (Luiselli et al., 1998). Students requiring intensive supports can be placed into a more restrictive environment to address specific needs in an individualized manner. These environments may consist of pullout services, self-contained special education classrooms, special education schools, and hospital-based services (Rozalski, Stewart, & Miller, 2010). If the severity of a student's disability prevents him or her from achieving adequate progress within the home school district, placement to a more restrictive environment is required

to meet the student's needs. A private school may be better equipped to support students with severe needs when a school district is unable to provide an appropriate program (Rozalski et al.). IDEIA (2004) mandates a free and appropriate education for all students with disabilities, which makes available secured funding for private school placement when it is considered to be the least restrictive environment possible to meet the individual needs of a particular student.

Increased supports offered in more restrictive environments, including private schools; often comprise fewer students per teacher; highly structured schedules; an extended school year; interdisciplinary teams; a peer review process; and individualized medical, rehabilitative, behavioral, and educational services (Behrens & Satterfield, 2007; Brown et al., 2004; Luiselli et al., 1998). These multifaceted systems provide intensive, multiple layers of service often required by students with severe problem behavior. Moreover, students who attend private day or residential schools that offer intensive services to treat severe problem behavior show improved functioning and outcomes (Baenen, Stephens, & Glenwick, 1986; Behrens & Satterfield, 2007; Rey, Enshire, Wever, & Apollonov, 1998).

Once it is established that an alternate placement with increased supports is necessary, families and educators must next identify an appropriate program that meets the student's needs. A number of resources are available to guide families in evaluating and/or locating programs with the

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capacity and expertise to implement increased supports including online guides (e.g., National Autism Center, 2011), conceptual articles that guide practice (e.g., Van Houten et al., 1988), best practices assessment tools (e.g., Crimmins, Durand, Theurer-Kaufman, & Everett, 2001), and materials produced by professional organizations or special interest groups (e.g., Autism Special Interest Group of the Association for Behavior Analysis International, 2007). Despite providing increased supports and services relative to public schools, a private school placement may actually function as an appropriate and least restrictive environment for students with severe problem behavior.

The purpose of this chapter is to demonstrate how the principles, procedures, and information presented in Units I and II of this book can be integrated in a private school setting to address the unique needs of students with severe problem behavior. The chapter outlines systems supports and process variables in a private school that are useful for students with severe problem behavior. We recognize that specific system supports and processes will vary from school to school depending on the needs of the individuals being served; however, the general framework will be similar. For example, private school students benefit from a therapeutic environment regardless of the specific setting characteristics. Best practices also emphasize input from professionals with expertise relevant to a student's individual needs, analysis of problem behavior, and development and implementation of an assessment-driven behavior support plan (BSP) that is systematically evaluated and changed. To best illustrate the process of generating specific systems from general guidelines, we will use examples from the May Center for Education and Neurorehabilitation (i.e., May Center). The May Center is a community-based residential, private school that serves children and adolescents with acquired brain injuries who present with severe problem behavior. We encourage readers who might use the information presented in this chapter to evaluate a private school to consider the unique needs of the individual being served and how these needs would require similar or different systems supports and processes within the general framework presented here.

Preadmission

Before beginning private school placement, all stakeholders (e.g., student and his or her guardians, public school, and private school) must determine if the private school is an appropriate placement. From a guardian and public school district perspective, this determination will likely center on whether the private school will adequately meet the student's needs to a better degree than the current placement. If the student is transitioning from a *less*-restrictive placement (e.g., public school classroom), an important consideration is the potential benefits of a more restrictive placement relative to the drawbacks of being removed from a more naturalistic environment. If the student is transitioning from a *more* restrictive setting (e.g., hospital-based treatment facility), stakeholders must consider whether private school placement is the appropriate next step toward increasingly less-restrictive educational environments.

The private school will have a formal admissions process. Typical information gathered includes standardized testing results, diagnoses, and any other mental health or treatment information (e.g., current BSPs and individualized education programs). This information is reviewed by members of an interdisciplinary team (described in more detail in the next section) to determine if the applicant's needs are appropriate for treatment in that particular setting. Admission decisions are based on the level of care that will be necessary to produce positive outcomes and maintain student safety as well as the school's past success in treating students with various types and severity of problem behavior. For example, a student requiring intensive medical treatment (e.g., frequent PEG tube feedings) may be best served in a hospital setting; private schools that cannot provide those services on-site are not likely to admit that student or others with similar needs.

Following a review of relevant paperwork, a private school will schedule a face-to-face interview with a potential student and his or her caregivers. These interviews can occur in the

applicant's home, current school, and/or at the private school. Depending on the specific needs of the applicant (identified in the referral packet), various members of the interdisciplinary treatment team will be present for the interview.

Once an individual is accepted for admission, the interdisciplinary treatment team will conduct a detailed review to evaluate the student's needs and examine whether any modifications to protocols should be put in place when the student attends his or her first day at the private school. Behaviors that demand immediate attention should be addressed immediately. Some examples would be modifying the environment for an individual with pica, designating a peanut-free room for a student with peanut allergies, and securing areas for an individual that has a history of elopement.

Therapeutic Environment

A therapeutic environment may be defined as "a physical and social environment that is safe, humane, and responsive to individual needs." A therapeutic environment includes "access to therapeutic services, leisure activities, and materials that are enjoyable as well as instructive," and "imposes the fewest restrictions necessary" (Van Houten et al., 1988, p. 112–113). Effective treatment requires a comprehensive therapeutic environment to meet the needs of the particular population being served. A therapeutic environment is comprehensive in that a full range of needs are addressed within the confines of the private school setting including social and physical environments as well as therapeutic and leisure activities.

In order to develop a therapeutic environment, one must consider the future settings in which students will have to succeed once they are discharged from the private school program (DePompei & Blosser, 1993; Pace et al., 1999). That is, designing the current environment for a particular student involves considerations of when, where, and how students will be expected to perform skills in the future. In our experience, a *community-based* therapeutic environment is

most beneficial. Community-based programs are designed to be as similar as possible to the environment or school to which the student will return in the community. This is unlike a typical medical or psychiatric environment where the environment is designed primarily around treatment considerations, with little regard to where patients will ultimately be placed.

Another important component of a therapeutic environment is a focus on the continual development of new skills. Initially, services might focus on teaching those skills necessary for students to function effectively within the private school setting. As progress is made, there is a shift in focus to teaching skills required in the transition setting (e.g., a less-restrictive environment, adult services, vocational setting). There are a variety of tools available to identify appropriate target behaviors and monitor progress (e.g., Vineland Adaptive Behavior Scales, VABS-II, Sparrow, Cicchetti, & Balla, 2005; Assessment of Basic Language and Learning Skills, ABLLS, Partington & Sundberg, 1998). These tools can be used to plan a sequence of target behaviors toward less-restrictive environments.

School Setting and Classrooms

Private school classrooms often contain routine staffing ratios richer than those typically found in public school classrooms. Commonly, services may be delivered in one-to-one or one-to-two staff-to-student ratios, particularly in the early stages of treatment. These ratios are designed to promote functional skill development, high-quality delivery of services, and safety of students and staff. Safety is a primary concern when working with students with severe problem behavior. As a student makes progress at the school, staff-to-student ratios are systematically adjusted to better approximate the level of staffing in the transition environment. For example, students who transition back to public school environments must learn to manage problem behavior and benefit from instruction with less staff/teacher support. Similarly, students transitioning to adult services or a vocational environment must learn

self-management techniques across settings and with potentially less supervision.

Private schools are often arranged so that fewer students are educated within each classroom. Both staffing ratios and smaller class sizes are designed to provide the necessary supports to meet individual needs. As an example, the May Center classrooms tend to have six or seven students. Depending on the classroom and student needs, two to five educators are responsible for delivering educational and behavioral services to these students. Daily or hourly instruction might range from 1:1 support, to students working in pairs, to small group instruction of the entire class.

Private schools typically contain physical spaces similar to a public school including a gymnasium, library, and playground. Students' schedules accommodate learning in these environments as well. However, additional space might be reserved for the delivery of individualized services based on the unique needs of the students. For example, the May Center developed a school store to serve a dual purpose: (1) to provide vocational training and (2) to allow students to purchase items of value as part of a behavior management program that capitalizes on choice of rewards in a more naturalistic setting. Also available is a dedicated "reinforcer room" where students can earn access to video game systems and televisions for watching movies. Private schools might also have space specially designed for behavior de-escalation in a safe manner (e.g., empty rooms with soft padding). The therapeutic use of these areas can foster the acquisition of self-management strategies while remaining in a safe and monitored environment. Individual private schools will vary in terms of the specific physical spaces available to students; however, physical spaces need to be available that meet a variety of needs to the students served at that school.

Interdisciplinary Teams

Interdisciplinary teams are an important component of an effective therapeutic environment (Russo, Dunn, Pace, & Coddington, 2007). It is critical for professionals from a variety of disciplines

to work together toward common student outcomes including setting goals, developing interventions, and progress monitoring. The composition of the interdisciplinary (i.e., treatment) team should be specific to the nature of the students' disability and problem behavior. The goal is to accumulate teams of professionals where each person brings unique expertise to the decision-making process.

Behavioral psychology departments within private schools play a critical role in treating children with severe problem behavior (Van Houten et al., 1988). Individuals with graduate training in behavior analysis, certification as a behavior analyst (Board Certified Behavior Analyst, BCBA), and competence in the principles and science of behavior analysis are necessary to successfully address severe problem behavior. Individuals working within this department may be trained in different disciplines (e.g., school or clinical psychology, special education, behavioral science), but a guiding philosophy toward behavioral treatment unites them. A behavioral psychology department may be made up of doctoral and master's level BCBAs as well as training positions for individuals learning how to treat challenging behavior and working toward certification. As part of the May Center's behavioral psychology department, there is one BCBA clinical director, two BCBA staff members supervised by the clinical director, and training positions (the number of training positions varies at any given time). Additionally, two to three predoctoral and/or postdoctoral interns and master's level behavior analysis students are typically involved with the activities of the department. High-quality behavioral services are fostered when members of the behavioral psychology department are intimately involved with the classrooms. We accomplish this by assigning a manageable number of classrooms to our behavioral team who functions as consultant to the classrooms.

Certified educators are an essential discipline in any private school and would benefit from the support available from an education department. Certified teachers are in a unique position to plan, provide, and evaluate educational programming for students. These professionals can be scaffolded

into a system whereby the most experienced and knowledgeable teachers supervise less-experienced teachers and teachers-in-training. An education department can provide support, resources, and individualized help to the teachers working day-to-day in classrooms with children and arrange professional development opportunities useful to teachers. The department can also serve as a liaison with each student's home school district. Certified educators are best able to address the legal aspects of providing education for students being served through an Individualized Educational Program (IEP). At the May Center, three certified teachers comprise the education department and provide weekly supervision, feedback, and staff development to the classroom teachers. Additionally, they communicate with students' local school districts. In each of the classrooms, a "lead teacher" supervises and implements educational programming, reports to the education department, and supervises several direct care staff.

A variety of additional disciplines may be a part of a private school's interdisciplinary team based on the needs of the students attending the school. Different populations have different needs. For instance, populations with physical disabilities are likely to require physical therapists, occupational therapists, and nurses. Populations that receive pharmacological treatment are likely to require a medical doctor to oversee prescriptions in addition to nurses who carry out daily medication regimens. When evaluating an interdisciplinary team, one should consider the needs of the student and whether there is expertise to address the range of needs of that student.

The May Center will be used to illustrate the link between student needs and the coalescing of an interdisciplinary team. This private school serves children with acquired brain injury who engage in severe problem behaviors, have multiple physical and speech disabilities, and have significant learning disabilities (Russo et al., 2007). Severe problem behavior is addressed by the behavioral psychology department, and learning difficulties are addressed by certified teachers (described above). A rehabilitation department consisting of speech and language pathologists,

occupational therapists, and physical therapists conducts comprehensive assessments to determine a student's current functioning level and short- and long-term rehabilitation goals. These professionals also develop individualized intervention plans that they implement or oversee, and assist in making behavioral recommendations regarding physical limitations of certain students when physical management is required. A vocational department concentrates on teaching job-related skills, identifies potential work sites, selects skills needed to function in those settings, and trains functional skills, all in order to obtain work experience to prepare students for adult services and vocational opportunities. A nursing department coordinates medications administered during school hours and addresses the medical needs of students who cause harm to themselves or others. Complementing the nursing department is a consulting psychiatrist with expertise in treating individuals with severe problem behavior and coordinates medications that are prescribed in conjunction with behavioral interventions. Finally, certified mental health counselors participate in the treatment team as well as a family service department that schedules meetings with parents and arranges behavioral supports between school and home settings. In total, a number of professionals with unique expertise are brought together to address the range of concerns presented by students with acquired brain injury. While one department primarily deals with particular issues, input is obtained from all departments.

Overall, the types of professionals who are involved strongly influence the therapeutic environment. Departments bring in professionals with unique expertise, and the departments work together on interdisciplinary teams at all levels of assessment, treatment development, and progress monitoring.

Data Supports

Collecting data to monitor and evaluate behavioral interventions is an important component of the services offered by private schools for

children with severe problem problems and is an essential feature of a therapeutic environment. The types of data collected depend on student needs. Data are a way to communicate student progress and evaluate the effectiveness of treatment. Thus, each department involved in an interdisciplinary team should have some mechanism in place to monitor treatment effectiveness. Equally important is the involvement of all staff members in data collection. While individual student data may be of primary concern, data on the accuracy and consistency of treatment (i.e., treatment integrity) is also necessary in order to evaluate the effectiveness of treatments. That is, without evidence that treatment was implemented as planned, it is challenging to make decisions about the effectiveness of that treatment.

Assessment of Problem Behavior

Previous chapters in this book have provided information and examples about how to assess and treat problem behavior. In this section, a description of procedures used at the May Center will illustrate how these processes are integrated into a broader system. Regardless of the specific forms and protocols, every private school should have a system in place to address problem behaviors that are based on sound behavior analytic principles and research. Specifying a timeline and defined actions for assessment and treatment of problem behavior is an important component of this system.

The May Center developed a specific baseline protocol for use with every admitted student. The baseline protocol is followed until an individualized BSP (see BSP development below) is developed. There are two distinct phases of baseline each lasting approximately 2 weeks: (1) initial gathering of information as the student transitions and acclimates to the May Center and (2) individualized assessment resulting in a BSP.

Baseline: Phase 1

The purpose of this phase of baseline assessment is to identify a student's range of potential problem behavior and to establish the frequency and

intensity of those behaviors. An established baseline pattern of behavior permits an evaluation of the effectiveness of intervention plans. During phase 1 there are no individualized programmed consequences for problem behavior other than redirecting students back to task. Staff place typical demands on the student by presenting opportunities for interaction in instructional materials; however, refusal of a demand results in no specialized intervention.

Staff are encouraged to provide verbal praise for desired behavior and compliance, but they do not establish student-specific reinforcement contingencies (e.g., token systems, behavioral contracts). For example, if a student complies with a staff request to "sit down," staff would deliver verbal praise (e.g., "thanks for sitting Jonny."). Conversely, staff would not implement a programmed consequence other than directing a student back to the current activity/task if the student does not sit. Although these procedures are generally implemented when a student enters the program, specific consequence procedures are considered when problem behavior includes self-harm and/or environmental disruption (e.g., property destruction, aggression toward others).

During the initial phase of baseline, data are collected to estimate the frequency, intensity, and topography of challenging behaviors. The baseline protocol data sheet (see Fig. 20.1) provides spaces for recording data on episodes of self-injury, aggression, property destruction as well as inappropriate social and vocal interactions with others. The data sheet also provides dedicated space for other behaviors to be added and recorded. Using different data recording forms, staff also record performance data on academic skills, activities of daily living, and social and communication responses. Additionally, a generic data sheet is available to allow staff to record the activities and stimuli the student approaches in the classroom. Standardized preference assessments are conducted during the second phase of baseline, which is described next.

Baseline: Phase 2

After the first phase of baseline is complete, the interdisciplinary treatment team meets to review

Baseline Data Sheet

Student's Name: _____ Date: _____ Staff Initials: _____

Behavior	Frequency		Severity				
	Tally Record each observed instance of behavior between 1 and 11	Summarize Note the number of occurrences of the behavior for the day/shift	1 Not Severe at all	2	3	4	5 Very Severe
Self-Injurious Behavior: Any instance of a student injuring or attempting to injure him or herself.		☐ 0 ☐ 1-5 ☐ 6-10 ☐ 11+					
Aggressive Episode: Any instance of a student attempting to hit, kick, bite, scratch, spit at, or throw objects at others.		☐ 0 ☐ 1-5 ☐ 6-10 ☐ 11+					
Destructive Episode: Any instance of a student attempting to cause damage to objects in their environment.		☐ 0 ☐ 1-5 ☐ 6-10 ☐ 11+					
Inappropriate Social: Any verbalization out of context, making noises out of context, mimicking peers, staring at others, making faces at others, or laughing out loud out of context.		☐ 0 ☐ 1-5 ☐ 6-10 ☐ 11+					
Inappropriate Speech: Swearing, yelling, name calling, back talk, demanding, speech, condescending remarks, raising their voice above conversational level in anger, or use of argumentative statements.		☐ 0 ☐ 1-5 ☐ 6-10 ☐ 11+					
Other:		☐ 0 ☐ 1-5 ☐ 6-10 ☐ 11+					
Other:		☐ 0 ☐ 1-5 ☐ 6-10 ☐ 11+					

The student follows directions approximately _____% of the time: ☐ 0 – 25% ☐ 26 – 50% ☐ 51 – 75% ☐ 76 – 100%
Protective Holds (Record time of incident and duration):

Fig. 20.1 Baseline data sheet used during phase 1 of the baseline protocol. Frequency and estimated severity of behavior are recorded for five standard behaviors. Room is provided for adding challenging behaviors at the bottom of the grid

phase 1 data and to identify and operationally define student-specific target behaviors. A member of the behavioral psychology department then designs a student-specific data sheet and data collection method before initiating phase 2 assessment.

For behaviors such as aggression, destruction, and inappropriate social behavior, all-day frequency data are useful for gaining a broader understanding of the behavior. If students have extremely high rates of a target behavior that occur evenly across the day, time sampling procedures can reduce data collection efforts while producing an accurate estimate of behavior. For example, for a student who engages in repetitive behavior throughout the school day, frequency data could be collected twice daily during 10-min periods. Alternatively, 10-min periods can be divided into 30-s intervals during which staff record behavior occurrence at any time during each of the smaller intervals (partial interval recording). Behaviors may vary in length (e.g.,

tantrums) and a duration measure can be adopted. Data may be collected on less severe problem behaviors as well. For instance, latency to comply with demands could be collected for a student who is passively noncompliant (e.g., no aggression). Student-specific data sheets are individualized to each student's needs; but, regardless of the form, they can track several behaviors simultaneously much like the data sheet in Fig. 20.1.

A functional behavioral assessment (FBA) is conducted during phase 2, the purpose of which to identify the environmental variables that affect target behaviors. The results of the FBA are used to produce assessment-driven BSPs. For detailed information on FBA, readers are encouraged to see Chaps. 8 (indirect and direct assessment) and 9 (functional analysis) of this handbook.

As a supplement to functional assessment, this phase involves conducting more formalized preference assessments. The goal of a preference assessment is to identify potential reinforcers that

can be used to reward prosocial behaviors (e.g., social skills, compliance with demands). Stimuli identified via preference assessment are used in a function-based treatment plan to compete with the reinforcers obtained by engaging in severe problem behavior.

Educators are encouraged to routinely conduct systematic preference assessments (Cooper, Heron, & Heward, 2007). Although asking caregivers and the student to identify items they prefer and that can be used as potential reinforcers, this procedure is often ineffective when used in isolation. We encourage readers to supplement surveys with a more formalized stimulus preference assessment. Common assessments include, but are not limited to, the single stimulus preference assessment (Pace, Ivancic, Edwards, Iwata & Page, 1985), paired stimulus preference assessment (Fisher et al., 1992), and multiple stimulus without replacement assessment (MSWO; DeLeon & Iwata, 1996). The MSWO assessment is commonly used at the May Center because it is easy to implement and has good utility for selecting potential reinforcers for use with students who engage in problem behavior (Daly et al., 2009; Paramore & Higbee, 2005). MSWO preference assessment involves placing several items in an array in front of a student, asking the student to choose one item, and then allowing the student to interact with the selected item. Once selected, the item is removed from the array. This process is repeated until the student selects and interacts with all items. A hierarchy of potential reinforcers is generated in as little as 5–10 min. The efficiency allows for this assessment to be conducted on a regular basis without interfering with the student's daily routine and valuable instructional and treatment time.

In this section we described the two phases of the baseline protocol used at the May Center. This process was developed based on the population of students served. Private schools serving children with problem behavior maximize safety and long-term treatment success if an established process is in place during an initial admission period. We typically spend 4 weeks observing the student, gathering assessment information, and allowing time for the student to acclimate to the

new school environment and routine. Behavioral data are brought to a treatment team meeting, and professionals from a variety of disciplines collaborate to determine what behaviors should be further assessed. A formal data sheet is developed and individualized baseline data are gathered. Simultaneously, behavior analysts from the behavioral psychology department begin a comprehensive, individualized FBA, the results of which will be used to develop a treatment plan.

Behavior Support Plan Development and Revisions

Treatment plans are developed based on various sources and types of data gathered during baseline, including the FBA. Baseline protocols identify specific target behaviors, and the FBA identifies antecedents and consequences of problem behavior. These data are reviewed by the interdisciplinary treatment team members who then collaborate to provide recommendations for constructing an individualized BSP. The BSP is used to guide the classroom staff in intervening to decrease targeted behaviors.

A BSP has several components, starting with operational definitions of the intervention target behaviors. All severe problem behaviors observed during baseline should be defined on the BSP. Figure 20.1 provides generic operational definitions for self-injurious behavior, aggression, property destruction, inappropriate social interactions, and inappropriate speech. It should be noted that these are operationally defined for a general, inclusive purpose. Operational definitions are refined to describe the physical, observable aspects of behavior (Cooper et al., 2007). Definitions should be easy to read and delineate what does and does not qualify. At the May Center, individualized operational definitions are developed following phase 1 of the baseline protocol. For example, the definition of self-injury during phase 1 (any instance of a student injuring or attempting to injure him or herself) would be individualized to the student's topography in phase 2 (e.g., any instance of the student hitting his head against a hard surface or making contact

with his fist to head). Staff are better able to discriminate between target and nontarget behaviors if non-examples are provided (e.g., self-jury does not include the student putting his head down to sleep or scratching his head). Since a generic definition allows for many behaviors to be recorded as self-injury and relies on the subjective judgment of observers, it is important to clarify examples and non-examples so that instances of behavior that look injurious, but are not, are not recorded.

The remaining portions of the BSP detail specific interventions or actions for staff to follow (Crone & Horner, 2003). These interventions include activities that staff should perform to prevent target behaviors (antecedent procedures, e.g., transition warnings) and consequences that follow target behaviors (e.g., praise and access to tangible items). From an organizational standpoint, the designers and writers of the BSP must consider how to best communicate antecedent and consequence strategies in the written document to promote staff understanding and correct implementation. The BSP can be divided so that the first half discusses antecedent strategies and the second half describes consequence strategies. Alternatively, the BSP can read in the order of target behaviors and describe antecedent and consequence strategies per target behavior. Readability and organization of a BSP can be difficult, especially when there several operationally defined target behaviors and numerous procedures. Behavior analysts might consider organizing their BSP by functional response class (common behavioral function for multiple target behaviors). However, if behavioral functions differ, readability may increase by organizing the BSP according to each target behavior and the relevant antecedents and consequences for that behavior.

A well-written BSP defines the actions of treatment providers in clear and easy-to-understand language (i.e., high school level writing). An important task of behavior analysts is to also provide high-quality staff training to ensure staff are able to implement the BSP in the classroom. Chapter 5 of this handbook summarizes staff training research.

Review of BSP

Frequent evaluation of data and review of a student's BSP by the treatment team is necessary to ensure a student continues to make progress on a variety of goals (Bergan & Kratochwill, 1990). This commonly takes place in review meetings during which the treatment team assembles to review data, discusses aspects of the BSP that may or may not be effective, and makes decisions about how best to proceed. A number of outcomes of review meetings are possible. The group may decide that student progress is adequate and changes to the BSP are unnecessary. Additionally, the group may decide that the student has met target goals and revisions to the BSP are necessary to fade interventions toward more naturalistic contingencies. Alternatively, progress may be slow or lacking and changes are needed to the BSP to address the concerns of the team. When changes are needed, the interdisciplinary team can make recommendations for changes to the plan or additional assessment data necessary to directly inform BSP revisions. At the May Center, the interdisciplinary team reviews each student and BSP quarterly. The student's parents, members of the student's home school district, and any other individuals involved in treatment of the student are invited to attend the review meeting every 6 months. The primary communication tool at all review meetings is graphed data of target behaviors. These guide decisions about continuing, fading, or revising a BSP.

Changes in behavior do not necessarily occur in accordance with the timeline of scheduled student and BSP reviews. Thus, it is beneficial to have an additional mechanism in place in order to review issues as they arise. Students may be reviewed on a quarterly basis, but the review meetings are held weekly so that all students can be reviewed at least one time during a quarter. If a situation arises, time can be allocated at the end of these meetings, called peer review meetings, to address issues requiring immediate resolution for a particular student. Situations necessitating immediate attention are varied and can include a need to address sudden weight gain, a plan to address noncompliance that has suddenly

occurred during occupational therapy sessions, or lack of problem behavior reduction. These meetings often result in modifications to the BSP and data system and/or retraining of classroom staff. Any changes are evaluated at the next scheduled meeting or the student's quarterly progress meeting, whichever comes first. This process of systematic reviews coupled with additional review and support, as needed, ensures that student progress is addressed.

Staff Training and Treatment Integrity

BSPs cannot be properly evaluated if they are not implemented accurately. There are a number of ways to increase the probability that interventions are implemented accurately. Empirically supported interventions that are easy to implement, use positive procedures, and are perceived as effective by treatment implementers are all variables that increase the likelihood that an intervention will be implemented accurately (Telzrow & Beebe, 2002). That is, these variables act as antecedent strategies that can increase treatment integrity.

Adequate staff training is necessary in order for staff to implement treatment plans with integrity (see Chap. 5 of this handbook). Training occurs at various levels. At the most general level, in-service trainings can occur that provide instruction relevant to the largest number of staff. In services may range in topic; many private schools have an orientation meeting that instructs staff on general rules and procedures for the school. For private schools that serve children with severe problem behavior, instruction on the principles of behavior analysis will help staff to understand why they are engaging in the behaviors prescribed in the BSP. At the May Center, all staff receive a 3-h structured orientation to behavior analysis consisting of an introduction to behavior analytic principles, data collection, the importance of consistent implementation of BSPs, and graphing classroom data.

Direct training of specific actions in a BSP constitutes a second, more individualized level of training. This is done prior to the implementation

of any individual BSP, and all classroom staff are individually trained by the behavior analyst who wrote the BSP. The training should include a competency-based component where the behavior analyst observes the staff implement the plan and provides performance feedback.

Once initial trainings are conducted, ongoing treatment integrity checks are used to monitor the accuracy of BSP implementation (Gresham, Gansle, & Noell, 1993). Treatment integrity is an important aspect of the therapeutic environment. At the May Center a member of the behavioral psychology department conducts a 30–60-min treatment integrity observation one time monthly for each student in the school.

Treatment integrity checklists are constructed to reflect each step of a student's BSP (Coddington, Feinberg, Dunn, & Pace, 2005). Figure 20.2 provides an example of the form developed and adopted at the May Center. The antecedent and consequence procedures for each target behavior are presented on the treatment integrity list. For each component, the observer specifies whether that component was implemented consistently, implemented but not consistently, not implemented, or if there was no opportunity to observe the component (e.g., no opportunity to observe consequence intervention for aggression because there was no aggression during the observation). The last component on this integrity form involves data collection. Every student with a BSP has a data sheet which requires data to be collected throughout the day. During treatment integrity observations, data collection is scored as either being up to date to the last hour, being collected during the shift, or not collected during the shift. Different integrity percentages are calculated by dividing the number of components rated in each category (implemented consistently, implemented but not consistently, not implemented) by the total number of components observed. The behavior analyst provides performance feedback to the staff implementing the BSP following each treatment integrity observation. At the May Center, a behavior analyst will provide retraining to a staff member if his or her overall integrity score is below 80 % and another integrity check is conducted within 2 weeks. If treatment integ-

Date: _____

Student: _____

Staff: _____

Observer: _____

Start Time: _____

End Time: _____

Type of Procedure	Description of Plan Components (Indicate which of the following procedures are part of the BSP by placing a check in the box)	Implementation Rating	Comments and Examples (Provide an example of how the staff implemented the procedure)
Antecedent	☐ Schedule: Each morning, teacher writes schedule on board, child copies schedule to piece of paper, teacher praises child for making schedule	☐ Implemented Consistently and as Written ☐ Inconsistent/Partial Implementation ☐ No Implementation ☐ No opportunity to observe	
	☐ Transition Warnings:- 5min before transitioning to new activity teacher tells student the name of activity. ☐ A second transition warning provided 1-min before transition	☐ Implemented Consistently as Written ☐ Implemented Inconsistently ☐ NOT Implemented as Written ☐ No Opportunity to observe	
Consequence	☐ Avoidance of demands. When student vocally refuses task, every 20-seconds teacher places work demand in front of student and say, "Finish your work"	☐ Implemented Consistently as Written ☐ Implemented Inconsistently ☐ NOT Implemented as Written ☐ No Opportunity to observe	
	☐ Praise Compliance. When begins work within 10-second of demand, teacher praises child	☐ Implemented Consistently as Written ☐ Implemented Inconsistently ☐ NOT Implemented as Written ☐ No Opportunity to observe	
	☐ Token economy for work completion. When child completes a task with no vocal refusals, teacher provides child a token. Tokens turned in for back-up reinforcers during class-scheduled breaks.	☐ Implemented Consistently as Written ☐ Implemented Inconsistently ☐ NOT Implemented as Written ☐ No Opportunity to observe	
	☐ Token exchange. During class-scheduled breaks, teacher asks child if he wants to exchange tokens for back-up reinforcers.	☐ Implemented as Written ☐ Implemented Inconsistently ☐ NOT Implemented as Written ☐ No Opportunity to observe	
Data Collection	☐ Are data collected?	☐ Data current (through last full hour) ☐ Data taken during shift, but not current ☐ No data taken during shift	

#of Total Steps in BSP: 6_

#of Total Steps Observed: _____

Steps observed where implementation was consistent: _____ % _____

Steps observed where implementation was partial or inconsistent: _____ % _____

Steps observed where there was no implementation: _____ % _____

Fig. 20.2 Sample treatment integrity checklist

ity is 80 % or higher, additional integrity checks are not scheduled. Repeated observations below 80 % result in a referral to the school's education department, which may involve direct intervention

from the education department supervisor (e.g., staff training) or disciplinary action.

The collection of treatment integrity in the classroom has many advantages. First, if treatment

integrity data are shared with classroom staff, it provides an opportunity to deliver specific feedback and additional training on the implementation of BSPs for classroom teachers and aides, which has been shown to improve educator performance (e.g., Coddington et al., 2005; Di Gennaro, Martens & Kleinmann, 2007; Noell, Duhon, Gatti, & Connell, 2002). Collecting these data provide a structured, regularly scheduled opportunity for behavior analysts to observe how staff are interpreting the content that is written in the BSP. This has helped the May Center professionals working in the behavioral psychology department design BSPs that both address the behavioral needs of the student and can realistically be implemented by classroom staff. Finally, treatment integrity measures can be used to help make data-based treatment decisions. When treatment is not progressing as expected, treatment teams often question if the lack of progress is due to an inadequate BSP or inconsistent implementation of the BSP (Arkoosh et al., 2007). Identifying which of these are taking place influences the decisions behavior analysts make about how to proceed with treatment. If the plan is implemented correctly but gains are not observed, then the BSP is revised. If the plan is not being implemented correctly, staff retraining is addressed. Without treatment integrity data, there are no data available to the team to make a decision on which alternative to choose. However, if integrity data are consistently collected, tracked, and graphed, the team has a data-based solution to this common treatment dilemma.

Analytical Culture

One of the hallmarks of applied behavior analysis involves adopting an analytical approach (Baer, Wolf, & Risley, 1968), which involves “demonstrate[ing] a functional relation between the manipulated events and a reliable change in some measurable dimension of the targeted behavior” (Cooper et al., 2007, p. 17). Behavior analysis strives to demonstrate functional relations between intervention components and improvements in target behaviors. To promote an

analytical culture—which can be defined as social transmission of learned behavior (Glenn, 2004; Tosti & Herbst, 2009)—human services professionals and private school personnel must have antecedents in place to promote analytical behavior and consequences to reinforce analytical behavior.

Shaping Everyday Language

One way to promote an analytical culture is by focusing on quantities of behavior under different conditions. In all organizations, casual, colloquial conversations occur regarding student behavior. This includes teachers commenting that a student, “Had a bad day,” or “Seemed off today.” Data supports (e.g., data on student behavior, BSPs) can be used as an antecedent intervention to prompt quantitative statements that can then be reinforced. With data supports in place, conversations are driven by the conditions under which the behavior occurred and attempts to document the frequency of the behavior. “Had a bad day” can be quantified and compared to the frequency of behavior yesterday and last week and can be used as a yardstick for examining behavior tomorrow. As discussed earlier in this chapter, all staff should participate in collecting data on student behavior which allows descriptions of behavior to incorporate numbers. Conversations do not have to end with “bad day”; instead, conversations can end with a quantification of behavior such as “he aggressed towards his teacher six times today.” Conversations about student behavior can then be translated into comparisons of numbers. Frequency of target behaviors in recent days and weeks can establish whether “bad days” are getting worse, getting better, or part of the overall variability of that student’s behavior that has yet to be understood.

Going hand-in-hand with quantifying behavior is having a good description of the student’s environment. Having detailed BSPs and treatment integrity checks facilitates a good understanding of the antecedents and consequences of behavior *because the antecedents and consequences were programmed*. Treatment integrity allows staff to know which of the antecedents and

consequences were and were not part of the student's environment. A BSP may specify that a student creates a schedule of activities at the beginning of each day because that student has difficulty with transitions. Treatment integrity checks will reveal whether the student is, in fact, creating a schedule in the morning. The integrity checks allow for a more accurate description of the student's environment by tracking if a schedule was or was not created.

Documentation of changes to BSPS also facilitates establishing functional relations between the student's environment and frequency of his or her behavior. This prompts questions such as "Was today's 'bad day' worse or better than before we changed the BSP? Can we back this up with data?" Because BSPs specify the conditions under which interventions are to be implemented, this language is also incorporated into discussions of the student. "He aggressed towards his teacher six times today" becomes "he aggressed towards his teacher six times today, three times during individual work, two times during afternoon groups, and once during gym time."

Overall, an analytical culture is promoted by focusing on data, following detailed BSPs (i.e., precisely defined antecedents and consequences), and comparing today and this week's data to previous data. In this way, teachers and direct care staff in a private school can participate in the analytical culture.

System Level

System-level supports can contribute to an analytical culture. System supports can both promote and reinforce the behavior of approaching problems analytically. A number of private schools have adopted a "corporate university" model (Gould, 2005). Specifically, a number of behavior analytic private schools and intensive care units have adopted this model. A corporate university pairs the needs of a human service organization "to maintain and expand the expertise of their [workforce]" (p. 508) with university academic training programs. These programs offer certificate programs, master's degrees, and

doctoral degrees. For private schools serving students with severe problem behavior, a useful corporate university model would include graduate education in behavior analysis. With this model, staff work at the private school and take after-school courses including basic behavioral principles, single-subject research design, assessment and measurement of behavior, and others. Additional classes could be offered that focus on the particular populations served at the school, which could be students diagnosed with autism and developmental disabilities, students with acquired brain injury, students with intellectual disabilities, or others.

Another way to participate in the corporate university model is to develop formal internships. A number of private schools and hospital-based intensive care units have American Psychological Association (APA)-approved internships and postdoctoral fellowship programs. APA-approved internships have pre- and postdoctoral professionals who work full time toward licensure requirements in a human service organization.

The corporate university model does not promote an analytical culture per se, but the requirements of these programs can promote and reinforce analytical approaches to solving problems. Academic programs often have research requirements, and these can also be a part of internship requirements. Research projects can be required to use single-subject methodology and target socially significant behaviors. This type of requirement prompts students enrolled in the corporate university to consider ways to accomplish this requirement within his or her daily work. Passing the research requirements reinforces analytical behavior.

The May Center, like many behavior analytic human service organizations, has adopted the corporate university model. There are academic partnerships with local universities to provide a master's degree in behavior analysis and a second certificate program through another university that prepares students to sit for the exam offered by the Behavior Analyst Certification Board®. The master's program requires a research-based thesis using single-subject experimental design that has the ability to detect functional relations.

The May Center also has a postdoctoral fellowship program and APA-approved predoctoral internship program. These programs tend to attract research-minded candidates and individuals who want to experience treating students with severe problem behavior. The internship program requires a single-subject research design project and a system-level project.

Together, system-level inputs can help to promote and reinforce an analytical culture. For direct staff the lexicon is shaped through collecting data and administering specific BSPs. The behavior analysts, who are analytical by trade, have contingencies in place that ensure formal demonstrations of analytical research. The ultimate reward of an analytical culture is improved student and staff outcomes.

Conclusion

This chapter addressed private school settings for children with severe problem behavior. We presented and discussed several key components of program design, emphasizing assessment, assessment-derived treatment formulation and ongoing review, staff training, and interdisciplinary collaboration. Certainly, there are additional system features that comprise private schools depending on treatment philosophy and orientation. Our emphasis is on behavior analytic methodology, technology, and practices for designing the most clinically responsive, evidence-supported, and formative behavioral crisis service setting.

Acknowledgments We would like to thank all of the students and families for their hard work and dedication, and the staff of the May Center for their efforts to enrich the lives of the students.

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Treating Severe Problem Behavior Within Intensive Day-Treatment Programs

21

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Managing crises involving severe problem behavior exhibited by individuals with developmental disabilities frequently involves attempting to reduce the behavior as quickly as possible. Such efforts to rapidly end individual instances of problem behavior are generally motivated by avoidance of serious consequences such as injury to the individual in question or his/her caregivers. Unfortunately, this approach often results in the use of strategies that would otherwise be contraindicated. For example, a single episode of problem behavior such as a tantrum may end once a reinforcer is delivered. This cessation of tantrum behavior can be reinforcing for caregivers, increasing the probability that they will similarly reinforce tantrums in the future. This and some other antecedent-based strategies can successfully reduce individual instances of problem behavior by altering or diminishing possible motivating operations (Vollmer, Iwata, Zarcone, Smith, & Mazaleski, 1993). That is, when problem behavior is maintained by access to preferred consequences, providing access to such items or events continuously or on a dense schedule of reinforcement can eliminate a given instance of problem behavior because there is no longer any motivation for the individual to emit

such responses. When the problem behavior in question is unexpected, highly dangerous, or extremely destructive, and no plan exists for dealing with it appropriately, short-term use of such crisis management approaches may be necessary and appropriate to ensure the safety of everyone involved.

However, although the aforementioned treatment strategies may result in immediate or short-term success, they may have deleterious consequences over time. For example, making access to preferred events contingent upon problem behavior is likely to be adequately reinforcing, such that an increase in the rate of problem behavior is observed over time. Such crisis management approaches are only justifiable for brief periods until an effective behavioral intervention can be developed. After the first few episodes of problem behavior, a pattern can often be established, making it difficult to argue that future occurrences are unexpected. Beyond this point, continuing to implement a crisis management approach that does not incorporate adequate behavioral intervention components is therefore difficult to justify.

In contrast to such crisis management approaches to dealing with severe problem behavior, the purpose of a behavioral intervention is to identify and implement the procedures required to decrease the probability and/or intensity of the problem behavior over the long term. Intensive day-treatment programs are well suited to this purpose for a variety of reasons. Clinical programs

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that fit the description of a day-treatment setting, or what is sometimes referred to as “partial hospitalization,” are defined by the fact that daily services are delivered for less than 24 h each day (most often 4–8 h/day) while the patient or individual continues to reside at home (Center for Medicaid and Medicare Services, 2010). This service delivery model allows for a high degree of control over relevant environmental variables while conducting the requisite assessments and evaluations necessary to determine the function of severe problem behavior and evaluate interventions for treating the same. Intensive day-treatment programs are also often staffed at higher ratios than is possible within most residential or educational settings, helping to ensure high procedural fidelity and the validity of data. In addition, a large percentage of the day can be spent on assessment and treatment without incurring the associated costs of overnight care (when the individual would usually be sleeping anyway).

However, not every intensive day-treatment program will be well equipped for the purpose of behavioral intervention for this population. There are many factors and processes that can enhance the probability for successful treatment of severe problem behavior. Thus, this chapter will focus on describing the processes by which intensive day-treatment programs can be used to identify and evaluate effective interventions for problem behaviors exhibited by individuals with developmental disabilities, with the intention of supporting the individual’s return to a less restrictive setting.

Referral Sources

There are several stakeholders that may refer an individual to an intensive day-treatment program for the assessment and treatment of severe problem behavior. Two of the most common are the caregivers of the individual and organizations that provide services to him/her, such as a school system. Readers are also referred to this chapter of the book for more information about referral and placement decisions. Each of these types of referrals comes with caveats that must be considered.

Caregiver referrals are most typically instigated by problem behavior occurring within the home or in the community at levels the caregiver deems unmanageable due to safety concerns, property destruction, or other disruptions to the household routine. Caregivers are frequently under significant stress at the moment they make such a referral and generally wish for services to begin immediately. As a result, it may be difficult for some caregivers to continue dealing with problem behavior in the home while it is assessed and an effective treatment is developed in the day-treatment setting.

In addition, individuals referred by caregivers may or may not engage in similar levels of problem behavior in other settings. For example, a child may engage in high rates of intense aggression within the home but much lower rates at school. When the levels of problem behavior experienced in other settings differ in frequency or intensity from what is experienced by caregivers in the home, care providers from other organizations may be less supportive of an admission to an intensive day-treatment program. Such organizations may hold the belief that it is unnecessary to remove the individual from the services they provide for an extended period of time to address problem behavior they observe rarely or not at all. This lack of outside support can be particularly troublesome when attempting to generalize treatment procedures across settings. Thus, members of the clinical team from the intensive day-treatment program may wish to contact administrators from these service organizations as early into the admission process as possible and maintain contact in an effort to build rapport. These individuals may have influence over the degree to which treatments are implemented in such settings following an admission to a day-treatment program. Explaining the purpose of the admission and any training opportunities that can be provided to them once an effective treatment is identified may result in greater cooperation when it comes time to generalize the treatment to those settings.

Referrals from other service providers such as schools frequently only happen once all internal resources and treatment options have been

exhausted. Typically, by the time such a referral is made, problem behavior is occurring at rates or intensities that are no longer manageable by the staffing ratios present in that setting. Furthermore, attempts to decrease the problem behavior to manageable levels with less intensive interventions have generally failed. Because internal interventions administered by such organizations may effectively reduce less intense or complex behaviors, it may be the case that individuals who respond to these interventions tend to be less likely to be referred to an intensive day-treatment setting. The result may be a propensity towards other service providers selectively referring problem behavior that is more severe and/or complex. School systems in particular may hesitate to refer to outside intensive day-treatment programs because doing so likely means discontinuation of, or at least decreased time devoted towards, achieving individualized education plan (IEP) goals. Given the emphasis on making demonstrable progress towards the goals outlined in the IEP (Individuals with Disabilities Education Act [IDEA], 2004), it is not surprising that school systems may hesitate to refer a student to a day-treatment program that will devote so much time towards other activities. Temporarily focusing such a significant portion of the individual's time towards the assessment and treatment of problem behavior will hopefully result in the student being able to work towards IEP goals more effectively because he/she is not also engaging in problem behavior that prevents instruction. A strong case can be made that such an outcome is superior to maintaining the status quo in which a student is "working" on IEP goals in name only, but little progress is being made because a large proportion of instructional time is spent managing problem behavior.

Inclusion/Exclusion Criteria

Although intensive day-treatment programs are well suited to address a range of problem behaviors exhibited by individuals with developmental disabilities, a day-treatment model is not always best suited to the needs of all individuals, behaviors,

or caregivers. When it comes to making the decision regarding the appropriateness of an admission to an intensive day-treatment program, both false-negative decisions (i.e., electing not to admit an individual who would have been appropriate) and false-positive decisions (i.e., electing to admit an individual who is not appropriate) have implications for the individual and the program.

The ramifications of a false-negative admission decision are that an individual's behavior will continue to have a negative impact on him/her and those who care for him/her. Fortunately, many who work with individuals who exhibit the kinds of problem behavior that require intensive intervention have likely established a history of working with those who cannot receive services elsewhere. Thus, their tendency may be to admit any individual whom the program has the potential to help, possibly making false positives the more likely type of erroneous admission decision.

Yet false-positive admission decisions are not without costs: Inappropriate admissions can result in the allocation of significant resources without producing commensurate benefit. Similarly, allocating such resources towards an admission that would produce gains comparable to interventions administered through a less intensive model represents inefficiency. For programs with waiting lists, such a misallocation of resources towards an individual who does not require them or who will not benefit equates to the postponement of services for those who could. Finally, admissions of individuals whose problem behaviors are beyond the capacity for that program to treat can result in injury to the client or staff members, damage to program materials/property, etc.

Given the costs associated with each type of erroneous admission decision, it is important for clinicians to carefully consider inclusionary and exclusionary criteria. The most salient inclusionary/exclusionary factor may be the severity of the problem behavior to be addressed. Unfortunately, severity can be challenging to operationally define. The topography of the targeted problem behavior is commonly used in gauging severity

because certain behaviors such as aggression, self-injury, pica, elopement, and others have the potential to cause serious harm or even be life threatening. Yet not all instances of these behaviors would be defined as severe. Frequency and intensity can moderate ratings of severity, and so these variables are frequently included in an operational definition of severity. However, it can be challenging to objectively categorize severe behavior into levels of severity. For example, is aggression that occurs 25 times each day but leaves no marks or bruises on others more severe than aggression that only occurs a few times each week but results in bruising each time it occurs?

Even if clearly defined objective definitions that delineate which behaviors, frequencies, and intensities constitute various levels of severity can be agreed upon, obtaining reliable information on these factors can still be challenging. Caregivers may be inconsistent in how they report information such as the severity of their dependents' problem behavior (Achenbach, McConaughy, & Howell, 1987; De Los Reyes & Kazdin, 2005). The subjective nature of self-report data likely contributes to this inconsistency within or across individuals. In our experience, when asked to rate the level of severity of the problem behavior exhibited by their dependents, many caregivers report that the behavior is very severe. Such reports are not surprising, given that the subjective scale of reference for most caregivers is usually limited to their experiences with the problem behavior exhibited by their dependent. That is, for them, the behaviors exhibited by their dependent are quite often the most severe behavior that they have observed or experienced. A report by a caregiver that their dependent's behavior is "very severe" is therefore rational, if perhaps not very helpful for purposes of determining the appropriateness of an admission to an intensive day-treatment program. Unfortunately, attempting to directly observe problem behavior can be laborious and expensive and, unless significant time is devoted to such observations, may not always result in an opportunity to gauge the true severity of the behavior.

In summary, it can be difficult to identify a low-effort/low-cost yet objective methodology

for differentiating between which specific behaviors, at which intensities and frequencies, are more or less severe than another behavior and therefore warrant admission to an intensive day-treatment program. Thus, it may be most appropriate to instead base ratings of the severity of problem behavior, not upon the characteristics of the behavior itself, but instead upon the impact the problem behavior in question has upon the individual, his/her environment, and those who care for him/her. For example, self-injury that is causing or putting the individual at risk for serious health concerns is likely more severe than self-injury that is able to be safely managed, regardless of the specific topographies. Similarly, a disruptive behavior that results in placement in an educational setting that does not allow for interaction with peers is more severe than disruptive behavior that can be managed in inclusive settings. A rating scale that utilizes this approach can be found in *Appendix 1*. This type of scale can be completed by a clinician to determine the impact problem behavior is having on the individual and his/her caregivers. This information can then form one of several inclusionary/exclusionary criteria for an admission to a day-treatment program.

A second consideration when determining the most appropriate level of program intensity is the efficiency with which treatment goals will be achieved. As stated above, increasing levels of program intensities are generally correlated with increasing commitment of resources. More intensive treatment models also have additional costs for the individual and their caregivers. For example, inpatient and day-treatment programs may require discontinuing other services like educational programming. Inpatient admissions similarly require separation from caregivers, disrupting household routines and potentially making communication with clinicians more challenging.

When using severity and efficiency as factors that guide decisions about the most appropriate clinical model for an individual, it is important to consider the full continuum of program intensities and how each might best serve an individual's needs. Intensive day-treatment programs constitute

a middle ground between the most intensive models (e.g., inpatient/residential) and less intensive models (e.g., outpatient or home-/community-based). As such, it shares some of the benefits of both of these ends of the continuum but also some of their limitations. Consideration of how these strengths and limitations can best address any given level of severity can help determine whether an intensive day-treatment setting is best able to treat a particular problem behavior safely and efficiently.

One such important consideration is whether the problem behavior, which may persist in the home throughout an admission to a day-treatment program, can be safely managed by caregivers until they receive training in the treatment procedures. If this behavior cannot be managed safely, admission to a more intensive setting, such as an inpatient program, may be more appropriate. An admission to an inpatient program may also be more appropriate when problem behavior is secondary to, or complicated by, a medical condition that requires regular or continuous management by medical professionals who may not be available in a day-treatment setting.

In contrast, it may be less efficient or impossible to assess and treat some problem behaviors in an intensive day-treatment setting. For example, some problem behaviors are under sufficient stimulus control that they are unlikely to occur in unfamiliar settings. Such behaviors cannot be efficiently assessed if they cannot be observed nor can treatments be evaluated if a baseline rate of zero is established. In some cases the controlling stimuli (e.g., a caregiver) can be introduced into the day-treatment setting (Ringdahl & Sellers, 2000). However, when it is not possible to incorporate or reproduce the controlling stimuli, such problem behaviors are likely treated more efficiently in the environment containing those critical stimuli (i.e., in-home and community intervention programs).

Provided an admission to an intensive day-treatment program is safe and will efficiently achieve treatment goals, this model may be preferred over more intensive programs because day-treatment models are generally less expensive and less disruptive to the quality of life of the

individual. For example, individuals are able to continue to reside with caregivers throughout the duration of the admission. Intensive day-treatment programs may also more efficiently achieve treatment goals than less intensive models. Unlike most treatment models implemented in the natural environment and many outpatient settings, an intensive day-treatment format allows for a large proportion of each day to be devoted to assessment and treatment activities. Thus, problem behaviors that are likely to require more time in assessment and treatment activities are well suited to this type of clinical service. For example, behaviors maintained by sensory or other sources of reinforcement that are automatically produced by the behavior can be particularly challenging to address (Piazza et al., 1998). Extinction is harder to implement with such behaviors because caregivers and clinicians do not have control over the reinforcers maintaining them. Treating problem behaviors maintained by automatic reinforcement may thus require more time than can be afforded in less intensive settings. Similarly, behaviors that serve multiple functions (e.g., attention from caregivers and escape from task demands) can be challenging to treat because more than one treatment frequently needs to be implemented to address each function (Smith, Iwata, Vollmer, & Zarcone, 1993).

Complementary Measures

Once the decision has been made that an admission to an intensive day-treatment program is appropriate, obtaining key information as part of an intake process can improve the efficacy and efficiency of the treatment program and help to (a) ensure the safety of the individual and staff and (b) enhance external and social validity of treatment.

Direct Observations of Problem Behavior in the Natural Environment

As stated above, it can be challenging to arrange for direct observations of problem behavior due

to the time and effort required. Yet, if it is unfeasible to conduct direct observations as part of the admission decision process, it may be worth the investment of time and resources to do so during the intake process for those who will be admitted. Such observations have the potential to provide a wealth of valuable information regarding possible functions of problem behavior, as well as the level of staffing required, the need for protective equipment for the individual or for staff, and other equally important information. Direct observations in the natural environment are especially valuable because they may allow for observation of the antecedent variables that evoke the problem behavior and the consequences typically delivered afterwards.

In some cases it may be possible to obtain observational data from caregiver-collected video recordings of the problem behavior. However, such videos are typically limited in that they usually take one of two forms: Discrete or continuous recording. In discrete recording, the collection of video begins when the target behavior occurs. Using this method, it may be possible to capture footage of the behavior in question and any consequences delivered as a result. However, discrete recording cannot capture footage of antecedent events that may have evoked the problem behavior because recording is not initiated until the behavior begins. In contrast, continuous recording involves initiating and maintaining collection of video footage until an adequate sample of the problem behavior has been obtained. This method allows for recording of both antecedents and consequent events but is also likely to produce large amounts of extraneous video footage that does not include events of interest to the clinician. The need to view all of this video in order to identify the subset of relevant footage may be overly inefficient.

The recent development of human annotation and selective archiving technology (Hayes, Truong, Abowd, & Pering, 2005) has the potential to capitalize upon the strengths of both discrete and continuous recordings for the purpose of capturing video observations of problem behavior. This method consists of a camera system that continuously records video within a

temporal buffer that erases captured footage as more is recorded. When a targeted problem behavior occurs, a caregiver signals the system to store the footage in the buffer at that moment. Thus, the footage of the relevant problem behavior is captured and retained as well as any antecedent events or consequences that occurred during the preset interval prior to and following the moment indicated by the caregiver. Such a system seems well suited to capturing direct observations of behavior that would be highly relevant to the preadmission and functional assessment process. However, this technology is still in the preliminary stages of evaluation for this purpose and is expensive, and it remains unclear how much training of caregivers is required to ensure they capture the relevant samples of problem behavior (Andrus, Call, Arriaga, Swartzwelder, & Nazneen, 2011).

Background Information and Informal Assessments

Frequently it will be impossible to conduct direct observations of problem behavior, either in vivo or via video recording. Although caregiver report is generally considered to be less valid than direct observation (Hawkins, Mathews, & Hamdan, 1999), information obtained from this source can still help to operationally define targeted problem behaviors and shape hypotheses that may be evaluated through subsequent direct assessments. Experienced clinicians may have particular interview questions or questionnaires that they find most helpful in evoking responses that contain useful information from caregivers. However, if such caregiver interviews are to be conducted by less experienced clinicians or clinical aids/technicians, it may be worthwhile to use or develop standardized interviews. An example of such a list of standardized questions appears in *Appendix 2*.

An array of useful information can also be obtained through reviewing extant records such as medical and prior mental health documentation or the individual's IEP (when applicable). Records such as these frequently contain documentation of any prior diagnostic evaluations and

functional assessments. Such records may also include a treatment history, which may provide details about specific treatments that have proven ineffective, or obstacles to implementing treatment with high procedural fidelity. This last type of information can be especially important when it comes time to train caregivers to implement and maintain treatment. If barriers to implementing treatments can be identified *a priori*, then treatments can potentially be developed or additional training provided to avoid or overcome those barriers.

Functional Assessments

The function of problem behavior is the key determining factor in selecting treatments (Mace, 1994), making functional assessment a key activity once an admission has begun. A preliminary functional assessment that is less rigorous but also requires committing fewer resources, such as a brief functional analysis (FA) (Cooper et al., 1992; Derby et al., 1992; Northup et al., 1991; Wacker et al., 1994; Wacker, Berg, Harding, & Cooper-Brown, 2004), can be conducted to aid in shaping the decision of whether an admission is warranted for a given individual, as well as in developing initial hypotheses about the function of problem behavior (see Chap. 25). These hypotheses can then be evaluated more fully during subsequent FAs should an admission be deemed warranted.

Whenever possible, a brief FA can serve as a valuable first attempt at determining the function of problem behavior (Vollmer, Marcus, Ringdahl, & Roane, 1995). This format of FA can strike a balance between brevity and thoroughness. Although less comprehensive than more lengthy FAs, the fact that brief FAs are comprised of fewer sessions that are generally shorter in length can allow for rapid demonstrations of relationships between problem behavior and those environmental variables that are evaluated. Thus, the results of a brief FA may rule in or out hypotheses to be evaluated more thoroughly during a subsequent FA and thereby decrease the amount of time spent in assessment activities.

In general, research on brief FAs shows moderate to high correspondence with more lengthy FAs (Kahng & Iwata, 1999; Wallace & Iwata, 1999). However, conducting a brief FA does not obviate the need for a lengthier FA because such assessments allow for a more thorough evaluation of the relationship between problem behavior and consequences (Wacker et al., 2004). Furthermore, there is an increased probability for no problem behavior to occur during a brief FA than during a lengthier FA (Derby et al., 1992). However, such a false-negative result may serve as an indicator of an increased probability that no problem behavior will be observed in subsequent analyses. Again, the absence of problem behavior during an admission not only makes it difficult to empirically determine the maintaining reinforcers through FAs but also makes it impossible to empirically evaluate treatments because of a floor effect. Thus, determining early on in an admission whether a false-negative result is likely through the use of a brief FA can save time over the long run.

Another advantage of brief FAs is that caregivers may be more available to participate in a brief assessment than a more extended one because of the decreased time commitment (Cooper et al., 1992; Northup et al., 1991). The inclusion of caregivers in FAs may be helpful because results can be influenced by the type of individual who serves as the therapist (English & Anderson, 2004; Huete & Kurtz, 2010; McAdam, DiCesare, Murphy, & Marshall, 2004; Ringdahl & Sellers, 2000). Thus, results of a brief FA with caregivers serving as therapists can be compared to results of a subsequent FA to determine whether there are differences in the rate, topography, or function of problem behavior in the presence of novel therapists vs. familiar caregivers.

When it is not possible to include FAs that directly manipulate environmental variables as a complement to subsequent assessments and treatments, less formal functional assessments such as descriptive assessments can still provide some useful information (Camp, Iwata, Hammond, & Bloom, 2009; Samaha et al., 2009). Although there is low correspondence between the results of descriptive analyses and those of FAs in direct

comparisons (Anderson & Long, 2002; Hall, 2005; Ndoro, Hanley, Tiger, & Heal, 2006; Thompson & Iwata, 2007), descriptive assessments may be useful because they capture contingencies that occur in the natural environment (Thompson & Iwata, 2001). Such assessments may provide some insight into the type, quality, and schedule of reinforcement delivered by caregivers contingent upon problem behavior. In particular, this information can be used to enhance the external validity of subsequent FA test and control conditions, as well as treatment analyses. However, they should not be used as a replacement for an FA except when it is truly impossible to conduct one. The combination of a descriptive assessment (DA) and a brief FA is perhaps ideal, as the former may enhance external validity, whereas the latter is more internally valid. Thus, the combination of these two assessments may maximize both forms of validity. However, additional research is needed to demonstrate the clinical utility of combined DAs and FAs in terms of selecting more effective or externally valid treatments.

If neither a brief FA nor a DA is possible, indirect measures may be somewhat informative for the purposes of generating hypotheses regarding the function of problem behavior. Many rating scales that attempt to identify the function of problem behavior based on caregiver report have been developed, including the Motivation Assessment Scale (Durand & Crimmins, 1988), the Functional Analysis Screening Tool (Iwata, 1995), and the Questions about Behavioral Function (Paclawskyj, Matson, Rush, Smalls, & Vollmer, 2000). Analyses of the psychometric properties for this type of measure, such as reliability and construct validity, however, have not been conducted for most such structured indirect assessments. Those studies that have evaluated their psychometric properties have not always yielded favorable results (Duker & Sigafos, 1998; Zarcone, Rodgers, Iwata, Rourke, & Dorsey, 1991). Thus, there appears to be a consensus that the validity of most indirect assessments is inferior to that of experimental FAs (Fisher, Piazza, Bowman, & Amari, 1996; Green & Striefel, 1988; Kelley, LaRue, Roane, &

Gadaire, 2011; Lennox & Miltenberger, 1989). Unfortunately, some settings may lack the capacity to conduct experimental FAs. However, as described above, intensive day-treatment settings are likely to receive referrals for individuals who engage in behavior that has not been successfully treated through less thorough functional assessment and treatment methods. To successfully assess and treat such behaviors, intensive day-treatment settings should ensure that experimental FAs are viable. Tools such as indirect and descriptive assessments may still play an important role in such settings but should probably remain limited to assisting with developing hypotheses regarding function to be evaluated more thoroughly during FAs (Kelley et al., 2011; Umbreit, 1996).

Assessment and Treatment Model

A number of sources exist, some within this volume, that document best practices for the assessment and treatment of severe problem behavior (e.g., Fisher & Bouxsein, 2011; Geiger, Carr, & LeBlanc, 2010; Iwata & Dozier, 2008; Lerman & Toole, 2011; Smith, 2011; Vollmer & Athens, 2011; Wacker, Berg, Harding, & Cooper-Brown, 2011). The reader is referred to those sources for a more thorough discussion of those topics. There are caveats, however, to the effective assessment and treatment of severe problem behavior within an intensive day-treatment program that are unique to such settings. The following section will be devoted to these pragmatic issues and a model for assessing and treating severe problem behavior within intensive day-treatment settings specifically.

Caregivers as Treatment Agents

With only a few exceptions, caregivers will serve as the primary change agents for implementing the treatments for severe problem behavior (Allen & Warzak, 2000). These exceptions include instances in which treatments will be delivered in residential settings (in which treatment need not

be generalized to the natural environment) or instances in which problem behavior is completely eradicated such that no problem behavior ever occurs following a return to the natural environment. Neither of these exceptions typically applies to admissions in intensive day-treatment programs; generalization to the natural environment is always a necessity, and many admissions will not be of adequate length to allow for treatments to produce complete elimination of problem behavior. Therefore, the focus of most admissions to an intensive day-treatment program will be to establish a situation in which caregivers are capable of implementing effective treatments in the natural environment that will in turn produce lasting reductions in problem behavior.

A necessary first step towards accomplishing this primary goal of an admission is to identify what treatment(s) is capable of effectively reducing problem behavior. To date the research literature strongly points towards a treatment development process that includes systematic data collection and analysis, empirically identifying the function of problem behavior, and methodical evaluation of function-based treatments (Betz & Fisher, 2011; Ingram, Lewis-Palmer, & Sugai, 2005; Mace, Lalli, & Pinter Lalli, 1991; Mace & Roberts, 1993; Thompson & Borrero, 2011). Once a treatment has been shown to be effective, programming for generalization and training of caregivers to mastery levels should take place.

Unfortunately, some individual's targeted problem behavior will be of sufficient frequency or intensity that caregivers will be unable to implement treatment, no matter how effective it may be. For example, many treatments will include an extinction component, producing a temporary increase in the intensity, rate, and/or variability of the problem behavior (i.e., an extinction burst; Lerman, Iwata, & Wallace, 1999). Caregivers may lack the physical strength or stamina to persist with treatment implementation through the duration of the extinction burst. Thus, a second phase of an admission may be necessary to produce reductions in problem behavior to levels that will allow caregivers to

successfully take responsibility for treatment implementation. In this vein, the intensive day-treatment setting can serve as an opportunity to produce some reduction in problem behavior that can then be generalized to the natural environment.

Data Collection

Data collected on the targeted problem behavior is critical for determining its function and evaluating the effectiveness of treatment. Although all behavioral interventions should be data-based (Cooper, Heron, & Heward, 2007), the need for sound data collection and analysis procedures is heightened in intensive settings such as a day-treatment program. As described above, individuals referred to an intensive day-treatment program are likely to have already been the recipients of less intensive treatments, including those that utilized less systematic methods of measuring problem behavior and other variables of interest. If such methods were sufficient for the assessment and treatment of the problem behavior in question, then these prior attempts would likely have been more successful. As a result, the fact that an individual is in need of an admission to an intensive day-treatment program frequently reflects the fact that more intensive methods, including more consistent and precise data collection methods, are necessary.

Data collected throughout an admission can be divided into those collected during assessment and treatment sessions and outside of treatment sessions (e.g., during leisure activities, in the bathroom, at lunch). Assessment and treatment sessions are frequently conducted in rooms specifically equipped for this purpose. As a result, session data can be collected using paper and pencil or using computer-based data collection systems. Outside of specific session times, it may be more difficult to collect data on all relevant behaviors, antecedents, and consequences. The behaviors that are most important to track outside of sessions should thus be determined early in the admission so that operational definitions can be developed and accurate data can be collected

during these times. Paper and pencil, handheld or tablet computers, and tally counters are common methods of data collection outside of session times, as portability is essential for any such system. Finally, safeguards to promote the validity of clinical data, such as collection of interobserver agreement data, are also important.

Staffing and Supervision

Assessment and treatment activities within intensive day-treatment settings are delivered by a range of individuals at varying levels along the training and experience continuum. At the top of the hierarchy are case managers who oversee clinical decision making, design treatments, train staff, and ensure the overall quality of care. Several different degrees (e.g., Ph.D., Psy.D., Ed.D.) and credentials (e.g., BCBA-D, BCBA, BCABA) exist to certify the level of training required for this type of clinician. Just which certification is most appropriate is a topic of some debate in the field (Moore & Shook, 2001). Regardless, significant training and experience in the conceptual framework of applied behavior analysis, the theory and techniques of FAs, and treating severe problem behavior are clear prerequisites. The number of such supervisors present at any particular intensive day-treatment program clearly depends on the census of the program. However, it is probably safe to conclude that the size of the caseload for supervising clinicians is limited by the high level of attentiveness to cases that is required to successfully treat the complicated and intense problem behaviors seen in such settings.

In the majority of intensive day-treatment programs, the bulk of the assessment, treatment, and direct care activities designed by the supervising clinician will be enacted by more junior staff members. The number and level of training for these individuals who directly deliver most services in an intensive day-treatment program may need to vary depending on a number of factors, not the least of which is the type and severity of the problem behavior being treated. A sufficient number of staff members must be available to

conduct both clinical procedures (i.e., conducting FAs and treatment sessions, collecting primary and interobserver agreement data, and working with individuals outside of sessions) and direct care activities (e.g., assisting with activities of daily living, mealtimes), as well as manage any sudden instances of dangerous or destructive behavior. It would likely be challenging to meet these staffing needs at anything less than one staff member per individual, and in some instances ratios much higher than this may be necessary to ensure the safety of all involved.

At a minimum, staff members should receive instruction in the fundamentals of applied behavior analysis (i.e., important terminology and concepts used frequently within the program), emergency procedures including personal protective procedures and the use of protective equipment, how to conduct specific protocols that are commonly conducted within the program such as preference assessments and FAs, and data collection procedures. Some research exists on methods for training some of these skills (Iwata et al., 2000; Moore et al., 2002), with many showing the use of some combination of didactic instruction, role playing, and in vivo training with supervision and feedback to be effective. In many cases, such training will have to be provided by the program itself, as there may not be opportunities to receive training in these skills elsewhere. Regardless of whether staff are selected for these skills or training takes place during the early stages of their employment, it is prudent for their supervisors within the intensive day-treatment program to provide ongoing educational activities to ensure maintenance of these skills.

Finally, a number of ancillary personnel fulfill important roles within an intensive day-treatment setting: Nurses must be available to provide medical care for staff injuries that may occur when working with individuals who exhibit severe aggression, as well as to administer medications to clients and address any other complicating medical conditions. Similarly, social workers who can assist caregivers in accessing support services in their community provide an important service that can help ensure maintenance of strategies in the natural environment by decreasing

stressors that might otherwise impact treatment effectiveness. Finally, it may be useful for a psychiatrist to be available for consultation or the management of medications while the individual is being served in the intensive day-treatment program because many individuals served in these programs are prescribed psychotropic medications (Aman, Singh, & White, 1987; Hill, Balow, & Bruininks, 1985).

Preference Assessments

Preference assessments have been demonstrated to be one of the most effective and efficient means of identifying stimuli that are likely to function as positive reinforcers (Hagopian, Long, & Rush, 2004). Conducting a preference assessment as an adjunct to an FA has become common practice (Hanley, Iwata, & McCord, 2003). Such assessments ensure that the stimuli included within certain test and control conditions have the highest probability of demonstrating the capacity for such stimuli to maintain problem behavior. In addition, because the effectiveness of many treatments hinges upon the use of reinforcers that are more highly valued than the reinforcer(s) maintaining problem behavior (Mace & Roberts, 1993), it is important to identify the most potent reinforcers possible.

Various formats of preference assessments have been developed, evaluated, and compared, and each has advantages and disadvantages (Hagopian et al., 2004). When selecting a specific preference assessment methodology, consideration should be given to several factors: First, is the individual able to indicate choice? Several commonly used preference assessment formats such as the paired stimulus (Fisher et al., 1992) or multiple stimulus without replacement (MSWO; DeLeon & Iwata, 1996) rely upon selection responses to indicate preference. However, individuals who lack speech or motor skills to indicate choice, or who have orthopedic impairments that create a lateral bias (e.g., always selecting the option on the right-hand side), may be inappropriate for this type of preference assessment. For such individuals, a single stimulus (Hagopian,

Rush, Lewin, & Long, 2001) preference assessment may be a more valid measure. Second, how much time is required to conduct each type of assessment and how often assessments will be conducted should be considered. Often, a preference assessment is conducted at the onset of an admission and not repeated for several weeks, if at all. Although there is some evidence that preferences as identified by certain preference assessment formats are relatively stable over time (Carr, Nicolson, & Higbee, 2000; Hanley, Iwata, & Roscoe, 2006), these studies also found that preferences of individuals may shift. Thus, it may be beneficial to initially conduct preference assessments on a regular schedule or frequently enough that shifts in preference can be identified if they occur. If it is demonstrated that an individual's preferences are stable over time, then the frequency of preference assessments can be decreased. For those individuals whose preferences shift frequently, it may be necessary to conduct brief preference assessments such as the MSWO as frequently as multiple times per day.

Demand Assessments

Although less common, demand assessments fulfill a similar role for potential negative reinforcers as preference assessments do for positive reinforcers. That is, demand assessments can help determine which demands or stimuli are more likely to function as negative reinforcers when discontinued. As with preference assessments, identifying demands that may be aversive can help to design FA conditions intended to evaluate the role of negative reinforcement in the maintenance of targeted problem behavior. Demand assessments appearing in the literature have identified likely negative reinforcers by measuring the latency to the first instance of problem behavior when a demand is introduced (Call, Pabico, & Lomas, 2009) or the rate of problem behavior during demand conditions of fixed length (Roscoe, Rooker, Pence, & Longworth, 2009). However, for some individuals it may be important to assess whether discontinuation of activities or stimuli other than

demands functions as negative reinforcement. For example, individuals have been shown to engage in problem behavior maintained by discontinuation of noise (O'Reilly, Lacey, & Lancioni, 2000), or even attention (Hagopian, Wilson, & Wilder, 2001). Including these types of stimuli in assessments designed to identify potential negative reinforcers may increase the probability of demonstrating the capacity for negative reinforcement to maintain an individual's problem behavior.

Functional Analyses

FA methodology has been well validated for the purpose of identifying the reinforcers responsible for maintaining problem behavior and selecting subsequent treatments (Iwata, Dorsey, Slifer, Bauman, & Richman, 1982/1994; Hanley et al., 2003; Iwata & Dozier, 2008, etc.). Few clinical procedures have been so impactful for individuals who engage in problem behavior (Axelrod, 1987; Iwata, Vollmer, Zarcone, & Rodgers, 1993; Mace, 1994; Mace et al., 1991; Pelios, Morren, Tesch, & Axelrod, 1999). Thus, a thorough FA of problem behavior is perhaps the key component of an admission to an intensive day-treatment program that may set this clinical model apart from settings in which conducting such an analysis would be challenging or impossible. Fortunately, there is a robust literature on the topic of conducting FAs (e.g., Hanley et al., 2003), and it is not the purpose of this chapter to summarize that body of work (see Chap. 9). However, some consideration of the following issues is particularly warranted when conducting an FA in an intensive day-treatment setting.

Prior to conducting an FA, it is important to decide which potential reinforcers to evaluate. A review showed that the vast majority of published FAs (>80 %) included conditions designed to test for a social negative reinforcement function and a social positive reinforcement function in the form of attention (Hanley et al., 2003). That same review found that about 60 % and one third of the published FAs reviewed included a test condition designed to evaluate the role of automatic

reinforcement (Iwata et al., 1982/1994) and positive reinforcement in the form of access to a preferred tangible item (Day, Rea, Schussler, Larsen, & Johnson, 1988), respectively. Thus, these seem to be the most commonly evaluated FA test conditions. Furthermore, an outcome study from an intensive day-treatment program showed that these conditions accounted for 96 % of the categories of reinforcers found to be maintaining problem behaviors encountered in such settings (Asmus et al., 2004).

However, the research literature also contains examples of many FAs that included test conditions designed to evaluate the relationship between problem behavior and less common sources of reinforcement (e.g., Call, Wacker, Ringdahl, & Boelter, 2005; Carr, Yarbrough, & Langdon, 1997; McCord, Iwata, Galensky, Ellingson, & Thomson, 2001; Smith, Iwata, Vollmer, & Pace, 1992). Such less commonly utilized test conditions may further refine hypotheses regarding the function of problem behavior and provide useful information for treatment development. Certainly the value of conducting a given test condition must be weighed against the additional time required to include it within the FA. Additional time spent in the FA may cause the postponement of treatment. However, a distinct advantage of the intensive day-treatment setting is that such a clinical model often allows for the time required to conduct more thorough FAs, including those that incorporate additional test conditions. Greater specificity about the reinforcers maintaining problem behavior can aid in developing effective treatments for problem behaviors that have been resistant to previous interventions.

Treatment Development

Behavioral interventions such as those that are developed and evaluated within intensive day-treatment programs have been shown to effectively reduce a wide range of problem behaviors (Asmus et al., 2004). Yet, despite such successes, behavioral interventions alone may be unable to produce clinically significant reductions in all

problem behaviors for all individuals. For example, behaviors that are maintained by reinforcers that clinicians or caregivers have little to no control over can be particularly challenging to treat (Vollmer, 1994), especially when no other available consequences are sufficiently potent as reinforcers or punishers to compete with or reduce problem behavior. Additionally, some problem behaviors are related to medical conditions such as seizures (McDermott, Mani, & Krishnawami, 1995). Thus, behavioral interventions may have some effect on problem behavior but may not be effective in producing clinically significant reductions until the medical condition is resolved. As such, it is advantageous to determine as early into the treatment development process as possible whether or not a particular individual's problem behavior is amenable to behavioral intervention. It can be worthwhile to utilize the intensive nature of the day-treatment setting to first attempt the most rigorous treatment that can be identified, while temporarily setting aside concerns over other factors such as social validity. Such treatments may include dense schedules of reinforcement, the use of the most potent reinforcers that can be identified, high staffing ratios, and implementation of treatment procedures such as extinction with near perfect fidelity. These treatments may lack social validity due to the intensity, amount of time and energy, or number of people required to implement them with high fidelity. Although social validity is unquestionably important (Bosch & Fuqua, 2001), beginning with a less intensive treatment package could expend precious admission time with little gain if such lower-intensity treatments are eventually found to be ineffective. That is, when a low intensity but highly socially valid treatment proves to be ineffective, the tendency will be to begin incremental increases in treatment intensity. Such a process can lead to devoting significant time to adding treatment components with no appreciable gain until it is finally determined that behavioral interventions alone are unlikely to effectively reduce problem behavior. Beginning instead with relatively intense versions of a treatment may allow clinicians to determine quickly whether it is possible to develop behavioral interventions that will

reduce problem behavior rapidly. If treatment gains are demonstrated, the social validity of the treatment can be systematically increased. However, research is still needed to determine whether attempting the most intensive treatments first and then fading to increase social acceptability produces better outcomes for individuals served in an intensive day-treatment setting.

If, given adequate time to demonstrate an effect, this initial high-intensity treatment does not achieve clinically significant reductions in problem behavior, it may be the case that behavioral interventions alone are unlikely to do so. If combined behavioral and pharmacological treatments have not already been attempted, this may be a good time to consider doing so (Frazier et al., 2010). Similarly, referral to a more intensive setting, such as an inpatient unit, may be appropriate if the lack of a treatment effect can be plausibly ascribed to the lack of intervention in the natural environment during those times that the individual is not in attendance at the intensive day-treatment program. If it is not possible to attempt a more intensive intervention than what has already proven ineffective, it may be necessary to recognize that a certain rate of problem behavior will likely continue to occur despite behavioral interventions. At this point, it may be most productive to instead focus on managing and minimizing the effects of the problem behavior. Again, the advantage of beginning with the most intensive treatment feasible may include the fact that determining as early as possible whether such a shift in emphasis will be necessary leaves adequate time to implement and train caregivers in these procedures. When it becomes necessary to develop strategies to manage, rather than reduce, problem behavior, a number of treatment activities remain available. For example, caregivers can be trained in techniques to physically manage aggressive behavior and/or implement blocking techniques so that aggression or self-injurious behaviors do not produce injury. Similarly, the effectiveness of protective equipment can be evaluated (Moore, Fisher, & Pennington, 2004). Even if a function-based treatment is unsuccessful at reducing behavior to clinically significant levels, such interventions may still produce some reduction in

problem behavior and therefore justify implementation. Minimally, function-based interventions are likely to reduce the probability of problem behavior worsening through ongoing reinforcement in the natural environment. It is thus appropriate to train caregivers to implement recommended interventions with good procedural fidelity. Finally, interventions targeting the remediation of skill deficits are likely to pose benefit for the individual. Broadening an individual's repertoire of adaptive behaviors such as communication, self-help, recreation, academic, or social behaviors may produce collateral reductions in problem behavior (Dunlap, Johnson, & Robbins, 1990), perhaps because such improvements result in an increased ability to extract reinforcement from the environment.

Reductive Procedures

In the event that reinforcement-based strategies alone do not decrease problem behavior to clinically acceptable levels, it may be necessary to consider the use of reductive (i.e., punishment-based) strategies to augment reinforcement-based approaches. The use of reductive procedures is undoubtedly one of the more controversial topics for those who develop treatments for severe behaviors, as exposing individuals to aversive consequences can itself be aversive for caregivers and clinicians. Perhaps for this reason, research on the use of reductive procedures as a treatment component is not nearly as well studied as the use of reinforcement-based strategies (Lerman & Vorndran, 2002).

Although much about the use of punishment may be debatable, including commentary on the ethics of using such reductive procedures vs. allowing severe behavior to continue to occur (Iwata, 1988), some guidance on the use of reductive procedures has been provided. As stated in the Behavior Analysis Certification Board (BACB) *Guidelines for Responsible Conduct for Behavior Analysts*, an individual should not be exposed to aversive stimuli more than is necessary to develop effective treatment (BACB, 2010). Thus, it would be prudent for any clinician

considering the use of reductive procedures to have well-developed policies dictating how, and under what circumstances, such treatments will be evaluated. At a minimum, the following should be considered when evaluating reductive procedures: The social validity/acceptability of any potential reductive procedures to be utilized should be carefully considered. Caregivers may be reluctant to implement some procedures due to social stigma or their own ethical concerns. The physical requirements of repeated implementation of some reductive procedures may also make it difficult or impossible to implement without assistance. Evaluating a consequence for use as a reductive procedure that has a low probability of being implemented with good procedural fidelity in the natural environment likely constitutes unnecessary exposure to an aversive stimulus that will have little effect on behavior. Caregivers should also be fully informed of the procedures to be evaluated and potentially utilized so that they can provide feedback on the acceptability of each. It is prudent to require caregivers to complete a structured social validity questionnaire prior to assessing each potential reductive procedure (e.g., Fisher et al., 1994). Any procedures that a caregiver indicates he or she is unable or unwilling to use should not be assessed.

Any potential reductive procedure that is acceptable to caregivers should be systematically evaluated prior to being incorporated into treatment. Fisher et al. (1994) proposed a methodology of evaluating aversive stimuli in which individuals were exposed to each putative punisher on a fixed time schedule. The aversiveness of each procedure was quantified using an avoidance index that consisted of the sum of negative vocalizations and avoidant movements, with positive vocalizations that occurred while in the procedure subtracted. The procedure with the highest avoidance index was then considered most likely to function as an effective reductive procedure, and a subsequent treatment evaluation confirmed this conclusion.

Once the potential reductive procedure is identified, the clinical team must also determine what reinforcement-based strategies will con-

tinue to be evaluated or implemented within treatment. Reductive procedures should be added to an existing reinforcement-based intervention rather than evaluated alone because reductive procedures do not teach replacement behaviors that will produce access to reinforcement. To ensure the most accurate evaluation of potential reductive procedures, data should be collected on the rate of problem behavior and the number of times the procedure is implemented. Because some procedures restrict the ability to simultaneously engage in problem behavior, the rate of problem behavior should be calculated only for the time when the procedure is not being implemented to determine if reductions have occurred. Data collection should continue even after discharge from the intensive day-treatment program to ensure the reductive procedure remains effective. The reductive procedure should be discontinued if low rates are not maintained, suggesting the procedure is no longer effective.

Finally, the overall effectiveness of the procedure should be evaluated and the reductive effects of the procedure should be weighed against the ethical implications of exposure to the aversive stimulus. If the benefits do not outweigh the concerns, reductive procedures should be discontinued and an alternative treatment identified.

Increasing Social Validity

If the most intensive intervention is successful in achieving a clinically significant reduction in problem behavior, then it becomes possible to begin to evaluate whether that treatment can be made more externally and socially valid. Particular attention may also need to be paid to the social reinforcers that maintain caregiver adherence or non-adherence to prescribed treatment protocols. For example, delays to reductions in problem behavior, or competing reinforcers such as avoidance of social stigma associated with their dependents' problem behavior, may prevent caregivers from implementing treatments with good fidelity (Allen & Warzak, 2000).

One of the most straightforward ways to enhance the social validity of behavioral interventions is to evaluate a range of different treatment options so that caregivers can be trained in a menu of interventions that can be implemented in various situations. For example, the treatment that is shown to be most effective may also be the one that is most challenging to implement. Caregivers can be trained to implement this treatment with good fidelity and instructed to do so whenever possible. Yet, it may be unrealistic to expect implementation of such treatments at high levels of procedural fidelity over long periods of time by caregivers who are under stress and have other responsibilities. However, caregivers can also be trained in other treatments that may be less likely to produce reductions as rapidly as this most effective treatment but are more feasible and therefore likely to be implemented. Thus, caregivers can implement the most effective treatment whenever they have the time and resources to do so but then implement a more feasible treatment at other times. Antecedent-based strategies, such as those that eliminate the motivating operation responsible for evoking problem behavior, may additionally be effective when problem behavior cannot be tolerated. Interventions such as this may not be ideal as a sole treatment because problem behavior is likely to return to previous levels as soon as the motivating operation returns to strength. However, such a strategy may serve as one treatment option among many available to a caregiver. Research is still needed to determine the impact of providing a menu of treatments such as this on social validity and effectiveness. It seems plausible that this approach would be preferred by caregivers. Alternatively, the requirements of being trained in multiple treatments and a decision-making process for determining when to implement each one may be taxing for caregivers, resulting in degradation of both social validity and procedural fidelity.

In many cases, the use of dense schedules of reinforcement will present an impediment to caregivers implementing the treatment in the natural environment. That is, reinforcing every instance of an appropriate response under a differential reinforcement of alternative behavior

(DRA) schedule, or brief intervals with no problem behavior under a differential reinforcement of other behavior (DRO), may not be realistic for some caregivers. Thus, schedule thinning and/or delay fading is an important step towards making a treatment that has been effective in a clinical setting more socially valid (Fisher, Thompson, Hagopian, Bowman, & Krug, 2000). In some instances, the use of a multiple schedule can be useful in establishing signaled periods of reinforcement contingent upon alternative behaviors and extinction in others (Hanley, Iwata, & Thompson, 2001; for an excellent review on this topic, see Hagopian, Boelter, & Jarmolowicz, 2011).

Attempts to make a treatment more socially valid may result in degradations in the effectiveness of the treatment. That is, thinning the schedule of reinforcement, reductions in staffing ratios, or less than perfect extinction can each result in problem behavior returning to baseline levels (Volkert, Lerman, Call, & Trosclair-Lasserre, 2009). When it becomes clear that only the most intensive treatments will effectively produce reductions in problem behavior, then it becomes necessary to consider how such a labor and time intensive treatment will be implemented following discharge from the intensive day-treatment program. Under such circumstances it may be necessary to consider the need for additional supports for caregivers, such as respite services, classroom paraprofessionals, or in-home therapists who can assist with treatment implementation. In situations where such supports are unavailable, it may be the case that the effective but intensive treatment can only be consistently implemented in a more intensive placement, such as a residential setting. When this situation arises, caregivers will likely require assistance in long-term planning to locate and investigate such appropriate settings.

Generalization Across Settings and Individuals

Once treatment is shown to be effective in a controlled environment with program staff, it is important to determine how effective it is in more

naturalistic settings where there are threats to treatment integrity or procedural fidelity (defined as the degree to which the treatment is implemented as planned). It is perhaps most prudent to begin generalization by gradually introducing stimuli that have a history of evoking problem behavior or serving as discriminative stimuli in the past (Wulbert, Nyman, Snow, & Owen, 1973). For example, for problem behavior maintained by negative reinforcement in the form of escape from demands, the effectiveness of a treatment that has been shown to effectively produce compliance with one demand can be examined when additional, and potentially more aversive, demands are introduced. Such a step is made simpler if a demand assessment has been conducted previously (see above). Similarly, caregivers who have a history of reinforcing problem behavior, and therefore may serve as discriminative stimuli for problem behavior, can also be introduced into the intensive day-treatment setting.

Such stimuli are best introduced into treatment within the session rooms/areas of the intensive day-treatment setting because any changes in behavior can be attributed to the introduction of these variables. Once the most salient stimuli have been introduced, the treatment can be evaluated in a semi-structured environment such as a classroom or play area contained within the intensive day-treatment setting. Such an environment may be less well controlled than a session room; however, it is still more controlled than the individual's home, community, or school environment. Including the evaluation of treatment effectiveness in these settings within the intensive day-treatment program also allows for the presence of clinic staff. In the event that problem behavior reemerges, treatment can continue to be implemented with high integrity. This is an important step in ensuring that the treatment package will remain effective in less controlled environments.

Once the treatment has been shown to be effective within a variety of semi-structured settings and with a variety of individuals in the intensive day-treatment setting, it is important to train all relevant caregivers to implement the treatment package. Training should begin first within a controlled setting and then be extended

to the home and community whenever possible. Training caregivers within the home allows them to ask questions as they arise, problem solve situations that may not have been addressed or explored within controlled settings, and practice implementing treatment under a variety of conditions. When an admission is arranged by a school system, the transition back to the school setting generally includes training educators within the intensive day-treatment setting, modeling the treatment within the school setting, and then transferring the implementation of the treatment package to school personnel. Even when admissions for school-aged individuals are not arranged by their school system, training of school personnel is advisable, as they retain responsibility for the individual for a significant portion of the student's day.

Once training is complete and the individual is discharged from the intensive day-treatment setting, follow-up services may be provided to monitor treatment implementation and provide ongoing consultation. There is little research on the long-term outcomes of individuals treated in intensive day-treatment programs. However, anecdotal reports suggest that it is probably safe to assume that treatment integrity may decrease within a few weeks of discharge without ongoing monitoring, especially if some problem behavior continues to occur (Lovaas, Koegel, Simmons, & Long, 1973). Follow-up services may help increase long-term treatment integrity by providing caregivers with continued feedback, training, and coaching on the individual treatment components. In addition, treatment changes often need to be made after several weeks or months, as behavior improves or changes (Kendall, 1989). These changes can be made during follow-up visits, which in turn may increase the overall long-term outcomes.

Communication with Caregivers

There have been few studies establishing specific best practices for maintaining caregiver involvement and investment in the treatment process. Despite this lack of direction from empirical research on this topic, there are some practices

that are given, including maintaining frequent and ongoing communication between clinicians and caregivers. Such communication is important because, regardless of the reduction in problem behavior that occurs in the intensive day-treatment setting, if caregiver implementation of the treatment is poor, there is a high probability that long-term outcomes will suffer. Fortunately, the fact that the individual continues to reside at home throughout the admission likely increases the amount of contact clinicians have with caregivers because they are frequently the ones who must transport them to the intensive day-treatment program each day. Establishing a pattern of frequent formal and informal communication can minimize confusion or frustration and increase the chances of long-term success.

A possible source of frustration experienced by caregivers during the course of an admission to an intensive day-treatment program may stem from dissatisfaction with or unrealistic expectations about the treatment model. Some caregivers may expect all facets of the treatment to be completed entirely, with complete elimination of the problem behavior, within the confines of the intensive day-treatment setting. When caregivers have this misunderstanding, they may not be prepared to implement treatment post-discharge. Measures to avoid this situation include early and repeated discussion of the approach and goals of the intensive day-treatment program, including the need for caregivers to maintain implementation of the final treatment in the natural environment at the conclusion of the admission. Such discussions can begin prior to an admission by ensuring caregivers understand and are committed to the treatment model. This discussion should include a realistic depiction of the effort likely to be required to implement treatment so that caregivers have accurate expectations. It may be helpful to convey that the effort required to implement treatment is likely to decrease over time as rates of problem behavior decrease due to consistent treatment implementation. If any of these requirements are not acceptable to caregivers, discontinuing planning for an admission at such an early stage is far less costly than once an admission has begun and resources have been devoted towards assessment and treatment.

The topic of the treatment approach can be revisited on the first day of the actual admission, along with attempts to establish more concrete admission goals. Goals for the admission should be operationally defined so that it is clear to both caregivers and clinicians when they have been met. For those individuals who engage in several different topographies of problem behavior, it may also be helpful to ask caregivers to prioritize the importance of reductions in each topography so that should different topographies serve different functions, the most socially valid treatments can be attempted first.

Occasionally, caregivers will express frustration because they assumed that treatment (and reductions in problem behavior) would take place as soon as an admission began. That is, they were unaware that FAs and complementary assessments are a prerequisite step that can take several days or even weeks to complete. Once again, explaining the assessment process and its importance in developing effective function-based treatments *a priori* can prevent confusion on this matter. In addition, it is important to explain that until they have been trained and begun implementing treatment, caregivers may not observe differences in the rate or intensity of problem behavior in the natural environment.

Caregiver concerns over implementation of treatments in the natural environment can become complicated if the most intensive treatments are attempted first and then gradually altered to become more socially valid, as described above. Caregivers may require clarification about the purpose of this stage of treatment development. It has been our experience that caregivers may assume that these intensive interventions that are conducted early in the evaluation process are the ones that they will eventually be expected to implement in the natural environment. Given that many caregivers will lack the time, training, and resources to implement such treatments, their concern over such an expectation is perhaps reasonable. Anticipating this reaction and preemptively explaining the purpose of this stage of treatment can reduce the need to deal with these concerns later.

Not only can clinicians provide useful information to caregivers, but caregivers may provide information on events outside of the intensive day-treatment setting that may pertain to the assessment and treatment process. For example, illness, other medical events such as seizures, changes in medication regimen, sleep disturbance, etc. may all produce changes in behavior (Kennedy & Meyer, 1996) within the intensive day-treatment setting that would otherwise be difficult to explain. Being made aware of these events can aid clinicians in interpreting data and conducting the most effective assessment and treatment analyses.

Summary and Conclusion

The intensive day-treatment clinical model has several distinct advantages for the assessment and treatment of severe behaviors exhibited by individuals with developmental disabilities. It represents a median between more intensive and costly clinical models and less intensive but potentially less comprehensive ones. Successful treatment of severe problem behavior utilizing this model depends on several factors: First, the intensive day-treatment model should be reserved for those individuals for whom it is most appropriate. Establishing and implementing methods for identifying these individuals will reduce the probability of false-positive or false-negative admission decisions. Second, the identification of maintaining consequences is necessary to develop the most effective interventions in an efficient manner. Without a clear understanding of the function of the problem behavior, time and resources may be misallocated towards ineffective treatments. To complete the analyses necessary to identify function and evaluate treatments safely and efficiently, appropriate numbers and training of staff should be considered such that direct care personnel have the skills to follow protocols as well as provide assistance with daily living activities and maintain safety. Similarly, case managers must have the training and expertise necessary to design and oversee each assessment and evaluation. Finally, caregiver buy-in and ability to implement treatment is an important consideration for

long-term improvements. If caregivers are not able to implement treatment with high fidelity upon discharge, long-term gains are unlikely. Because of the potential impact of social validity, caregivers should be provided information and support as early in the admission process as possible so that they have a clear understanding of the expectations following discharge.

Appendix 1: Problem Behavior Severity Assessment

Therapist should collect all referral, intake assessment, indirect assessments, and medical record information that is possible. Refer to the Client Summary Sheet (CSS), the Descriptive Assessment Summary Sheet, or the Brief CSS in the client's e-folder to gain access to most of this information. All answers should be based on the primary referral behavior(s). For example, if the primary concerns are aggression and self-injury but pica and elopement also occur; this scale should be completed based upon the results of the aggression and self-injury together, but should not consider the pica or elopement.

Note: This assessment is not designed to be used as a questionnaire. Answers should be based upon compiled data, not caregiver driven.

Topography of Primary Problem Behavior(s):

Current State of Problem Behavior

Complete the following questions based upon compiled data and reports that reflect the **current** state of problem behavior (i.e., within the past 6 months). Scores should be based upon instances that have **actually occurred**, not the probability reported.

1. How has the behavior problem affected the family's current daily routines?
 - a. Does not interfere.
 - b. Changes have been made to family routines (e.g., changes in mealtime, bedtime, always leave TV on or never turn it on).
 - c. Child or the family no longer engages in certain activities outside of the house (e.g., going to restaurants, shopping malls, movie theaters, church).
- d. Structural modifications have been made to home/school (e.g., changing the location of door locks, installing shatter proof windows, changing the arrangement of the classroom, installing alarms).
- e. Resulted in more restrictive educational or residential placement (e.g., child has been moved to school other than home school or self-inclusive classroom [due to problem behavior, not educational delays] or 1-on-1 paraprofessional is required due to problem behavior, foster care, emergency respite, hospitalizations, residential/group home).
2. Has the behavior problem caused any physical harm to the individual or others?
 - a. No physical damage to self or others
 - b. Soreness, redness, or surface scratches without bleeding
 - c. Bruising, minimal broken skin (with bleeding and/or scabbing), callusing, or damage to teeth and gums (bleeding or enamel erosion)
 - d. Any damage requiring medical attention such as broken bones, stitches, infection, or damage to internal organs that could be addressed by medications (e.g., taking medication to address esophageal damage)
 - e. Permanent damage to either the individual or others such as loss of sight or hearing, permanent deformities, or damage to internal organs that require medical procedures (e.g., surgery of any kind)
 - f. Required outside personnel to gain control of the situation (e.g., emergency calls to police, emergency hospitalizations, residential placement) or to treat physical damage (24 h or more in hospital)
3. Has the behavior problem caused any damage to property?
 - a. No damage
 - b. Ripping paper, hitting or kicking walls and floors without denting or breaking holes, destroying school materials such as pencils, crayons, etc.
 - c. Throwing, pushing, or knocking over large objects (e.g., small appliances)

- d. In **less than 50 %** of all occurrences, resulted in broken windows, doors, furniture, or dents or holes in walls
 - e. In **more than 50 %** of all occurrences, resulted in broken windows, doors, furniture, or dents or holes in walls
 - f. In **more than 85 %** of all occurrences, resulted in broken windows, doors, furniture, or dents or holes in walls
4. What is the highest level of intensity of current intervention used to manage or decrease the behavior problem?
- a. Behavior problem is ignored, blocked, or redirected; a verbal reprimand is given; or items or extra attention is given to the individual to manage behavior problem.
 - b. Interventions that may include a time-out procedure, the removal or restriction of a preferred item/activity, or corporal punishment.
 - c. Behavioral intervention plan which does not require additional individuals to implement. For example, token economies, multiple schedules, or any intervention that can be implemented by one individual while also engaging in other activities simultaneously. If restraint has been implemented, it was safely implemented by one person.
 - d. Individual requires one-on-one monitoring in any location; individual cannot be left alone for any period of time; child has been moved to school other than home school or self-inclusive classroom (due to problem behavior, not educational delays). If restraint was implemented, it required two or more people to safely implement.
 - e. Individual requires two or more individuals to safely manage behavior problems at all times, the individual is ever placed in total seclusion (to protect others from harm), or protective equipment (e.g., helmet, arm splints, arm guards) is ever used to protect either the individual or those working with the individual.
- be based on what might happen in the next 6 months should no new interventions be implemented and the current trend in problem behavior continues. Scores should not be based on any projected changes or trend in problem behavior beyond 6 months (e.g., in the next 12 or more months).
5. If problem behavior continues to follow its current trend for the next 6 months, how would the family have to change its routines?
- a. No changes.
 - b. Changes in daily routines within the house (e.g., changes in mealtime, bedtime, always leave TV on or never turn it on).
 - c. Child or the family would not be able to engage in certain activities outside of the house (e.g., going to restaurants, shopping malls, movie theaters, church).
 - d. Structural modifications would need to be made at home or school (e.g., changing the location of door locks, installing shatter proof windows, changing the arrangement of the classroom, installing alarms).
 - e. Changes to more restrictive educational or residential placements may be made, including additional individuals to manage the individual, change in classroom placement to self-inclusive classroom, transition from home to foster care, emergency respite residence, or residential setting.
6. If problem behavior continues to follow its current trend for the next 6 months, what harm may be caused to others or the individual?
- a. Less than 20 % chance
 - b. More than 80 % chance that soreness, redness, or surface scratches without bleeding will occur
 - c. More than 80 % chance that bruising, minimal broken skin (with bleeding or scabbing), callusing, or damage to teeth and gums (bleeding or enamel erosion) will occur
 - d. More than 80 % chance that broken bones, infection, or the need for stitches or other medical attention will occur
 - e. More than 80 % chance that permanent damage to either the individual or others such as loss of sight or hearing, permanent deformities, or damage to internal organs that require medical procedures (e.g., surgery of any kind)

Potential State of Problem Behavior

Complete the following questions based upon compiled data and reports that reflect the **potential** state of problem behavior (i.e., what is projected or expected) for the next 6 months. Scores should

- f. More than 80 % chance that outside personnel will be called to gain control of the situation (e.g., emergency calls to police, emergency hospitalizations, residential placement) or to treat physical damage (24 h or more in hospital)
- 7. If problem behavior continues to follow its current trend for the next 6 months, what damage to property may occur?
 - a. Less than 20 % chance
 - b. More than 80 % chance that minor damages to the environment will occur including ripping paper, hitting or kicking walls and floors without denting or breaking holes, destruction of school materials including breaking pencils and crayons
 - c. More than 80 % chance that property damage such as throwing, pushing, or knocking over large objects (e.g., small appliances) will occur
 - d. More than 80 % chance that windows, doors, and furniture will be broken or dents and holes will be put in walls but in less than 50 % of all occurrences of problem behavior
 - e. More than 80 % chance that windows, doors, and furniture will be broken or dents and holes will be put in walls in more than 50 % of all occurrences of problem behavior
 - f. More than 80 % chance that windows, doors, and furniture will be broken or dents and holes will be put in walls in greater than 85 % of all occurrences of problem behavior
- 8. If problem behavior continues to follow its current trend for the next 6 months, what interventions will be necessary if intervention does not occur immediately?
 - a. Others can ignore, block, redirect, or verbally reprimand problem behavior or provide items or extra attention to the individual to manage problem behavior, but no formal intervention.
 - b. Informal behavioral interventions such as time-out, removing or restricting access to items, or corporal punishment would be necessary to keep the individual or others safe.
 - c. A formal behavioral intervention plan that does not require additional individuals to implement such as token economies, multiple schedules, or any intervention that

can be implemented by one individual while also engaging in other activities simultaneously would be necessary to keep the individual or others safe. In addition, should restraint be required, only one person would be necessary to implement.

- d. One-on-one monitoring would be necessary in any location, the individual could not be left alone for any period of time, or the individual would be moved to a school other than his/her home school or placed in a self-inclusive classroom (due to problem behavior, not educational delays) to keep the individual or others safe. If restraint should be required, two or more individuals would be necessary to implement.
- e. Any behavioral intervention would require at least two individuals to implement in order to keep the individual or others safe, total seclusion may be necessary to ensure the safety of others, or the use of protective equipment for the individual or others may be required for safety.

Appendix 2: Standardized Interview Questions

1. What are the specific forms of the problem behavior you are observing at home or school? (*Be sure to discuss specifics, not just SIB, but head hitting, face slapping, etc.*)
2. When did it start?
3. What is its current frequency (h/day/week)?
4. What is its intensity (typical vs. most severe instance caregiver can recall)?
5. Has anyone gotten hurt?
6. Has he/she hurt himself/herself?
7. Has he/she broken any furniture, windows, etc.?
8. What is the typical duration of the target behavior (e.g., lengthy tantrum vs. specific instance of behavior)?
9. Are there any predictable times or events that take place that precede the behavior?
10. In what settings does the behavior occur?
11. With whom does the behavior occur?
12. If there was one specific thing that I could do that would result in the behavior occurring, what would it be?

13. What do you do when the behavior happens?
14. How does this work?
15. What does he/she do when you do this?
16. Have you tried responding differently in the past?

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Intensive Treatment of Pediatric Feeding Disorders

22

Suzanne M. Milnes and Cathleen C. Piazza

As indicated in Chap. 10 of this handbook, the primary crises in pediatric feeding disorders are caused by significant deficits of calorie, nutrient, or fluid intake. The most severe cases, those that are primarily the result of acute dehydration, will necessitate an emergency room visit. Generally, the goal of the emergency room team will be to rehydrate the child, which is often accomplished via intravenous fluids. Repeated emergency room visits may prompt the child's primary care physician to suggest the placement of a nasogastric (NG-) tube. An NG-tube is a flexible, plastic tube that is inserted through the nose, past the throat, down the esophagus, and into the stomach. The NG-tube is taped to the child's cheek in order to secure placement and prevent dislodgment. Nutrition is then delivered through the tube, directly into the stomach. Nasogastric tubes are also used for children who are experiencing poor weight gain or weight loss. The NG-tube is meant to serve as a temporary bridge to provide hydration, nutrition, and/or calories until the child is able to sustain his or her own hydration, calorie, and/or nutritional needs. Table 22.1 lists the advantages and disadvantages of NG-tube feedings.

In cases where the child has recurrent dehydration and/or is chronically failing to gain weight, the child's primary care physician will often recommend placement of a more permanent method of supplemental feeding such as a gastrostomy (G-) tube. Although there are other methods of providing supplemental nutrition (e.g., jejunostomy), the G-tube is the most common. A G-tube is a flexible tube that is surgically inserted through the skin of the abdomen wall and into the stomach, typically by a pediatric surgeon. There are two basic kinds of gastrostomy tubes that are used. One kind is held in place by a mushroom-shaped disc inside the stomach wall. The other is held in place by a balloon inflated with saline. Table 22.1 lists the advantages and disadvantages of the G-tube.

Although supplemental feeding provides hydration, calories, and nutrition, it does not necessarily promote oral feeding (Luiselli & Evans Luiselli, 1995). The extent to which nutrition can be delivered via the oral route depends largely on the child's cooperation and ability to feed orally. Some children with long histories of interruption of oral feeds or unpleasant experiences as a result of eating (e.g., emesis as a result of reflux disease) do not have the skills to feed orally or demonstrate an aversion to oral feeding (Cohen, Piazza, & Navathe, 2006). Thus, progress to age-appropriate, oral feeding may be undermined by the child's lack of skill or motivation to ingest solids and liquids (Nucci, Barksdale, Yaworski, Beserock, & Reyes, 2002). Data from pediatric

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Table 22.1 Advantages and disadvantages of nasogastric and gastrostomy tubes

	Advantages	Disadvantages
Nasogastric tube	Food and medication can be deposited directly into the stomach	Insertion can be uncomfortable
	Improved growth and nutrition	May irritate nose and throat
	Does not require surgery	Increased mucus secretion
	Insertion is relatively quick	Skin irritation
	Caregiver can be trained to place the NG-tube	Tube is visible on the face
		Risk of aspiration and pneumonia if tube becomes dislodged
		May interfere with nasal breathing
Gastrostomy tube		May increase probability of difficulties with oral feeding
	Food and medications can be deposited directly into the stomach	Requires surgical placement
	Improved growth and nutrition	Can malfunction
	Less risk of dislodgment than NG-tube	May cause intra-abdominal leakage and infection
	Can be hidden by clothing	Can cause irritation at skin around site due to stomach acid leakage
		May increase the probability of reflux
		May increase probability of difficulties with oral feeding

Essex and Wooliscroft (2011), Rossi, Brodsky, and Arvedson (2002)

populations with chronic medical problems have demonstrated that these children have a higher prevalence of intractable feeding problems (Bazyk, 1990; Benoit, Wang, & Zlotkin, 2000; Blackman & Nelson, 1985; Dellert, Hyams, Treem, & Geertsma, 1993; Derrickson, Neef, & Cataldo, 1993; Geertsma, Hyams, Pelletier, & Reiter, 1985; Piazza et al., 2003; Vantini et al., 2004). There is evidence that a history of NG- or G-tube feedings may increase the probability of oral feeding problems (Bazyk, 1990; Blackman & Nelson, 1985; Dellert et al., 1993; Geertsma et al., 1985). For example, Blackman and Nelson (1985) showed that some children required extensive outpatient (up to 2½ years) or inpatient therapy to wean tube feeds. Blackman and Nelson state, “parents often find it difficult to attempt oral feeding at home without professional support because they cannot cope with the behavior that children exhibit when it is initiated” (p. 437). A viable alternative or complimentary method to supplemental tube feedings is enrollment into an interdisciplinary, evidence-based program designed to increase oral feeding (Fig. 22.1).



Fig. 22.1 Entrance sign to the pediatric feeding disorders clinic

Overview of Evidence-Based Interdisciplinary Feeding Disorder Programs

As indicated in Chap. 10 of this handbook, children develop feeding difficulties as a result of a complex interaction between medical, physiological, and behavioral problems. Thus, the child’s failure to eat is not the result of a

single etiology, which can be treated by a single professional, but a complex interaction between a variety of factors, which warrant intensive treatment by an interdisciplinary team (Rommel, De Meyer, Feenstra, & Veereman-Wauters, 2003). Kerwin (1999), Luiselli (2006), and Volkert and Piazza (2012) analyzed data from studies on treatment of pediatric feeding disorders and showed that the only treatments that had empirical support were those with an applied behavior analytic orientation.

The pediatric feeding disorders program at the University of Nebraska Medical Center's Munroe-Meyer Institute and similar programs (e.g., Milton S. Hershey Medical Center, Kennedy Krieger Institute) deliver empirically supported treatments like those described by Kerwin (1999) and Volkert and Piazza (2012). In fact, these groups have conducted many of the studies that provide empirical support for the applied behavior analytic approach to the treatment of pediatric feeding disorders (e.g., Freeman & Piazza, 1998; Gulotta, Piazza, Patel, & Layer, 2005; Kelley, Piazza, Fisher, & Oberdorff, 2003; Mueller et al., 2003; Mueller, Piazza, Patel, Kelley, & Pruett, 2004; Patel et al., 2006; Patel, Piazza, Kelly, Ochsner, & Santana, 2001; Patel, Piazza, Layer, Coleman, & Swartzwelder, 2005; Patel, Piazza, Martinez, Volkert, & Santana, 2002; Patel, Piazza, Santana, & Volkert, 2002; Piazza et al., 2002; Piazza, Anderson, & Fisher, 1993; Piazza, Fisher, et al., 2003; Piazza, Patel, Gulotta, Sevin, & Layer, 2003; Reed et al., 2004). These types of programs evaluate and treat infants and children who fail to eat and/or drink a sufficient quantity or variety of foods or liquids to meet their nutritional and/or hydration needs. They serve children with a variety of disorders, including, but not limited to, medical, congenital, or acquired disease processes, which result in impaired or inappropriate feeding behavior. The programs are committed to high-quality interdisciplinary care delivered in a cost-effective manner, to the training of health professionals, and to research related to feeding disorders.

Pediatric feeding disorders programs such as the one at the University of Nebraska Medical Center's Munroe-Meyer Institute have many unique features, which differentiate them from other feeding programs. A primary characteristic is a goal-oriented, data-based approach that allows the program to objectively assess feeding-related behaviors, develop individualized treatment plans, efficiently and systematically evaluate and refine treatment development, and track success for individual patients and for the program as a whole. For example, the success rate for severe feeding problems in the pediatric feeding disorders program at the Munroe-Meyer Institute is 86 % (i.e., 86% of patients meet greater than 90 % of the goals set for their admission).

These programs are housed in a specialized physical plant that facilitates effective, efficient, and safe assessment and treatment of feeding behaviors. Additionally, the interdisciplinary treatment team monitors the child's growth pattern, nutritional status, and hydration status. The team acknowledges and addresses potential barriers to treatment (e.g., any issues that might impact the child's food refusal or the caregivers' ability to carry out the treatment plan). The treatment team develops assessment and treatment procedures targeting eating and drinking based on data collected during mealtimes. These procedures are carried out by trained therapists during therapeutic meals. All of the child's feeding therapy occurs in the context of the meal, and all of the individuals that feed the child follow the same protocol with 90 % or greater accuracy. The philosophy of the program is that to be a good eater, the child has to practice eating in the context of nutritive stimuli (i.e., food and drink). Therapists and/or caregivers conduct sessions to test the effects of specific treatments directly on food consumption, food refusal, and inappropriate mealtime behavior. Assessments and treatments for each child receive regular peer review by multiple senior behavior analysts, staff, and the interdisciplinary team. Caregivers are trained to criteria to implement the treatments that are developed during the child's admission.

Pediatric Feeding Disorders Program at the University of Nebraska Medical Center's Munroe-Meyer Institute

Physical Plant

The program is housed in an approximately 3,000 sq ft area within the Munroe-Meyer Institute. The program has six, 4m × 4 m therapy rooms equipped with one-way observation and two-way sound monitoring. Children have access to a feeding playroom, which is a 10m × 7m room equipped with toys and games appropriate for children (Fig. 22.2). The feeding playroom is connected to a caregiver lounge (Fig. 22.3), which is a 7m × 7m room equipped with two small sofas, chairs, a television, refrigerator, microwave, sink, and storage. The playroom and caregiver lounge are separated by a glass window so parents may either remain in the playroom with the child or observe the child from the parent lounge. The program also has a nap suite, which consists of four 3m × 3m rooms adjacent to the caregiver lounge. Each room has either a portable crib or cot on which the child may nap (if appropriate). Children and families have access to an indoor and outdoor playground, which are equipped with play equipment, some of which has been adapted for children with disabilities.

The program maintains a variety of seating options (e.g., high chairs, booster seats) to accommodate children of different ages, sizes, developmental disabilities, and behavioral challenges. The program also maintains a large supply of feeding utensils and other items (Fig. 22.4) necessary for effective and efficient treatment of children with feeding problems. Lastly, the program houses a pantry (Fig. 22.5) for simple food manipulation. The pantry contains a commercial-grade refrigerator with freezer, a dishwasher, microwave ovens, and a variety of small appliances (e.g., food processors) necessary for simple food manipulation.

Interdisciplinary Team

The pediatric feeding disorders' interdisciplinary team consists of professionals who have



Fig. 22.2 Feeding playroom

specialized training, expertise, and interest in the assessment and treatment of pediatric feeding disorders. The team consists of a physician, psychologist, dietitian, speech therapist, and social worker. Other professionals (e.g., nurse, physical therapist) are available based on the individual child's needs. Master's and bachelor's level therapists with specialized training in behavior analysis and management of feeding disorders also function as critical members of the team.

Physician: During the comprehensive feeding evaluation, the physician evaluates the medical stability of the child relative to oral feeding, evaluates the child's need for medical work-up (e.g., genetics, endoscopy), completes or refers the child for medical work-up as indicated, and recommends necessary therapy related to the findings of the work-up (e.g., medication). During the admission, the physician participates in daily rounds, meets with the child and family two to three times per week, and examines the child based on the child's medical needs. The physician also manages intercurrent illness and acute or chronic medical problems.

Dietitian: The dietitian delineates, implements, and evaluates nutrition management for each patient and evaluates the child's nutritional status during admission by monitoring growth, dietary intake, hydration, elimination, laboratory indices, and tolerance to feeding regime. He or she also provides nutritional counseling to families to meet nutrition management goals and identifies caretakers' understanding and



Fig. 22.3 Parent lounge



Fig. 22.4 Commonly used feeding utensils. From left to right: rubber-coated baby spoon, nuk brush, nosey (cut out), maroon© spoons

expected level of compliance with nutritional recommendations.

Speech and Language: The speech and language therapist evaluates each child’s oral motor status and provides recommendations regarding procedures to address any oral motor deficits. He or she also evaluates the child’s ability to manage food types and textures and provides input regarding appropriate food types and textures during assessment and treatment. The speech therapist provides recommendations for stimulation of communication. He or she assesses the safety of the child for oral feeding, determines the necessity of a modified barium swallow study, and schedules and performs the study as needed.



Fig. 22.5 Pediatric feeding disorders clinic pantry

Social Work: The social worker provides intervention for social, individual, and/or familial problems; facilitates the team's understanding of the family's perspective, strengths, and limitations; and assists the family in understanding of the child's diagnosis, treatment program and prognosis, and expectation for caregiver training. He or she is also responsible for discharge planning, including resource development and referral.

Psychology: The psychologist identifies specific problems that contribute to the individual child's feeding difficulties. This professional also is responsible for overseeing the development of the data collection procedure, the assessment of the child's feeding behavior (e.g., level of acceptance, swallowing) during presentation of solids and/or liquids under different environmental conditions (e.g., attention, escape), and in the presence of specific mealtime stimuli (e.g., spoon volume). The psychologist develops the treatment protocols to address specific feeding behavior exhibited by the child and directs the evaluation of the effectiveness of the treatments. He or she oversees the training of the caregivers, educates the caregivers on the conceptual framework of treatment, identifies concerns and limitations of the caregivers, and assists the caregivers in maintaining positive interactions with the child during the admission. In addition, the psychologist is responsible for overseeing follow-up to maintain and advance feeding skills. He or she educates and trains the interdisciplinary team regarding the conceptual framework of assessments and treatments and facilitates and maintains communication among interdisciplinary team members. The psychologist supervises the evaluation of the child's tolerance of feedings (oral and enteral), in addition to supervising the feeding therapists.

Feeding Therapists: These are individuals with bachelor's and master's degrees in psychology, education, or a related field. The feeding therapists are present at every meal and supervise the child's inter-meal activities on a case-by-case basis. These staff are responsible for preparing food items for individual meal sessions, collect-

ing data on individual child, caregiver, and/or therapist behavior during assessment and treatment sessions, analyzing data collected during individual meal sessions, and entering data into spreadsheets and constructing graphic representations of data. Each child is assigned a team of feeding therapists that typically consists of two permanent team members and a group of three to five other feeding therapists that work with the team on a rotating basis. Thus, the two permanent team members typically are present at each meal, and a third person from the rotating pool is present at approximately 33 % of the meals.

Program Population

The target population for our program is children between the ages of 0 and 12 whose feeding problems are severe and compromise growth and/or nutrition. Children over the age of 12 are considered for admission to the program on a case-by-case basis. The criteria for admission are generally related to the factors that led to the child's feeding crisis (i.e., dehydration, growth failure). Admission criteria are as follows.

Child evidences any *one* of the following characteristics:

1. Child consumes less than 20 % of nutritional needs by mouth.
2. Child consumes between 20 and 50 % of his or her nutritional needs by mouth and has high to moderate levels of inappropriate behavior during meals.
3. Child consumes less than 70 % of nutritional needs by mouth and has high levels of inappropriate behavior during meals.
4. Child exhibits a deceleration of growth across established percentiles that suggest failure to thrive. Child is diagnosed with dehydration or malnutrition, which results in emergency treatment.
5. Child has NG-tube with no increase in the percentage of calories obtained via oral feeding for 3 consecutive months.
6. Child has inappropriate mealtime behavior, which interferes with the child obtaining sufficient calories, volume of fluids, and/or

varieties of food to sustain the child's growth and/or nutrition.

7. Child has aberrant feeding patterns, which interfere with the child obtaining sufficient calories, volume of fluids, and/or varieties of food to sustain the child's growth and/or nutrition.
8. Child has had at least 3 months of outpatient feeding therapy with no or minimal improvement in feeding behavior.
9. Child in need of caloric supplementation, although such supplementation was introduced prior to admission and growth is stable.
10. Child with any oral motor dysfunction that interferes with ability to feed orally, although growth is stable.
11. Child's feeding pattern is significantly different from same-aged peers.

The exclusion criteria are:

12. The results of a modified barium study suggest that the child is not safe for oral feeding.
13. The child has unstable medical problems (e.g., uncontrolled reflux disease), which contraindicate treatment.
14. The child is diagnosed with an eating disorder (e.g., anorexia, bulimia).

Evaluation Clinic

Referral: Admission into a pediatric feeding disorders program begins with a referral. Typically, pediatricians, occupational therapists, psychologists, gastroenterologists, and/or speech and language pathologists refer caregivers of children with feeding problems to the intensive feeding program when growth or nutrition is compromised, other interventions have failed to achieve success improving feeding behavior, and/or an emergent feeding problem (e.g., recurrent dehydration) is beyond the expertise of the relevant professional. The treatment team's insurance coordinator will conduct a telephone intake, gather insurance information, and request relevant medical records.

Insurance Clearance: The treatment team's insurance coordinator files appropriate paperwork with the caregiver's insurance provider and begins the process of obtaining clearance for a comprehensive feeding evaluation and treatment,

if indicated. Once the insurance provider approves the evaluation and/or treatment, the insurance coordinator contacts the family and schedules an interdisciplinary feeding evaluation.

Interdisciplinary Feeding Evaluation: The primary purpose of the interdisciplinary feeding evaluation is to assess the severity of the feeding problem and the child's current nutritional status, determine appropriateness for services and level of service necessary, assess potential barriers to treatment, and provide recommendations for treatment and/or referrals.

At the beginning of the evaluation, the dietitian assesses the child's nutritional and growth status. He or she weighs the child and measures the child's height. The dietitian conducts a nutritional analysis of a 3-day food log (i.e., all foods and liquids the child consumes orally or via tube are recorded by the caregiver over the course of 3–5 days prior to the evaluation). He or she calculates the child's daily intake and estimated needs and indicates the severity of the child's current growth and nutritional status.

The treatment team will conduct several assessments designed to observe the caregiver and child's interactions during meals. During the *home baseline* assessment, caregivers are asked to simulate a typical meal in terms of foods served, method of presentation, responses to appropriate and inappropriate behavior, duration of meal, utensils used, and items present. The treatment team observes the meal in an observation room adjacent to the feeding therapy room (Fig. 22.6) and collects data using laptop computers. These observations assist the team in developing initial hypotheses about possible maintaining variables of the child's feeding difficulties.

Next, the team observes the caregiver-child interaction during meals in which the team imposes minimal structure and simple rules. The *standard outcome baseline* is similar to the home baseline in that the caregiver(s) is asked to behave as he or she naturally would during meals; however, the treatment team defines what the caregiver(s) feeds the child and how often he or she presents bites and/or drinks. The caregiver presents liquids and four standard



Fig. 22.6 Feeding therapists in an observation room using laptop computers to collect data on child and caregiver behavior

foods (i.e., a protein, starch, vegetable, and fruit) at both pureed and table textures in both a self- and non-self-feeder format in a series of sequential sessions. The treatment team asks the caregiver to present a drink or bite every 30 s during a five-trial session. The imposed structure and standardization of this assessment allow the treatment team to compare the child's behavior at the time of the evaluation with the child's behavior at various points of the admission. Additionally, observations during this assessment assist the treatment team in developing hypotheses about the child's current oral-motor ability. Following the behavioral observations, a member of the treatment team conducts a semi-structured interview to obtain additional information about the child's feeding and medical history, the child's current living situation, and potential barriers to treatment.

Recommendations: At the end of the evaluation, one or more team members meet with the caregivers to summarize the results of the evaluation, answer the family's questions, recommend services, and/or refer the family for medical work-up (e.g., allergy testing) or alternative services. The team will determine whether the child is appropriate for the program and what level of service the child will require. Intensive day treatment consists of daily therapy (Monday to Friday) from approximately 8:30 am to 5 pm. Intensive

outpatient treatment includes 3–5 days of therapy per week for approximately 1–4 h per day. Outpatient treatment consists of therapy 1–2 times per week for 1–3 h per day.

We evaluate the severity of the child's feeding problems to determine the level of services (i.e., day treatment, intensive outpatient, outpatient) and frequency of visits. Severity is defined primarily by the percentage of calories the child consumes orally at admission and the level of inappropriate behavior during meals. The child's inappropriate mealtime behavior is identified as high, moderate, or mild. A high level of inappropriate mealtime behavior completely prevents the caregiver from placing a spoon or cup on or near the child's mouth during more than 80 % of bite or drink presentations, and/or the behavior is a danger to the child or caregiver (e.g., the child bites self or feeder). A moderate level of inappropriate mealtime behavior prevents the caregiver from placing a spoon or cup on or near the child's mouth between 30 and 80 % of bite and/or drink presentations. A mild level of inappropriate mealtime behavior is defined as the child exhibiting inappropriate mealtime behavior during less than 30 % of bite and/or drink presentations. We also take into account the degree to which the child's feeding behavior is or is not age appropriate with respect to other variables (e.g., texture, self-feeding, distribution of calories of solid vs. liquid). The goal of the day treatment program is to effect a large change in the child's feeding behavior (e.g., increase oral caloric consumption from 0 to 50 % of the child's caloric needs) and train the caregivers to implement the treatment. We use the intensive outpatient program to stabilize the child's behavior. Finally, we advance the child to age-typical feeding patterns during the outpatient program. We estimate an approximate 2-year time course to reach this goal for the most severely affected individuals. The numbers provided in Table 22.2 for weeks of each type of therapy are *approximate* as frequency and timing of treatment is goal, rather than time oriented.

The course of treatment is relatively similar, independent of the level of service in which the child is admitted for initial treatment. Therefore,

Table 22.2 Type and length of service based on percentage of oral intake and level of inappropriate mealtime behavior

Oral intake	Level of inappropriate mealtime behavior		
	High	Moderate	Mild or none
None	Day (6–8 weeks)	Day (6–8 weeks)	Day (4–6 weeks)
	IOP (4–6 weeks)	IOP (2–4 weeks)	IOP (2–4 weeks)
	OP (48–90 weeks)	OP (50–90 weeks)	OP (50–90 weeks)
>20 %	Day (6–8 weeks)	Day (6–8 weeks)	Day (4–6 weeks)
	IOP (4–6 weeks)	IOP (2–4 weeks)	IOP (2–4 weeks)
	OP (48–90 weeks)	OP (48–90 weeks)	OP (50–90 weeks)
20–50 %	Day (6–8 weeks)	Day (4–6 weeks)	
	IOP (2–4 weeks)	IOP (2–4 weeks)	IOP (6–8 weeks)
	OP (48–90 weeks)		OP (44–96 weeks)
51–70 %	Day (2–4 weeks)	IOP (4–6 weeks)	
	IOP (2–6 weeks)	OP (48–90 weeks)	OP (24–52 weeks)
71–100 %	IOP (4–6 weeks)	IOP (2–4 weeks)	
	OP (48–90 weeks)	OP (20–48 weeks)	OP (24–52 weeks)

Note: day = day treatment, IOP = intensive outpatient, OP = outpatient

we will describe the course of treatment in general terms, keeping in mind that this course of treatment would be followed regardless of whether the child is in the day treatment, intensive outpatient, or outpatient program.

Goals and Objectives

One of the first steps in the admission is goal setting. The team and the caregivers develop specific short-term goals for the child, usually in 3-month increments. Thus, all assessments and treatments are goal oriented and data driven. Each child is admitted with a different constellation of feeding problems; therefore, goals are unique for each child. Common goals include increasing caloric intake, increasing acceptance and consumption of solid food, increasing acceptance and consumption of liquids, decreasing supplemental feedings, increasing texture of consumed foods, increasing variety of foods, decreasing inappropriate mealtime behavior, and caregiver training. Figure 22.7 shows a sample goal sheet for a child. The long-term goal of the program is for the child to become an age-typical eater (i.e., consume solids and liquids in a manner similar to other children of the child's chronological age or development as appropriate).

Assessment

The initial evaluation begins with a replication of home baseline and standard outcome baseline assessments as described previously to determine whether the child's feeding behavior has improved, maintained, or worsened since the time of the evaluation. As indicated previously, we use these data to develop hypotheses about current environmental events that may maintain child appropriate and inappropriate behavior. The subsequent assessments are individualized, depending on what we observe during the caregiver-fed meals.

Children with high levels of inappropriate mealtime behavior during caregiver-fed meals would participate in a functional analysis to determine how specific environmental events affect child behavior (Piazza, Fisher, et al., 2003). The assessment may be conducted by the caregiver or a therapist. The functional analysis typically consists of three or four conditions that allow us to observe the child's behavior when inappropriate behavior results in (a) adult attention, (b) breaks from presentations of liquids or solids, (c) access to a tangible item (e.g., preferred toy or food), or (d) no differential consequence (control). We conduct these conditions in a pair-wise fashion (Bachmeyer et al., 2009) in

P.O. Goals

Increase Total P.O. (from _____ kcal to _____ kcal)

Please circle range (determined during goal meeting)

90%-100%	80%-90%	70%-80%	60%-70%	<u>50%-60%</u>
40%-50%	30%-40%	20%-30%	10%-20%	0%-10%

1. ☒ clinic – 3 out of the 5 last treatment days in clinic
2. ☒ home – 1 day in the home using the final treatment protocol

Decrease Tube Feeding (from _____% to _____ %)

3. ☒ clinic – decrease by the last treatment day at the clinic
4. ☒ home – decrease by the last day in the home

Liquids Goals

Example: Increase non-self drinking

Acceptance (from _____% to 80% or greater)

5. ☒ clinic – 3 out of the 5 last treatment days in the clinic with mean 5-s acceptance at 80% or greater
6. ☒ home – 1 day in the home with mean 5-s acceptance at 80% or greater

Mouth Cleans (from _____% to 80% or greater)

7. ☒ clinic – 3 out of the 5 last treatment days in the clinic with mean mouth cleans at 80% or greater
8. ☒ home – 1 day in the home with mean mouth cleans at 80% or greater

Decrease Inappropriate Mealtime Behaviors (from _____ rpm to _____ rpm)

9. ☒ clinic – 3 out of the 5 last days in the clinic with mean 80% or greater reduction in problem behavior
10. ☒ home – 1 day in the home with mean 80% or greater reduction in problem behavior

Solids Goals

Example: Increase variety to 20 new foods at pureed texture in a non-self-feeder format

Acceptance (from _____% to 80% or greater)

11. ☒ clinic – 3 out of the 5 last treatment days in the clinic with mean 5-s acceptance at 80% or greater
12. ☒ home – 1 day in the home with mean 5-s acceptance at 80% or greater

Mouth Cleans (from _____% to 80% or greater)

13. ☒ clinic – 3 out of the 5 last treatment days in the clinic with mean mouth cleans at 80% or greater
14. ☒ home – 1 day in the home with mean mouth cleans at 80% or greater

Fig. 22.7 Example goals

Decrease Inappropriate Mealtime Behaviors (from ____ rpm to ____ rpm)

- 15.

X

 clinic – 3 out of the 5 last days in the clinic with mean 80% or greater reduction in problem behavior
- 16.

X

 home – 1 day in the home with mean 80% or greater reduction in problem behavior

Caregiver Training Goals

Example: Liquids Treatment

Caregiver Name:

Clinic

- 23.

X

 Incorrect attention less than 10% for 3 out of the last 5 meal blocks conducted in clinic
- 24.

X

 Incorrect praise less than 10% for 3 out of the last 5 meal blocks conducted in clinic
- 25.

X

 Incorrect escape less than 10% for 3 out of the last 5 meal blocks conducted in clinic

Home

- 26.

X

 Incorrect attention less than 10% for 1 day in the home
- 27.

X

 Incorrect praise less than 10% for 1 day in the home
- 28.

X

 Incorrect escape less than 10% for 1 day in the home

Fig. 22.7 (continued)

which levels of acceptance and inappropriate mealtime behavior in each test condition (attention, escape, tangible) are compared to those in the control condition. This analysis provides us with information regarding possible ways that we can alter the mealtime environment to improve the child’s eating. That is, the results of the functional analysis result in a specific, prescribed treatment for the child.

Children with high levels of inappropriate mealtime behavior in the presence of specific foods would participate in a food preference assessment (Munk & Repp, 1994). The caregiver nominates 8–16 foods (two to four foods in each of the food groups of protein, starch, fruit, vegetable) that the child refuses to eat, but that the caregiver would like the child to eat. The therapist presents the foods in pairs and pairs each food with every other food once. During the paired presentations, the therapist instructs the child to “pick one.” The results of this assessment provide information about the hierarchy of food preferences for the child and are used to develop treatment to increase the child’s acceptance of foods that are refused.

Children with high levels of inappropriate mealtime behavior in the presence of specific

textures of foods would participate in a food texture preference assessment (Adelinis, Piazza, Fisher, & Hanley, 1997; Munk & Repp, 1994; Patel et al., 2005; Patel, Piazza, Santana, et al., 2002). The caregiver nominates 8–16 foods (two to four foods in each of the food groups of protein, starch, fruit, vegetable) that the child refuses to eat, but that the caregiver would like the child to eat. The therapist presents these foods in different textures to assess which textures and foods the child will eat and which textures and foods that child refuses. The therapist presents foods in pairs, and each food is presented with every other food. During the paired presentations, the therapist instructs the child to “pick one.” The results of the texture preference assessment are used to identify a hierarchy of texture preferences for the child and are used to develop treatment to increase the child’s acceptance of a variety of textures of foods.

We often conduct preference assessments to identify preferred items to use as reinforcement (Fisher et al., 1992). We use the Reinforcer Assessment for Individuals with Disabilities (RAISD; Fisher, Piazza, Bowman, & Amari, 1996) to assist caregivers in identifying approximately 16 items that the child prefers.

During the preference assessment, the therapist presents items to the child in pairs, and each item is paired with every other item. The therapist instructs the child to “pick one.” The results of the preference assessment can be used to identify a hierarchy of child preferences. We may use the most highly preferred items based on the results of the preference assessment during treatment (Mueller et al., 2003, 2004; Patel et al., 2001, 2005, 2006; Patel, Piazza, Martinez, et al., 2002; Patel, Piazza, Santana, et al., 2002; Piazza et al., 1993, 2002; Piazza, Fisher, et al., 2003; Piazza, Patel, et al., 2003; Reed et al., 2004).

Treatment

Treatments are individualized based on the results of the assessment(s). We use current research literature to determine which treatments are appropriate for individual children. We implement a treatment based on negative reinforcement with children whose inappropriate mealtime behavior is maintained by escape from presentations of liquids or solids (based on the results of the functional analysis). Typical negative reinforcement-based treatments include providing a break following appropriate behavior (e.g., acceptance, swallowing) and elimination of escape for inappropriate mealtime behavior (i.e., escape extinction; Bachmeyer et al., 2009; Freeman & Piazza, 1998; Kelley et al., 2003; LaRue et al., 2011; Patel, Piazza, Martinez, et al., 2002; Piazza, Fisher, et al., 2003; Piazza, Patel, et al., 2003; Reed et al., 2004; Vaz, Volkert, & Piazza, 2011). We implement a treatment based on positive reinforcement with children whose inappropriate mealtime behavior is maintained by attention (based on the results of the functional analysis). Typical positive reinforcement-based treatments include providing attention or tangible items following appropriate behavior (e.g., acceptance, swallowing) and elimination of attention for inappropriate behavior (i.e., attention extinction; Bachmeyer et al., 2009; Kelley et al., 2003; Piazza, Patel, et al., 2003; Reed et al., 2004).

These types of treatments typically focus on increasing acceptance of food and decreasing

inappropriate mealtime behavior. However, there may be other variations of these treatments that are implemented for children who show resistance to escape and/or attention extinction. For example, we might blend preferred and nonpreferred foods together to increase acceptance of nonpreferred foods (Mueller et al., 2004; Piazza et al., 2002). This treatment would be used with a child who exhibits higher levels of acceptance and mouth clean (a product measure of swallowing) of some foods relative to others. We also might change behavior by altering some component of the mealtime environment gradually (i.e., fading; Freeman & Piazza, 1998; Groff, Piazza, Zeleny, & Dempsey, 2011; Patel et al., 2001; Rivas, Piazza, Patel, & Bachmeyer, 2010). This procedure would be used with a child who is cooperative with some aspect of the feeding situation (e.g., will put an empty spoon in her mouth), but not others (e.g., will not put a spoon with food in her mouth). We also might precede presentation of a food or liquid with a low probability of acceptance by a food or liquid with a higher probability of acceptance (Dawson et al., 2003; Patel et al., 2006, 2007). We might use this procedure with a child who demonstrates acceptance of some foods but not others.

Increases in acceptance for some children might be accompanied by increases in expulsion (spitting out the food). Such a response would necessitate the addition of treatment components designed to reduce expulsion. For example, we might represent expelled food. We also might evaluate how texture of food affects expulsion (Patel, Piazza, Santana, et al., 2002). We have also demonstrated that a chin prompt may be effective when representation alone is not effective in reducing expulsion (Wilkins, Piazza, Groff, & Vaz, 2011).

Some children hold or pocket accepted food, a behavior we call “packing.” There are a variety of treatments to reduce packing and increase swallowing. One treatment involves redistribution of packed food in which the feeder uses a spoon or a nuk brush to remove packed food from the child’s mouth and places it back on the child’s tongue (Gulotta et al., 2005). We also might reduce the texture of one or more food items (Patel et al., 2005).

Our group has shown that presentation with a flipped spoon reduces packing and improves mouth clean for some children (Rivas, Piazza, Kadey, Volkert, & Stewart, 2011; Volkert, Vaz, Piazza, Frese, & Barnett, 2011). We also have combined the flipped spoon and chin prompt (Dempsey, Piazza, Groff, & Kozisek, 2011) to treat packing.

Eating is a complex behavior that consists of a number of skills, including, but not limited to, accepting bites of presented food or liquid, forming or maintaining that food or liquid into a bolus, chewing foods (if necessary), elevating the tongue and propelling food backward through the oral cavity, swallowing foods or liquids, and keeping swallowed foods or liquids down (i.e., not vomiting). Feeding problems may involve disruption at one or more places in this sequence of behaviors. Thus, it is difficult, if not impossible, to describe every treatment we might use because sometimes treatments are developed for idiosyncratic problems that emerge for individual children. Generally, however, we use the same data-based, outcome-oriented approach to develop treatments for whatever problem an individual child might exhibit. Treatments always are based on the research literature, and we constantly refine, update, and improve our treatments. This process often helps us identify new methods for assessing and treating feeding problems, which we share with our colleagues in peer-reviewed journals.

Caregiver Involvement and Training

After we have completed our initial assessment with caregivers (i.e., the home baseline and standard outcome baseline as described above), the team decides whether the caregiver will continue to feed the child during the subsequent assessments and treatments. Some factors that influence who feeds the child initially are the level and type of child inappropriate mealtime behavior, the size of the child and his or her caregiver, input from the caregiver regarding his or her perceived readiness to feed the child, and the degree of technical difficulty of the assessment and treatment protocols. The caregiver is expected to participate in the program independent of whether he or she

feeds the child during the initial assessments and treatment development. Most caregivers remain at the center throughout the day. They observe all sessions when they are not feeding. The team takes this opportunity to educate the caregiver(s) (e.g., explain why a particular treatment is being implemented).

Once we have established an effective treatment, all caregivers are trained to implement treatments to criterion. We use the same data-based methods for training parents that we use for evaluating child behavior (Mueller et al., 2003). Initially, caregivers implement the treatment in the clinic environment. We begin by providing verbal and written descriptions of the treatment procedures and ask the caregivers to observe treatment sessions. Following each observation, the primary therapist and/or senior therapist meet with the caregiver to answer questions and role-play treatment procedures. Caregivers then sit in the feeding therapy room so that we can observe child behavior during meals in the presence of the caregiver. When the caregiver reports that he or she is ready to begin feeding, the therapist will feed the child, while the caregiver provides prompts and praise. When the caregiver's prompts and praise are above 90% accuracy for several sessions, the caregiver will take over feeding, while the therapist provides feedback to the caregiver during the feeding sessions. Caregivers begin implementing the treatments at home once they have demonstrated that they can implement the treatments in clinic at 90% or greater accuracy. We generally have the caregivers only feed a small amount of solids or liquids at home (e.g., five bite or drink presentations) initially. Caregivers keep records on child behavior at home and report back to us. We maintain, increase, or decrease the number of presentations or alter other aspects of the feeding treatment (e.g., increase bolus size), depending on child behavior. Therapists also observe the caregiver implementing the treatment in the home. A therapist typically spends the last week of the day treatment admission in the home, ensuring that caregivers are able to implement the established treatment protocols with 90% accuracy. The therapist also trains any person that

will feed the child in the natural environment (e.g., siblings, school staff, nurses, and extended family). We use the same data-based criterion for training these individuals as we would use for training the primary caregivers.

All caregivers receive a handbook at the beginning of the admission that describes the rationale for the procedures we use. The caregiver handbook provides parents with information regarding where to buy the specific tools we use during the meals (e.g., bowls, spoons, cups, scales, high-chairs). Caregivers also receive copies of their child's individualized protocol(s) for feeding. The protocol(s) describes the procedures the caregivers will use when presenting solids and liquids to the child. The protocol also provides parents with information about type, texture, and quantities of food and liquid to present and a schedule of meals and snacks. Caregivers are instructed to continue to follow the child's specific protocol. Changes to the protocol and advances in feeding skills are accomplished individually for each child during follow-up. Caregivers record child behavior at home following discharge so we can track child progress. The follow-up schedule is individualized for the child, but generally includes weekly, 1-h appointments in the clinic at a minimum. Follow-up continues until the child is an age-typical eater.

Criteria for Discharge

As indicated above, the child progresses through the continuum of services (day treatment, intensive outpatient, outpatient) based on his or her behavior. When the child meets the goals set for each 3-month interval, the team determines whether the child is ready to transition to a less intensive level of service (e.g., from day treatment to intensive outpatient). Progress toward goals is assessed and documented on a daily basis. The child remains in the program as long as he or she is making progress toward each goal. Any child who fails to continue progressing toward the goals is evaluated for discharge by the interdisciplinary team. The child continues in the program if the team determines that the current

treatment is not effective, but alternative treatments are available and can be implemented with the child to progress him or her toward the goals. The child is discharged to a less intensive level of service (e.g., intensive outpatient) if the child's progress plateaus, and the team determines that this plateau is a condition that will change only with time and/or practice of skills. The child is referred elsewhere if the team determines that the current treatment is not effective and that we do not have alternative treatments that would progress the child toward his or her goals. The child is discharged if the caregivers fail to cooperate with the treatment plan.

A discharge planning meeting is held if the team transitions the child to a different level of service. During the discharge meeting, the team reports on the extent to which the child met his or her goals, shows and explains treatment graphs marking progress and/or areas of weakness, and plays a video that includes footage of the child's mealtime sessions at each stage of feeding therapy (e.g., assessment, treatment, caregiver feeding). Ultimately, therapy is discontinued once the child becomes an age-typical eater.

Summary

A child who fails to gain weight and/or grow and/or who experiences recurrent dehydration and/or malnutrition warrants intervention by a professional who specializes in pediatric feeding disorders. Although crisis management (e.g., NG-tube) may be necessary in some cases, a long-term approach to intervention should be adopted in which the child participates in an interdisciplinary feeding program that provides goal-oriented, data-based assessment and treatment. Programs that offer a continuum of services at varying intensity levels are able to address the most difficult feeding problems and progress the child through the continuum until he or she is an age-typical eater. Importantly, the program should incorporate treatments based on applied behavior analysis, which is the treatment approach with the most empirical support in the literature for treatment of pediatric feeding disorders. Outcome

data from such programs suggest that most children reach the goals set for treatment (Cohen et al., 2006; Greer, Gulotta, Masler, & Laud, 2008; Laud, Girolami, Boscoe, & Gulotta, 2009; Piazza & Carroll-Hernandez, 2004; Williams, Riegel, Gibbons, & Field, 2007).

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Several epidemiological studies have shown that treatments based on the results of a functional analysis are often successful in reducing problem behavior across subgroups of children evaluated in inpatient (Asmus et al., 2004; Iwata et al., 1994), outpatient (Derby et al., 1992; Kurtz et al., 2003), and home (Wacker et al., 1998) settings. Parents often bring their children to outpatient clinics for their health care, and they often request assistance with problem behaviors displayed by their children. For this reason, the development of brief functional analysis procedures was important. The initial applications of functional analysis procedures to 90-min outpatient evaluations (Cooper, Wacker, Sasso, Reimers, & Donn, 1990; Northup et al., 1991) demonstrated that functional analyses could be modified to meet the severe time restrictions of these clinics. Thus, even under those restrictions,

functions of problem behavior were often identified (Derby et al., 1992), and treatment probes based on the results of brief functional analyses were often shown to be effective (Northup et al., 1991) within the clinic setting.

In this chapter, we provide a historical overview of brief functional analysis procedures conducted in 90-min outpatient clinics and provide current exemplars of these procedures via case studies. Our goal in these clinics is to identify a function of problem behavior as quickly as possible and then to demonstrate a treatment that is matched to the identified function. By function, we are referring specifically to the reinforcers maintaining problem behavior. However, as discussed by Hanley, Iwata, and McCord (2003), functional analyses can also identify antecedent variables, such as the presence of specific demands or people (Ringdahl & Sellers, 2000), that occasion problem behavior or are correlated with problem behavior. Some analyses, such as those based on the procedures described by Carr and Durand (1985), focus specifically on antecedent variables (e.g., Cooper et al., 1990). We have adapted brief functional analyses from both the consequence-based (Iwata, Dorsey, Slifer, Bauman, & Richman, 1994) and the antecedent-based (Axelrod, 1987) assessment approaches with good success (Wacker, Berg, Harding, & Cooper-Brown, 2004) in identifying functions that were used to develop treatments.

One reason to conduct a pretreatment functional analysis of problem behavior is to develop an

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effective reinforcement-based treatment (Pelios, Morren, Tesch, & Axelrod, 1999). Effective treatments are identified because the results of the assessment identify the antecedent and consequence conditions that occasion and maintain problem behavior (Iwata et al., 1994). When these conditions have been identified, treatments based on differential reinforcement can be conducted by, for example, placing problem behavior on extinction and providing the reinforcer identified via the functional analysis contingent on desired behavior. Treatment is often successful because the response–reinforcer relation is disrupted for problem behavior (extinction) and the response–reinforcer relation for desired behavior is strengthened via contingent reinforcement.

Brief Historical Overview

Our outpatient clinics primarily serve children with and without developmental disorders who display severe problem behaviors and whose parents seek guidance on how to reduce these behaviors. Although more severe forms of problem behavior (e.g., self-injury) often create a crisis for parents, other common forms of problem behavior (e.g., screaming, tantrums, and noncompliance) can also create major difficulties at home because of their frequency, duration, or intensity. In our clinical experience, parents report that they view their child's behavior as being unpredictable or related to various events (e.g., sleeping patterns) outside of their control. Thus, one reason for the crisis is that the parents believe that they cannot control their child's behavior.

Functional analyses serve two clinical roles in these situations. First, as described previously, they identify the function of problem behavior. Second, they demonstrate environmental control over behavior. Parents conducting or observing a functional analysis witness increases and decreases in problem behavior as they implement the assessment conditions, which typically involve free play, diverted attention, demand, and restricted access to tangibles. Conducting the functional analyses within a multielement design, in which the conditions are counterbalanced, provides the

parents with repeated opportunities to determine that they very often have at least some control over their child's behavior. This clinical outcome of conducting functional analyses within single-case designs, plus the information provided by the results, permits the clinician and the parent to focus on how to most effectively treat the behavior. Because functions are often identified quickly, treatment can also be implemented in the clinic on the same day that the functional analysis is completed. Thus, even when time is severely restricted, as in our 90-min evaluations, we can often complete a brief functional analysis and initiate treatment (e.g., Northup et al., 1991). The identification of the function of problem behavior and the initiation of treatment constitute the goals of our outpatient assessment. If we can accomplish these goals, then we most often ask the parent to try the treatment at home, and we continue to consult via phone or e-mail, or connect them to local service providers.

Derby et al. (1992) provided a summary of the first brief functional analyses we conducted in our outpatient clinic. As discussed by the authors, the biggest problem we had in our clinic was false negatives; over one-third of the clients evaluated did not display problem behavior. As discussed by Wacker et al. (2004), this problem of false negatives (a failure to identify a function for problem behavior) has continued to occur and is one of the biggest problems that arise with brief functional analyses. In these cases, there are several options. The first option is to progress to extended functional analysis (Vollmer, Marcus, Ringdahl, & Roane, 1995). For example, we might schedule the individual to attend our day treatment program (Asmus et al., 2004) so that an extended functional analysis can be completed. This is an especially good option if parents report the behavior as being severe. We also frequently consider this option if the behavior involves self-injury that does not appear to be responsive to social reinforcers (i.e., serves an automatic function). Other options include using alternative forms of assessment and comparing the effects of different treatment approaches within a multielement design. These options are discussed later in this chapter.

Our initial outpatient clinic evaluations of problem behavior sought only to show that the brief functional analysis procedures could be useful in an outpatient setting (e.g., Cooper et al., 1992; Northup et al., 1991). We next adjusted the procedures in an attempt to increase their internal validity (Cooper et al., 1992; Wacker et al., 2004). For example, Cooper et al. (1992) discussed the benefits of incorporating “mini-reversals” within the multielement design by always repeating conditions that changed the frequency of target behavior after also repeating a control condition (ABAB with single data points). This procedural modification permits the clinician to better determine if the B condition is indeed responsible for increases in behavior. Other researchers (e.g., Kahng & Iwata, 1999; Wallace & Iwata, 1999) also evaluated the validity of the procedures and found them to be acceptable for clinical purposes.

Refinement of the procedures has continued to occur (Boelter et al., 2007; Call, Wacker, Ringdahl, Cooper-Brown, & Boelter, 2004) and has focused on both antecedent and consequence variables. For example, Call et al. (2004) evaluated how motivating operations, such as diverted attention and demands, might be combined for children who do not show problem behavior initially in either condition. A second area of investigation has been the identification and evaluation of treatments. Northup et al. (1991) showed how functional communication training (FCT) might logically follow the completion of a brief functional analysis. These authors showed that appropriate mands, such as signed requests, could replace the occurrence of problem behavior within a brief period of time. The covariation of appropriate mands and problem behavior was demonstrated by a contingency reversal. If, for example, problem behavior was identified as functioning to maintain a tangible item, the contingency reversal involved first reinforcing problem behavior, then an appropriate mand (e.g., signing “please”), and then problem behavior. The results showed that both problem behavior and mands were emitted most often when only they were reinforced. Thus, reinforcing mands often reduced displays of problem behavior very quickly.

Over the last 20 years, our focus has shifted from exclusively conducting functional analyses of problem behavior to conducting choice (concurrent operants assessments) and treatment analyses in outpatient clinic settings. Concurrent operants assessments of social reinforcers (Berg et al., 2007; Harding et al., 1999) are frequently used when problem behavior does not occur during the functional analysis or the problem behavior does not lend itself well to a functional analysis (e.g., the behavior is infrequent or covert). The same social reinforcers that are tested within a functional analysis of problem behavior (gaining attention, gaining tangibles, and escaping demands) are presented to the child within a series of choices. For example, the child may be given the choice of playing with his mother without any toys on one side of the room and playing with toys by himself on the other side of the room to evaluate the relative value of gaining parent attention versus gaining access to preferred items. Each social reinforcer is paired against the other social reinforcers within a paired-choice format. The social reinforcer that is chosen most consistently can be provided contingent on an appropriate response within a differential reinforcement treatment and that reinforcer can be removed or withheld contingent on the occurrence of problem behavior. Although the concurrent operants assessment does not provide a direct assessment of the reinforcers that maintain problem behavior, the results identify the child’s preferences between social reinforcers, and the results can be used to promote appropriate responding and reduce problem behavior.

FCT as a treatment continues to be used in our clinics, but is now only one of several treatments we evaluate in the clinic. When possible, we match treatments to function (e.g., Northup et al., 1991; Stephens, Wacker, Cooper, Richman, & Kayser, 2003), meaning that we implement differential reinforcement procedures using the reinforcers identified via the brief functional analysis. Given the high number of false negatives that occur in clinic, we have also developed “default” treatments (Millard et al., 1993) composed of procedural components that match both negative and positive reinforcement functions.

For example, Millard et al. (1993) described a procedure that consisted of presenting demands clearly and breaking down difficult demands into easier sub-steps (escape function), providing positive adult attention while the child is continuing to work (attention function), and providing contingent access to preferred toys following the completion of work (tangible function). Although these types of default treatments often are successful, we are not sure why they are successful (e.g., what components are needed). If a functional analysis reveals a function, then treatments like the one designed by Millard et al. (1993) can still be used but with a greater emphasis on certain components. If the function is not identified, then a component analysis can be conducted as shown by Millard et al. to identify the critical components of treatment.

In the following sections, we describe our current outpatient procedures with case examples.

Current Outpatient Assessments

Overview of Procedures

Each outpatient evaluation begins with a patient referral from a local primary care provider, school team, parent, or practitioner from another clinic. The majority of the patients are children who are referred to the service for assessment and treatment of problem behavior such as self-injury, aggression, and destruction. Noncompliance and tantrums are also frequent referral issues. Patients typically receive a medical exam on the day of or prior to the behavioral assessment to rule out physiological causes that might contribute to problem behavior. The importance of a thorough medical exam as part of the initial behavioral assessment was underscored by the results of a study reported by Bosch, Van Dyke, Smith, and Poulton (1997). This team conducted medical exams on 25 patients referred to an inpatient unit for assessment and treatment of self-injurious behaviors (SIB). Physiological problems that could cause discomfort and contribute to problem behavior were identified in seven of the patients. Treatment of the underlying medical

problem resulted in decreased problem behavior for six of these patients.

Indirect descriptive assessments of the child's behavior are conducted prior to the day of the clinic evaluation. Behavior questionnaires are sent to the child's care providers and school team and returned to us prior to the clinic visit. The patient's medical chart is reviewed to identify psychological and medical diagnoses, information related to the history of the behavior, and ongoing services that the patient receives. A telephone call is made to the patient's primary care provider to identify the main concerns and the specific target behaviors to be addressed during the evaluation and to conduct an antecedent-behavior-consequence (ABC) interview. The ABC interview provides the context for target behavior and thus permits us to formulate a hypothesis (e.g., that attention or escape maintains problem behavior).

The descriptive information gathered for each patient is reviewed at a multidisciplinary staffing the morning of the clinic. The staffing team includes behavior specialists, behavioral psychologists, a speech and language pathologist, a family nurse practitioner, and a social worker. Although the roles vary, the speech and language pathologist evaluates the functional communication skills of the clients, the best mode of communication to use during functional communication training, and the overall language skills displayed by the client. The nurse practitioner evaluates possible medical conditions (e.g., constipation) that may be contributing to displays of problem behavior, and the social worker identified supports that the parent will need to implement the recommended treatment at home. The purpose of the staffing is to share information gathered from the chart review and parent interview, discuss the goal of the evaluation, develop an assessment plan, and assign roles to the members of the staffing team. The presentation ends with a hypothesis regarding why the problem behavior is occurring. The assessment strategy selected during the morning staffing is viewed as a starting point for the evaluation and is based on the hypothesis. The results of the initial assessment conditions are then used to

refine the assessment plan throughout the 90-min evaluation. In most cases, we begin with a free play and continue the free play until no target or problem behavior is occurring. When behavior is under control in free play, we then evaluate behavior in one or more test conditions, starting with the one hypothesized to maintain target behavior from the ABC interview. Most sessions are conducted for 5 min.

The clinical goal of the outpatient evaluations is to identify the antecedents and consequences associated with problem behavior and to use these findings to prescribe a function-based treatment plan for the patient. Follow-up is an important component of the outpatient clinics because we are not able to observe the child over a series of weeks or months to evaluate the effectiveness of the treatment recommendations. Therefore, we give our contact information (telephone number and e-mail address) to the parents during the clinic evaluation and encourage them to contact us with questions or offer to contact them within a few weeks. The two primary assessments used with the outpatient evaluations are a consequence-based brief functional analysis (Northup et al., 1991) and an antecedent-based functional analysis (Cooper et al., 1992). Other analyses include preference assessments conducted during free plays, evaluations of specific treatment components for their effects on behavior, and concurrent operants assessments to identify the relative value of social reinforcers that can be incorporated into a function-based treatment package.

Case Examples of Specific Procedures

Brief Functional Analysis of Problem Behavior

Consequence Analysis

Andy, a 3-year-old boy who was diagnosed with attention deficit hyperactivity disorder, was referred to the service by his primary care physician for behavior management strategies to address aggression, tantrums, noncompliance, and destruction. Andy's parents reported that Andy tantrummed when his mother's attention

was diverted from him and he was noncompliant when presented with demands such as grooming tasks. His parents reported that they had tried time out, redirection to other activities, and restricting Andy's access to items. None of these strategies had been successful in remediating Andy's behavior.

The results of the parent interview suggested that Andy's problem behavior was maintained by multiple social functions (i.e., attention and escape). A consequence-based brief functional analysis of problem behavior was conducted to evaluate the effects of each reinforcer on Andy's problem behavior. The functional analysis conditions were free play, attention, and escape. During the free-play condition, Andy had access to toys and his parents' attention. No demands were presented during the free-play condition, and no programmed consequences were delivered for any behavior. During the attention condition, Andy had access to toys while his parents spoke with each other at a nearby table. His parents were instructed to provide him with 20–30 s of attention contingent on any instance of aggression, property destruction, or tantrums. During the escape condition, Andy's parents instructed him to complete specific tasks (e.g., placing a puzzle piece into a puzzle board). Any instances of aggression, destruction, or tantrums resulted in a brief break from the task.

Figure 23.1 shows the percentage of 10-s intervals during which Andy engaged in problem behavior (e.g., tantrums, whining, noncompliance) during each brief functional analysis condition. Problem behavior did not occur during the free-play session (shaded circle), and only one instance of problem behavior occurred during the first of two escape sessions (shaded triangles). Andy whined, refused to stay in the play area, and repeatedly approached his parents during the attention sessions (open squares). These results showed that access to parent attention was a reinforcer for Andy and was likely maintaining at least some of his problem behavior. The lack of problem behavior during the escape condition did not match the results of the descriptive assessment and may have reflected a false negative as described by Derby et al. (1992). When we obtain

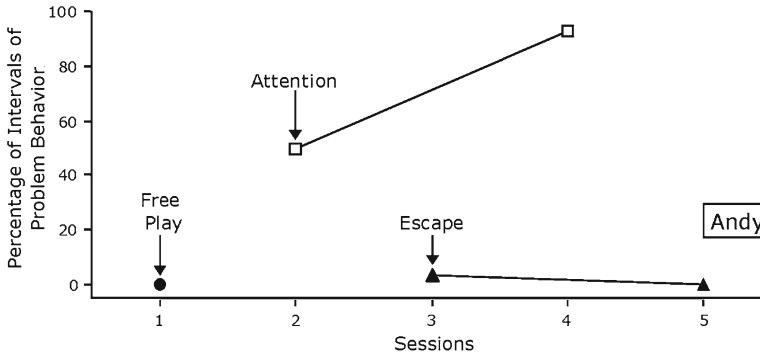


Fig. 23.1 Results of the brief functional analysis for Andy

results in which a function is identified in the brief functional analysis, we base the initial treatment recommendations on this finding.

The consistently high levels of problem behavior observed during the attention condition increased the confidence of Andy’s parents and the clinicians that attention at least partially reinforced problem behavior. This finding allowed us to make recommendations to address those behaviors. Recommendations were given to Andy’s parents to conduct daily practice sessions to teach Andy how to play alone with a toy appropriately while they engaged in a separate activity (e.g., folding laundry) for a brief amount of time. Follow-up phone calls were conducted at 2 and 4 weeks after the evaluation to determine if the recommendations were effective in reducing Andy’s problem behavior and to provide suggestions for modifying the recommendations if needed. Andy’s parents reported that they had implemented the recommendations and that Andy was showing improvements in playing alone appropriately. The results of Andy’s analysis constitute the typical evaluation we conduct in clinic. We focus on the identification of a function and then either discuss treatment (as in Andy’s case) or briefly model treatment, as described in the next case example.

Doug, a 4-year-old boy with cerebral palsy, developmental delay, and limited communication skills, was referred to the service by his primary physician. The behaviors of concern were self-injury, aggression, property destruction, and tantrums. The information provided by Doug’s

parents and his medical records suggested that Doug’s behavior might be maintained by gaining access to preferred tangibles, but, as is often the case, the information also suggested other possible social functions. A consequence-based functional analysis of problem behavior was conducted to evaluate the effects of social reinforcers on Doug’s behavior. The information provided by his parents suggested a tangible function for problem behavior; therefore, the functional analysis began with an evaluation of the effects of gaining access to positive reinforcers (i.e., preferred tangibles and adult attention) on Doug’s behavior. The first phase of the functional analysis compared the occurrence of problem behavior across free-play, tangible, and attention functional analysis conditions. The free-play and attention conditions were conducted using the same procedures that were used for Andy. During the tangible condition, Doug’s preferred toy was removed from the play area, and he was given a less preferred toy to play with. If he engaged in any of the target behaviors (e.g., self-injury, aggression, property destruction, tantrums), his parents were instructed to give him the preferred toy for approximately 30 s. After the tests for positive reinforcers were completed within the brief functional analysis, the effect of negative reinforcement (escape) was evaluated within a pair-wise design by alternating the escape condition with the free-play condition.

The left-hand panel of Fig. 23.2 shows the percentage of 6-s intervals during which Doug engaged in problem behavior during the functional

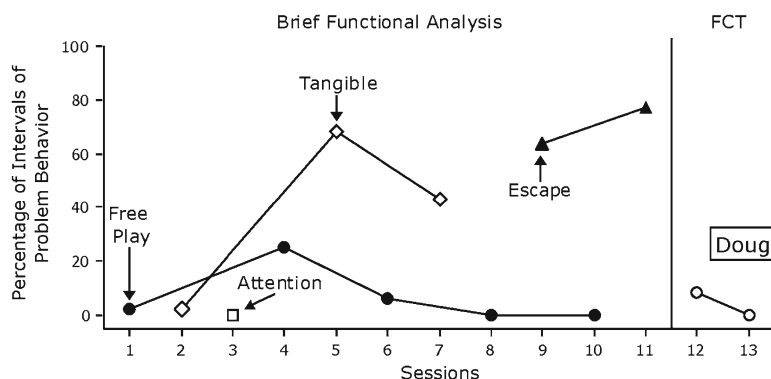


Fig. 23.2 Results of the brief functional analysis and functional communication training for Doug

analysis conditions. The first seven sessions showed that Doug engaged in problem behavior during the tangible (open diamonds) condition, and the remaining four sessions showed that problem behavior occurred during the escape (shaded triangles) condition. No problem behavior was observed during the attention session (open square), and elevated levels of problem behavior were observed during only one of the free-play sessions (shaded circles).

To address the multiple functions of Doug's problem behaviors and his communication difficulties, a two-step FCT package was evaluated during the outpatient evaluation. The first step of the FCT package was to present a brief task demand to Doug to complete (e.g., place one puzzle piece into a puzzle frame). As soon as Doug completed the brief task, the puzzle frame was removed and a prerecorded microswitch was presented to him. Doug was prompted to press the microswitch to request a break to play with his preferred toys (the second step of the FCT package). All problem behavior was ignored or neutrally blocked. The treatment package provided a structured opportunity for Doug's parents to (a) present him with brief demands and restrict his access to preferred toys, (b) provide him with reinforcement for completion of the demands (removal of the task and opportunity to request play with a preferred toy), and (c) teach him to use appropriate communication to request what he wanted (i.e., pressing the microswitch to gain access to 1 min of play with a preferred toy). The percentage of 6-s intervals with problem behavior

during the FCT treatment conditions are shown in the right-hand panel of Fig. 23.2. Two treatment sessions (open circles) were conducted, and multiple trials of presenting the task demand were conducted during each session. Doug engaged in problem behavior the first two times the demand was presented during the first session but quickly learned to complete the task and press the switch to request access to his toys. No problem behavior was observed following the completion of the first two tasks, and Doug completed each of the tasks presented to him and pressed the microswitch appropriately each time that it was presented. The results of the brief functional analysis identified social reinforcers (gaining access to preferred items and escaping demands) that maintained Doug's problem behavior, and the results were prescriptive for identifying a function-based treatment (i.e., FCT) that was effective in decreasing his problem behavior and increasing his appropriate communication.

Antecedent Analyses

Antecedent-based analyses can be useful tools for evaluating the effects of specific antecedent stimuli on a child's behavior without manipulating the consequences for problem behavior. They can be used to identify potential reinforcers for problem behavior as well as to evaluate the child's response to different treatment packages or prompting procedures. Antecedent-based analyses can also be useful to evaluate the persistence of problem behavior when reinforcement is withheld (i.e., extinction). Two types of antecedent

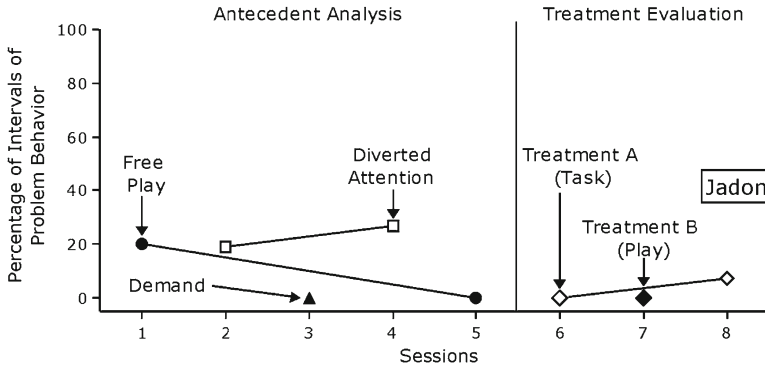


Fig. 23.3 Results of the brief antecedent analysis and treatment comparison for Jadon

analyses were conducted for the next case example. The first antecedent analysis was conducted to observe the child's response to specific environmental events such as low levels of adult attention and task requests, and the second analysis was conducted to compare the effects of two treatment packages in reducing the occurrence of problem behavior.

Jadon was a 5-year-old male diagnosed with a language delay. He was referred to the service by his local physician for concerns regarding aggression, destruction, and noncompliance with demands. The results of the indirect descriptive assessment conducted prior to the clinic visit suggested that Jadon was most likely to engage in problem behavior when his mother's attention was diverted from him. For example, Jadon's mother indicated that he was especially likely to engage in problem behavior when she was on the telephone or cooking dinner. His mother had tried using time out and redirection to other activities without any appreciable effect on Jadon's behavior.

An antecedent analysis was conducted to evaluate the environmental contexts that resulted in problem behavior. Three conditions were conducted to identify the conditions most likely to evoke Jadon's problem behavior and to observe his mother's response to those behaviors. The three conditions were similar to those conducted during the consequence-based functional analyses except that the antecedent conditions continued for the duration of each 5-min session and there were no scheduled consequences for problem behavior. During the first condition (free play,

shaded circles), Jadon and his mother played together with an activity that Jadon selected. During the second condition (demand, shaded triangle), Jadon's mother presented him with a work task to complete. His mother was instructed to continue presenting the work task until the 5-min session ended. The final antecedent condition was a diverted attention (open squares) condition. During this condition, Jadon was given toys to play with, and his mother was directed to look at a magazine for 5 min to simulate a situation in which her attention was diverted from Jadon. The results of this assessment (see Fig. 23.3, left-hand panel) showed that Jadon was most likely to engage in problem behavior when his mother's attention was diverted from him (open squares) and confirmed the results of the descriptive assessment. The assessment also revealed that Jadon's mother provided high amounts of attention for problem behavior and that this attention frequently took the form of redirection to preferred activities.

The evaluation was continued to compare the effectiveness of two treatments to increase the amount of time that Jadon would play independently without engaging in problem behavior. During the first treatment (Treatment A, open diamonds), Jadon was given the same task used in the preceding demand condition (i.e., putting together a puzzle) to complete while his mother's attention was diverted from him. The task was selected because it provided an activity with a clear beginning and end point, and its completion prompted him to request his mother's attention.

Thus, while his mother's attention was diverted, Jadon was instructed to complete a task that he had completed successfully during the preceding demand session (shaded triangle). During the second treatment condition (Treatment B, shaded diamond), Jadon was given a few highly preferred toys to play with while his mother's attention was diverted and a timer signaled his wait time. Both conditions were conducted during 5-min sessions, and Treatment A was conducted twice. Jadon's mother was directed to refrain from commenting on problem behavior for the duration of each treatment session. The treatment comparison (Fig. 23.3, right-hand panel) showed that both treatments might be effective in reducing problem behavior when adult attention was not immediately available to Jadon. Although we were limited to conducting only three treatment sessions due to the time constraints of the outpatient clinic, we were able to demonstrate each treatment option to Jadon's mother and to provide a brief evaluation of the effects of each treatment on his behavior. At the conclusion of the outpatient evaluation, Jadon's mother was encouraged to repeat the two treatment approaches several times at home to determine if one treatment resulted in lower levels of problem behavior and to determine if she or Jadon had a preference for one treatment over the other. The use of rapidly alternating conditions as conducted within a multielement design provided a way to demonstrate and compare each treatment in a brief amount of time.

In the next case example, an antecedent analysis was used to evaluate the effects of two types of task prompts on a young girl's compliance with completing task demands. Mia, a 4-year-old girl with developmental delay, was referred to the service by her primary care physician to address tantrums. Mia's mother reported that tantrums occurred when Mia was given demands such as lying down for a nap or picking up toys. Casual observations by a speech and language therapist within a play condition at the start of Mia's evaluation revealed that Mia did not respond to vocal prompts, but was cooperative when vocal prompts were paired with visual cues such as pointing and gestures. Based on this

observation, we hypothesized that at least some of Mia's noncompliance and tantrums might occur because she did not understand vocal requests. Therefore, an antecedent analysis of the effects of vocal prompts versus vocal plus visual prompts during demands was conducted. The antecedent conditions included three assessment conditions—free play, demands with vocal prompts, and demands with vocal prompts paired with visual prompts. During the free-play condition, Mia had access to toys and parent attention, and no demands were placed on her. During the demand with vocal prompts condition, a therapist provided vocal instructions for Mia to complete one-step demands (e.g., "Put the cow in"). During the demand with vocal plus visual prompts condition, the therapist provided one-step vocal directions to Mia but also provided a visual cue (e.g., the therapist said, "Put the cow in," while pointing to the correct location in the container).

The results of Mia's evaluation are presented in Fig. 23.4. The top panel shows the percentage of 10-s intervals that problem behavior (i.e., noncompliance or tantrums) occurred during each 5-min session. No problem behavior occurred during the free-play sessions (shaded circles) or when task demands were presented with vocal plus visual prompts (shaded squares). Problem behavior occurred during both sessions in which demands were presented with vocal prompts only (open squares). The lower panel shows the number of tasks that Mia completed during each demand condition. Mia completed three times as many tasks when vocal prompts were paired with visual prompts (shaded squares) than she completed when only vocal prompts were provided (open squares). The results of this evaluation showed that visual prompts were an important antecedent for increasing Mia's cooperation with task completion. Sufficient information was gathered during the descriptive assessment and anecdotal observations during play to lead to a hypothesis that Mia's noncompliant behavior was related to a skill deficit. This hypothesis was tested during Mia's evaluation, and we were able to identify and recommend specific prompts to increase Mia's cooperation with requests.

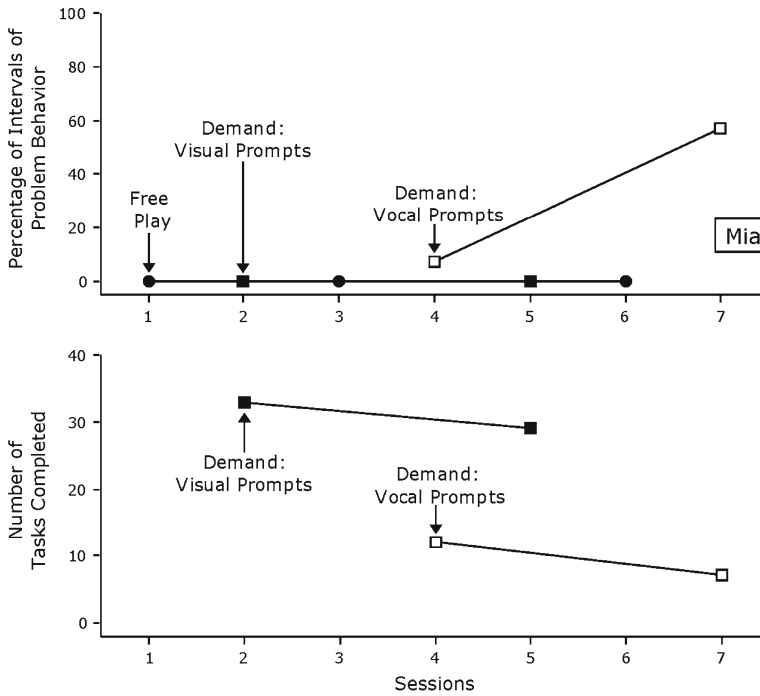


Fig. 23.4 Results of the brief antecedent analysis of prompt conditions for Mia

Brief Concurrent Operants Assessment

Concurrent operants assessments provide a method for identifying the relative value of social reinforcers for an individual. We often use this approach for patients who are not expected to engage in problem behavior during the outpatient evaluation, but we want to identify reinforcers that can be used within a treatment package. We also use this approach when a treatment package is not working, and we want to further assess the relative value of distinct reinforcers. In the following case example, a concurrent operants assessment was used to determine the relative value of two social reinforcers to identify a treatment package that promoted appropriate behavior and reduced problem behavior in a young boy.

Reno was a 6-year-old boy with borderline intellectual disability and mixed receptive-expressive language disorder who attended a special classroom for children requiring behavioral support. His teacher reported that Reno became aggressive and disrobed when he was given schoolwork that he perceived to be too difficult. The teacher hypothesized that Reno engaged in

the behavior to escape nonpreferred tasks (e.g., difficult academic tasks) and reported that she responded to the behavior by providing one-step instructions and using a three-step prompting sequence (i.e., say, show, do) to assist him with the more difficult assignments and to ensure task completion. The treatment strategies used by the teacher matched the hypothesized function of Reno's problem behavior (i.e., escape), but Reno's behavior continued to worsen at school. In reviewing the above behavior plan, we wondered if problem behavior was maintained by attention. When problem behavior occurred in the context of difficult demands at school, it was likely to result in increased one-to-one attention from Reno's teacher. To test the relative value of escaping task demands in comparison to gaining adult attention, we conducted a concurrent operants assessment (Berg et al., 2007). Specifically, we provided Reno with a series of choices in which he could choose to sit alone and do nothing (escape the demand but lose access to attention) or work on a task with adult attention (gain adult attention but not escape the demand).

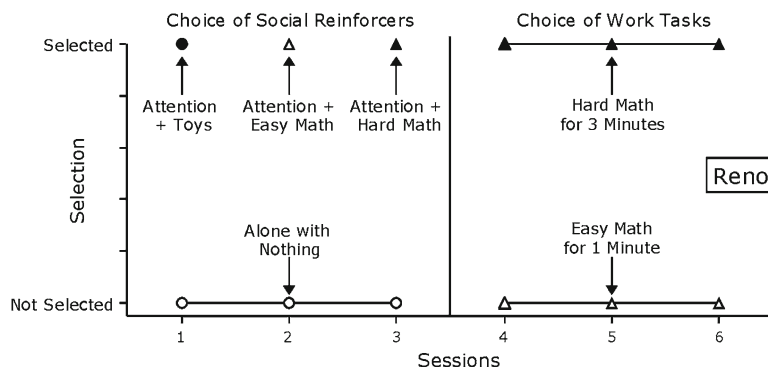


Fig. 23.5 Results of the concurrent operants assessment of the relative value of attention and escape from demands for Reno

Prior to the start of the concurrent operants assessment, a brief paired-choice preference assessment was conducted to identify Reno's preferences between four academic tasks (i.e., easy math, easy writing, difficult math, and difficult writing). Reno chose the easy math task each time the task was presented and never chose the difficult math task. The easy math task was used as the preferred academic task, and the difficult math task was selected as the nonpreferred academic task during the concurrent operants sessions.

Four conditions were conducted within the concurrent operants assessment. During the first condition, Reno was given the choice of playing with toys with his mother (shaded circle) or sitting alone and doing nothing (open circles). As expected, he selected the first option. This condition was conducted to determine if Reno understood the choice arrangement and if attention was preferred. During the second choice condition, Reno was given the choice of sitting with his mother and completing a sheet of easy math problems (open triangles) or sitting by himself with nothing to do. Reno chose to complete the easy math problems with his mother and completed the task without engaging in problem behavior. The same choice was provided to Reno during the third condition except that the difficult math problems (shaded triangles) were substituted for the easy math problems. Reno chose to sit with his mother and complete the difficult

math problems without engaging in problem behavior. The percentage of each choice condition that Reno allocated to the option that included adult attention and the option that allowed him to sit alone and escape task demands is shown in the left-hand panel of Fig. 23.5. The results of the first three concurrent operants sessions showed that adult attention was more important to Reno than avoiding or escaping nonpreferred academic tasks. To further determine if the reinforcer identified from the concurrent operants assessment (attention) could be used as a reinforcer for task completion, a fourth concurrent operants condition was conducted. During this condition, Reno was given a choice of completing a set of easy math problems to earn 1 min of play with his mother (open triangles) or completing the same amount of difficult math problems to earn 3 min of play with his mother (shaded triangles). This condition was repeated three times, and as shown in the right-hand panel, Reno chose to complete the difficult math problems to earn the larger magnitude of reinforcement (3 min of parent attention versus 1 min of parent attention) each time. Reno completed all of his work without engaging in problem behavior. Thus, results supported the hypothesis that Reno's problem behavior was maintained by attention at school and that attention was relatively more preferred than escaping difficult tasks. Recommendations to make adult attention contingent on task completion were provided to the school program.

Default Treatment

A number of factors can occur that lead us to exclusively implement treatment in the clinic rather than to first conduct a functional analysis. For example, if a functional analysis has been conducted previously but treatment is not working at home, we may implement a treatment package from the beginning of the evaluation. If the function of problem behavior has not been identified, we resort to a default treatment. The most common default treatment we use is based on Millard et al. (1993). We often use this treatment because it reduces the difficulty of demands by providing very clear, specific prompts and presenting tasks in a step-by-step fashion. It also provides both parent attention and preferred toys contingent on task completion. Thus, it addresses all of the functions of problem behavior that we typically assess. As mentioned previously, the problem with this approach is that (a) if it is successful, we don't know which components were responsible and (b) if it is unsuccessful, we don't know which components to change. However, we have often found this treatment to be effective in managing noncompliant behavior.

As discussed by Wacker et al. (2004), we attempt to conduct every assessment within single-case designs to increase the validity of the assessment. This is also the case when we implement treatment evaluations. The most common design we use is the multielement design in which we either compare two treatments (e.g., Fig. 23.3) or in which we compare treatment to a control condition. This latter approach was used with the next case example.

Ian, a 6-year-old boy with a medical history of prematurity, brain hemorrhages, failure to thrive, and chronic lung disease, was referred to our clinic by his primary care physician to evaluate aggression, screaming, and noncompliance. The parent interview was conducted during the clinic evaluation and revealed that Ian's behavior had improved with the start of medication, but problem behavior continued to occur in the context of demands. His mother used time out and redirection back to task to address the behaviors, but these strategies were ineffective. The information provided by Ian's mother during the ABC interview was consistent with an escape function for

problem behavior. We conducted the default treatment described earlier to address his non-compliance. The treatment began with a preference assessment to identify toys with which Ian enjoyed playing. After the preference assessment, a free-play condition was conducted as a warm-up period for the treatment package. After approximately 2 min of free play, Ian was informed that it was "time to work." If he transitioned to the work task, he was praised. If he continued to play, all toys were removed and he was directed to the task. During the work task, he was required to complete one task independently (e.g., trace one letter). When he completed the task, he received praise and access to toys and attention for several minutes. If Ian engaged in problem behavior, the prompt to complete the task was repeated and the correct response was modeled for him. The task remained present until Ian completed the task independently. The free-play and work-task conditions were alternated seven times.

The results of Ian's treatment evaluation are presented in Fig. 23.6. The open circles show the percentage of intervals that Ian engaged in problem behavior during each work-task trial and the closed circles show the percentage of intervals with problem behavior during the free-play trials. Ian engaged in problem behavior during the first four work-task trials only. A steady decrease in the amount of problem behavior occurred across trials to zero occurrences during the final three treatment trials. The amount of time required for Ian to complete the single task decreased from 60 s for the first two work-task trials to 12–18 s for the last three work-task trials. Although Ian engaged in high levels of problem behavior during the work-task trials, he immediately calmed down; problem behavior stopped after he completed each task, and no problem behavior occurred during the free-play trials. These results supported our hypothesis that problem behavior was maintained by escape from demands. The steady decrease in problem behavior observed during the treatment trials further supported the hypothesis that Ian's problem behavior was maintained by escape. Therefore, this strategy was recommended for use at home to further decrease Ian's problem behaviors when given task requests.

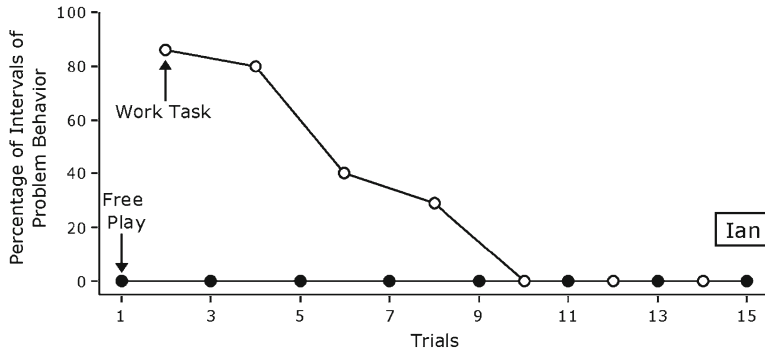


Fig. 23.6 Results of the brief treatment evaluation for Ian

Summary

In this chapter, we provided case examples representing some of the more common clinical analyses that we conduct in our behavioral clinics. Our preferred assessment, as shown in the first two case examples, is to conduct a functional analysis of problem behavior. The functional analysis can evaluate maintaining consequences, evocative antecedents, or both and in our view continues to be the “gold standard” for evaluating problem behavior. Even brief versions of functional analyses have been studied carefully and have been shown to be directly related to the development of effective treatments.

Antecedent evaluations are useful for studying some of the idiosyncratic relations that may occur between various environmental stimuli and problem behavior. In Fig. 23.4, for example, we provided an example of a child who resisted some demands but not others. When we receive reports of inconsistent responding, we consider the influence that antecedent variables may be having on behavior. For Mia, the results clearly showed that the type of prompt delivered was correlated with changes in behavior.

As discussed previously, a continuing concern with brief functional analyses is that a large percentage of children do not show problem behavior in the clinic setting. One approach that we have used is to conduct choice assessments to identify a child’s relative preferences. As shown

in Fig. 23.5, this approach can be highly effective in identifying response–reinforcer relations.

A final approach, and one that we are least likely to employ, is to conduct an analysis of a specific treatment package. As shown in Fig. 23.6, we are often successful in reducing problem behavior but not in better understanding the behavior.

We continue to advocate for direct assessments that are based on hypotheses. Indirect descriptive assessments such as ABC interviews can help us to focus on specific types of antecedent–response or response–consequence relations. Given the severe limitations imposed on an outpatient clinic, the more focused we can be, the more likely we are to identify behavioral relations. In addition, the analysis should be conducted within single-case experimental designs to improve the internal validity of the analysis. The design of the evaluations is then based on both the design itself and the behaviors observed. Multielement designs, like all designs, have certain rules that must be followed (e.g., counterbalanced or random order of conditions). However, we alter the design based on the behaviors that occur (e.g., the “mini-reversals,” Cooper et al., 1992). Thus, the designs are initially rule governed, but when the evaluation begins, they are also contingency driven. In this chapter, we have provided exemplars of the types of analyses we conduct and how we are able to use both hypothesis testing and single-case designs to improve the evaluations.

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Joel E. Ringdahl

Individuals with developmental disabilities are likely to engage in some type of problem behavior (Matson et al., 2010). At times, this problem behavior can be considered a danger to the individual (in the case of self-injurious behavior [SIB]), their care provider(s) (in the case of aggression), or their environment (in the case of property destruction). In addition, such behavior problems may result in limiting individuals' access to social, education, vocational, residential, and other important opportunities. A wide range of behavioral services exists to assist individuals who engage in severe problem behavior. These services include clinical options that range in intensity from brief outpatient to brief and extended inpatient services.

One unifying theme for each of these options is the reliance on a functional approach to both assessment and treatment. That is, these options typically include a functional analysis of problem behavior based on the methodology described by Iwata, Dorsey, Slifer, Bauman, and Richman (1982/1994). This assessment strategy allows for clinicians to identify the specific variables that occasion (i.e., antecedents) and reinforce (i.e., consequences) problem behavior. Once these variables are identified, function-based treatments can be designed and implemented during the relevant

situation(s) (i.e., antecedents) and incorporating the relevant reinforcer(s). Published research on this approach to treatment development has shown it to be an effective method for reducing severe problem behavior (e.g., Day, Rea, Schussler, Larsen, & Johnson, 1988) and for increasing the reliance on reinforcement-based treatment (Pelios, Morren, Tesch, & Axelrod, 1999). See Chap. 9 in this handbook for more detail regarding functional analysis.

Several large-scale clinical demonstrations have documented the efficacy of function-based assessment and treatment of severe problem behavior. For example, Iwata, Pace et al. (1994) provided epidemiological data related to the results of functional analyses of SIB for 152 individuals. Data from functional analyses and treatment outcomes were collected over an 11-year period. All of the assessments took place in one of two long-term placements: an inpatient setting (pediatric hospital) or a state residential facility. At least one behavioral function (social positive reinforcement, social negative reinforcement, or automatic reinforcement) was identified for 95.4 % of the sample. Additionally, successful implementation of a wide variety of function-based interventions was noted. Asmus et al. (2004) described similar outcomes for functional analyses and function-based treatments conducted in the context of a brief (i.e., 2 weeks) inpatient program. Specifically, these authors reported the identification of behavioral function for 96 % of their 138-person sample. A 90 % reduction in

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problem behavior during the last three sessions of treatment, compared to the baseline average, was obtained for 66% of the participants. This percentage increased to 76% when considering an 80% reduction in problem behavior, using the same comparison. In another example, Derby et al. (1992) provided a summary of the efficacy of functional analysis and function-based treatment strategies in an outpatient setting. A behavioral function was identified for 63% of their 79-case sample. This percentage increased to 74% when considering only individuals who exhibited problem behavior during the assessment. Positive treatment effects were observed with 84% of those individuals who engaged in problem behavior during the assessment.

Given the robust effectiveness of the functional analysis/function-based treatment approach to the assessment and treatment of severe behavior problems in long-term and short-term, inpatient and outpatient settings, the goal of this chapter is to describe a service-delivery model that lies between inpatient and outpatient services with respect to intensity, as it relates to time investment. This chapter will cover issues related to the referral process, clinical progression, and care provider training. Finally, data related to two individuals who received intensive outpatient services will be described.

Intensive Outpatient Services: An Overview

As indicated earlier, a wide range of service intensities exists to address the severe problem behavior exhibited by individuals with intellectual and/or developmental disabilities. These services may be as intensive as 24-h supervised observation, such as what is available in an inpatient admission, or as fleeting as a single, 1–2 h outpatient visit to a clinic-based service (see Chap. 23 in this handbook). Obviously, the full range of options is not necessarily feasible for every individual. Factors related to the severity of problem behavior, the constraints of insurance benefits, and the availability of services may determine which options are most appropriate, available, and/or realistic.

Some individuals may engage in problem behavior that, while disruptive, does not require the intensive 24-h supervision that comes along with an inpatient admission. Even in situations that include severe problem behavior, access to inpatient services may be limited due to community options and/or insurance coverage. In such situations, one viable option to consider if problem behavior has been unresponsive to an outpatient approach to treatment (i.e., one or several 1–2 h outpatient appointments) is enrollment of the individual in an intensive outpatient service that is clinic based and time limited.

Intensive outpatient services can be described as those services that fall somewhere between the intensity of services provided by an inpatient admission and the intensity of services found in a typical outpatient clinic. There are several similarities with respect to inpatient and intensive outpatient services. Intensive outpatient services, for example, take place during several, if not all, days of the week (with, perhaps, the exclusion of the weekend). Services on any given day may take place over the course of several hours. Likewise, there are similarities between intensive outpatient and more typical outpatient services. For example, both take place in a clinic-based setting, care providers are likely part of the assessment and treatment evaluation, and the services may take place over a defined or even predetermined amount of time. Kurtz et al. (2003) described one such intensive outpatient program. In their program, evaluations were conducted for 2–3 h during each visit, with visits occurring 2–3 times a week. Assessment and treatment evaluation was carried out over a 12- to 16-week period for any given individual. Similar to the studies previously described by Iwata, Pace et al. (1994), Asmus et al. (2004), and Derby et al. (1992), Kurtz et al. followed a function-based approach to the assessment and treatment of severe behavior problems. In their sample, a behavioral function was identified for over 87% of the patients served.

Intensive Outpatient Services: Referrals

Referrals to intensive outpatient services may be generated by a number of sources, including, but

not limited to, other clinicians (psychologists, psychiatrists, social workers, behavior analysts, etc.), educational professionals, residential and vocational service providers, and parents or guardians. Intensive outpatient services will likely represent a disruption to the patient's typical schedule and limit opportunities for ongoing academic education (or other learning), social activities, and family interactions. For this reason, the unifying characteristic for referred individuals is that behavioral strategies in a less-restrictive environment have been attempted with documented and limited effectiveness or failure.

There are several reasons that behavioral strategies may be limited in their effectiveness, including (a) the lack of development of a function-based treatment, (b) resistance of the problem behavior to treatment, (c) lack of consistent implementation of recommended treatments, and (d) lack of any implementation of recommended treatments. From the standpoint of referral to more intensive assessment and treatment settings, referrals will generally fall into categories (a) and (b). Referrals that fall into categories (c) and (d) should first go through the process of consistent implementation of treatment strategies to determine whether more intensive services are warranted. Certainly, there may be some situations that warrant different referral criteria. For example, if an individual is engaging in severe problem behavior that requires immediate attention, it may be more clinically expedient to refer that individual to an intensive outpatient service, as opposed to waiting for outpatient treatment failure. Similarly, there may be instances in which parents or other care providers can document that function-based treatment has been implemented well (i.e., with high treatment integrity; see Chap. 5 of this handbook), but limited success, outside of the context of outpatient clinic visits (e.g., a school psychologist conducted a functional assessment and implemented treatment, but behavior problems persisted). Factors related to the nature of the problem behavior also will also contribute to the decision to move toward more intensive services, as opposed to providing one or a disjointed series of 1–2 h outpatient visits. For example, the thorough assessment and treatment

evaluation of problem behavior that appears to be maintained by automatic reinforcement often requires an extended and varied functional analysis (see Vollmer et al., 1995 for an example) and treatment evaluation, not typically achievable in a brief, outpatient setting. Finally, social variables, such as care provider stress and impending changes in educational, vocational, or residential placement due to difficulty managing problem behavior, are clinical variables that can contribute to the decision to provide more immediate enrollment in intensive outpatient services.

Intensive Outpatient Services: Clinical Progression

There are several paths that could be followed regarding how a referral moves through an intensive outpatient service. The goal of this section of the chapter is to describe one such progression. This example is based on the intensive outpatient service that has been in place at the University of Iowa Hospitals and Clinics for much of the preceding decade. This particular progression includes pre-assessment collection of information (i.e., indirect assessment), preference assessment, functional analysis of problem behavior (and/or other relevant behavioral assessments), function-based treatment, and caregiver training on the implementation of treatment strategies.

Pre-Assessment

The first step in this clinical progression is to obtain clinically relevant information (e.g., topography of problem behavior, approximate frequency and settings, typical outcomes or management strategies, and previously attempted interventions and their results) regarding the behavior of interest. There are a number of ways to obtain this information. Direct observation of the referred individual would be the best method for obtaining at least a portion of this information. However, practical considerations (e.g., inability to leave the clinic setting to conduct such observations) often preclude this option. When direct observation is not an option, important pre-assessment information can be obtained

through interview(s) with the referred individual's parents and/or care providers (either in person or over the phone) and through a review of available records, including past medical and psychological reports, Individualized Education/Service Plans, and data collected by parents and educational, residential, and/or vocational service providers. The purpose of this information gathering process is to (a) allow the clinical team to develop initial operational definitions of the problem behavior, (b) develop hypotheses regarding the antecedents and consequences related to the problem behavior, and (c) identify what, if any, previous strategies have been attempted to address the problem behavior and their relative success. The pre-assessment process can vary from being relatively informal (e.g., using open-ended or structured interviews) to more formal (e.g., using indirect assessment tools, such as the Questions About Behavioral Function [QABF; Paclawskyj, Matson, Rush, Smalls, & Vollmer, 2000]). The main goal is to use the information to streamline the development of the formal assessment to be completed during the intensive outpatient evaluation. See Chap. 8 of this handbook for additional examples of informal and formal assessment tools.

Preference Assessment

Once information regarding the problem behavior has been obtained, direct assessments should be conducted. The first direct assessment to conduct is a stimulus preference assessment. A stimulus preference assessment is an assessment that is used to identify items and/or activities that may function as reinforcers for an individual's behavior. Clinicians can also use the results of such assessments to determine what stimuli should be included in the various conditions of the functional analysis of problem behavior (discussed later) that will be conducted. Because a stimulus preference hierarchy (i.e., high preferred, moderately preferred, and low preferred) is more useful than simply identifying a preferred stimulus, stimulus preference assessment formats that lend themselves to this type of outcome should be conducted. For example, the paired-choice (PC) assessment as described by Fisher et al. (1992) or

the multiple stimulus (MS) assessment described by DeLeon and Iwata (1996) may be the best options. That said, the decision regarding what type of preference assessment is conducted will be affected by the available information regarding problem behavior. Kang and colleagues have recently published a set of two studies demonstrating that behavioral function can interact with preference assessment format and affect the level of problem behavior exhibited during such assessments (Kang et al., 2010; Kang et al., 2011). Of particular interest is the relationship between problem behavior maintained by tangible positive reinforcement and the PC and MS format. If the information obtained during the indirect assessment suggests a tangible positive reinforcement function, the clinician may choose to avoid PC or MS assessments, as these formats may be evocative of problem behavior maintained by tangible positive reinforcement. In this scenario, a free-operant (FO) assessment as described by Roane, Vollmer, Ringdahl, and Marcus (1998) will be a better option. Time needed to complete the stimulus preference assessment will also play a role in determining which format to use. The FO format typically can be completed in 5 min, while the PC and MS formats require significantly more time (over 20 min; Roane et al.).

Functional Analysis of Problem Behavior

During the initial intensive outpatient visit, the care provider should be informed about the purpose of the assessment procedures that will be used, particularly if a functional analysis of problem behavior is to be conducted. Some steps to follow include emphasizing the assessment nature of the functional analysis, providing the care provider with a description of the various behavioral assessments including a description of the functional analysis conditions that will be conducted, obtaining informed consent to assess and treat, and assuring the care provider that ongoing "coaching" from clinical staff will be provided. It is important to explain to the care provider that problem behavior is likely to be exhibited during this type of assessment, the benefit of observing the behavior (i.e., the determination of behavioral function

and, subsequently, development of treatment), and the protective measures (discussed later) that will be in place during the functional analysis.

Following the stimulus preference assessment, assessment of the problem behavior should begin. In many cases, this assessment will include a functional analysis of problem behavior. While it is beyond the scope of this chapter to provide a detailed description of functional analysis as an assessment methodology, some points bear discussion. Functional analysis as a method for assessing severe problem behavior has emerged over the past 30 years as the standard assessment of such behavior. This strategy allows for the identification of the relevant response–reinforcer relationships maintaining problem behavior, thus providing prescriptive information related to the development of effective treatment strategies (Day et al., 1988) and reducing the reliance on punishment-based treatments (Pelios et al., 1999). The assessment has been demonstrated to be effective in identifying the variables maintaining a multitude of commonly encountered problem behavior, including SIB (Iwata, Dorsey et al., 1982/1994), aggression (Northup et al., 1991), tantrum (Vollmer, Northup, Ringdahl, LeBlanc, & Chauvin, 1996) bizarre speech (Mace & Lalli, 1991), vocal stereotypy (Ahearn, Clark, MacDonald, & Chung, 2007), and destructive behavior (Coleman & Holmes, 1998).

Procedural Considerations for the Functional Analysis of Problem Behavior in Intensive Outpatient Settings

Functional analyses of problem behavior can be conducted using a variety of experimental designs and procedures. However, given the additional time available to work with a patient in an intensive outpatient setting, relative to an outpatient clinic visit, the approach described in the seminal study describing functional analysis of SIB (Iwata, Dorsey et al., 1982/1994) is the best option. This process is the standard against which variations of the assessment are measured (e.g., Kahng & Iwata, 1999), and the base from

which extensions are launched (e.g., Vollmer, Marcus, Ringdahl, & Roane, 1995).

When using the Iwata, Dorsey et al. (1982/1994) procedures as a basis, questions regarding the specific implementation of the functional analysis may still exist. These questions may be related to how long sessions should last, who should serve as the therapist (i.e., the individual in charge of implementing the procedures, including delivering the programmed contingencies), and when changes to the assessment design should be made. Functional analysis research conducted over the past 30 years has addressed each of these questions, and can be incorporated into the development of assessments to be used in the intensive outpatient clinic. For example, Wallace and Iwata (1999) evaluated the influence of session length on functional analysis outcomes. The results of functional analyses that included session lengths of 5, 10, and 15 min were compared to each other for internal consistency. Results of this study suggested that there was virtually no difference between the 10- and 15-min functional analysis sessions. Additionally, minimal differences were reported if the session length was only 5 min. Several researchers have published data demonstrating the utility of 5-min sessions. For example, Asmus et al. (2004) used 5- or 10-min session lengths in the functional analyses conducted for the 100+ individuals in their study. As noted previously, behavioral functions were identified for almost all of the referred individuals' problem behavior.

Shorter session lengths may have at least two practical benefits. First, there may be fewer dangerous behaviors exhibited which may result in fewer sessions reaching termination criteria. Fewer interruptions in the assessment should result in being able to conduct more sessions, thus arriving at a conclusion sooner, and implementing treatment sooner. Second, shorter sessions may limit access to potential reinforcers (i.e., programmed consequences), thus maintaining the motivating properties of those reinforcers and reducing the likelihood of variations in response rate due to satiation. An additional benefit of shorter session lengths is that there will be limited response–reinforcer pairings, setting

the occasion for quicker treatment effects. Given the demonstrated utility of 5-min sessions and their potential benefit, one strategy to follow includes taking a graduated approach to session length. Specifically, begin the functional analysis of problem behavior using 5-min session durations. Session duration can be increased if no problem behavior is observed during the first two or three applications of each condition.

In the last decade or so, there have been a number of studies related to the role of therapist selection in the outcomes of functional analyses of problem behavior. Several studies have demonstrated that differentiated results can be obtained when clinic staff conducts the functional analyses of problem behavior. For example, a graduate student or inpatient unit staff member, trained in the implementation of functional analysis methodology conducted each of the assessments described by Iwata, Pace et al. (1994). Results of this study indicated an identifiable function of problem behavior for 95.4% of the cases. Similarly, other studies have demonstrated the utility of incorporating parents as therapists during functional analyses of problem behavior. For example, Wacker et al. (1998) reported the results of functional analyses of problem behavior conducted in the homes of 28 children. In most cases (22 of the 28), a parent assumed the role of session therapist with coaching from a clinician or member of the research team. Results of this study indicated that identifiable functions of problem behavior were identified for 86% of cases. Finally, several studies have evaluated the differences brought about as a function of who implemented the functional analysis sessions. Ringdahl and Sellers (2000) demonstrated that behavioral function and response levels fluctuated, depending on who conducted the functional analysis sessions (clinic staff or care providers). Huete and Kurtz (2010) obtained similar findings. Specifically, Huete and Kurtz found that functional analyses of problem behavior conducted by clinic therapists yielded no responding from the patient, failure to identify a particular variable maintaining problem behavior, and decreased response rates as compared to those functional analyses conducted by the patients' parents.

These results were obtained across five children, ranging in age from 2 to 5 years.

Given the limited time available for behavioral assessment with this intensive outpatient model relative to assessments in more time-intensive environments, clinicians may want to incorporate a familiar care provider as therapist when practical. The care provider presumably has a longer history with the referred individual and likely has an established history of providing reinforcement for the target behavior. Thus, assessment may yield clear results more quickly due to already established discriminative control of problem behavior. That said, there are at least three conceivable situations that may call for the care provider's participation in the assessment sessions to be limited. First, inclusion of the care provider should be carefully considered, and perhaps limited, if the problem behavior puts the care provider at undue risk. Second, a care provider should refrain from participating in the assessment if the assessment process is simply too overwhelming for the care provider. In such a situation, it is possible for the care provider's fidelity with assessment to be hampered, or their ability to conduct a thorough functional analysis to be compromised. Third, behavior may be under "good" control in one environment (e.g., home), but poor control in another (e.g., school). If the parent is the one accompanying the patient to the intensive outpatient visits, and is only associated with the home environment where behavior is under "good" control, it makes more sense to have clinic staff conduct the sessions. In such situations, this strategy will avoid the development, or renewal, of a history of reinforcement for problem behavior with the home-related care provider.

Functional Analysis Conditions

The original description of functional analysis methodology as an assessment for SIB (Iwata, Dorsey et al., 1982/1994) included three test conditions (attention, demand, and alone) designed to evaluate the impact of social positive, social negative, and automatic reinforcement. In the almost

30 years since the publication of that study, numerous test conditions have been developed in an attempt to individually tailor the assessment. For example, test conditions assessing the influence of contingent access to tangible items (Day et al., 1988) and social avoidance (Vollmer et al., 1998) have been developed. Additionally, some researchers (e.g., Call, Wacker, Ringdahl, & Boelter, 2005) have developed functional analysis conditions that combine multiple antecedents, instead of presenting single antecedents as was done by Iwata et al. Other researchers have developed test and control conditions to address hypothesized variables unique to an individual (e.g., Ringdahl, Christensen, & Boelter, 2009).

The decision regarding how to structure any given individual's functional analysis, including what conditions to use, should be based on the information detailed in the indirect assessment and the information obtained from the care provider at the outset of the evaluation. Doing so has at least two benefits. First, tailoring the assessment conditions allows for variables that may not otherwise have been tested to be included in the assessment. This process may increase the likelihood of a true positive outcome. For example, Call et al. (2005) described the development of functional analysis conditions that included a combination of various antecedents. These combinations were based on the results of descriptive analyses or previous assessments. However, without the inclusion of these combined antecedent conditions, the variables maintaining the participants' problem behavior would not have been identified. Second, leaving out test conditions that are unlikely to be related to any given individual's problem behavior allows the assessment to progress more quickly, and limits the potential of false-positive outcomes (Rooker, Iwata, Harper, Fahmie, & Camp, 2011).

Interpretation

The determination of a behavioral function is typically made based on visual inspection of a graphic depiction of the obtained data (Hanley, Iwata, & McCord, 2003). When inspecting a graph, a behavioral function is indicated when

responding in a test condition is consistently elevated above responding in the control condition (often, the *free play* condition). If a functional relation exists, data paths for the test and control conditions should have little, if any, overlap. It should be noted that more than one function could be identified for any individual's problem behavior, as illustrated by the results reported by Asmus et al. (2004). In their sample, 40 % of individuals engaged in problem behavior maintained by both social negative and social positive reinforcement. An additional 8 % engaged in problem behavior maintained by automatic reinforcement and one or more additional sources of social reinforcement. It should further be noted that, when multiple functions are identified, levels of responding will often differ from one test condition to another. However, the indication of function is based on the comparison of each test condition to the control condition, and not the comparison of one test condition to another.

Other Considerations Related to Functional Analyses of Problem Behavior

Often, the behavior of concern will be one that has the potential to result in injury to the individual, care providers, or clinic staff. In such situations, session-termination criteria should be developed to assist with decisions regarding when and if assessment should be halted. There are several resources that can assist with the development of such criteria. For example, in the original article describing the utility of functional analysis as an assessment for SIB, Iwata, Dorsey et al. (1982/1994) described session-termination criteria that included input from the individuals' physician. Each participant's termination criterion was, "...expressed in terms of either degree of injury or level of responding or both" (p. 199). In addition, medical advice was sought regarding the continuation of assessment if termination criterion was met. Finally, medical staff reviewed assessments on an ongoing basis during the functional analysis. Decisions regarding session

termination will need to take into account specific institutional guidelines, and should be geared toward maximizing protection of the individual, care providers, and staff, while obtaining useful information regarding the function of behavior and maintaining ethical standards regarding the practice of Applied Behavior Analysis and Psychology.

Hanley et al. (2003) provided a comprehensive review of the literature related to functional analysis of problem behavior. The reader is directed to this review as an excellent reference that further addresses issues related to the complexities of designing, conducting, and interpreting functional analyses of problem behavior.

Treatment Evaluation

Once the functional analysis of problem behavior has been completed, treatment strategies can be implemented and evaluated. It should be noted that the focus of the clinical services should be on obtaining clear results during the functional analysis of problem behavior in a time-limited scenario such as an intensive outpatient service. Thus, if the initial foray into the functional analysis of problem behavior does not yield clear results, making modifications to the conditions and procedures is warranted until (a) a clear function(s) is identified, or (b) it becomes reasonable to determine that contextual or other variables will preclude successful identification of a function(s) in the clinical setting. The reason for this emphasis is the importance functional analysis results have for designing treatment. Without definitive understanding of the functional variables related to problem behavior, treatment design is a best guess, and the likelihood of success diminishes.¹

¹ When possible, the best way to evaluate the effects of the designed treatment is within the context of a single-subject experimental design. However, several limitations, including (a) care provider willingness to reverse to nontreatment conditions after treatment effects have been observed, (b) ethical considerations related to that same point, (dangerous effects of the

Treatment Options

Once the function of problem behavior is identified, there are several treatment options that can be explored. The particular treatment selected will vary based on the goals for the individual. In general, though, treatment should consist of an extinction component for problem behavior based on the identified function, and a reinforcement component to develop, increase, and/or maintain appropriate behavior. At least three options for treatment approaches exist: extinction-based treatments, noncontingent reinforcement (NCR)-based treatments, and differential-reinforcement (DR)-based treatments, among others. While the details of these treatment options are beyond the scope of this chapter, a brief description of their advantages and disadvantages will be provided.

Extinction-Based Treatments

Perhaps the most straightforward approach to changing problem behavior is to place it on extinction (i.e., withhold the functional reinforcer following occurrences of problem behavior). While such approaches to treatment can be effective (e.g., Iwata, Pace, Kalsher, Cowdery, & Cataldo, 1990) and simple to implement, they may result in temporary increases in problem behavior (Lerman, Iwata, & Wallace, 1999) and do not program explicitly for the teaching or expression of alternative, appropriate behavior (though, incidental increases in appropriate behavior such as compliance have been noted, as described by Iwata et al.).

NCR-Based Treatments

An option that may alleviate some of the side effects of extinction but still be simple to implement involves the noncontingent or

problem behavior), (c) time remaining in the evaluation period, and (d) other treatment-relevant choices such as training for generalization and/or care provider training, may make this goal difficult to achieve for every patient. These issues will need to be balanced with the pursuit of experimental control during treatment evaluation.

response-independent delivery of the functionally relevant reinforcer(s). Such treatments have been demonstrated to reduce responding when the time-based schedule of reinforcement is either more dense or leaner than the pretreatment schedule of reinforcement (Ringdahl, Vollmer, Borrero, & Connell, 2001). One drawback of NCR is the potential for inadvertent reinforcement of problem behavior (e.g., Vollmer, Ringdahl, Roane, & Marcus, 1997) if scheduled reinforcer deliveries coincide with problem behavior. This drawback can be addressed by requiring that no problem behavior occur during a short window of time just prior to reinforcer delivery. However, such a change introduces a contingency, and may increase the complexity of the program. A second drawback to NCR-based treatments, similar to extinction-based treatments, is that they do not explicitly program for the acquisition or exhibition or appropriate alternative behavior. However, also similar to extinction-based treatments, appropriate behavior has been reported in NCR-based treatments (e.g., Coleman & Holmes, 1998).

DR-Based Treatments

A third treatment option involves differentially providing functional reinforcers following the occurrence of appropriate behavior (e.g., compliance and communication) or following the omission of problem behavior (i.e., differential reinforcement of other [DRO] behavior). This approach to treatment can be more difficult to implement than extinction and NCR, but has the advantages of reducing extinction-related side effects and promoting the acquisition and exhibition of appropriate behavior. Several examples of such treatments exist in the behavioral literature. One particularly effective example is functional communication training (FCT; Carr & Durand, 1985). This approach to treatment consists of differential reinforcement of an appropriate, communicative response using the functional reinforcer(s) identified during the functional analysis of problem

behavior. A number of studies have been published demonstrating the effectiveness of this treatment (see Tiger, Hanley, & Bruzek, 2008 for a review). The approach works best when extinction for problem behavior, or some other reductive procedure, is included (Hagopian, Fisher, Sullivan, Acquistio, & LeBlanc, 1998), and has been demonstrated to be effective across a wide variety of communication response topographies (Hagopian et al.).

Other Treatments

Certainly, other treatment approaches and components exist and should be included as deemed necessary or desired. Reductive procedures such as response cost (RC; Athens, Vollmer, Sloman, & St. Peter Pipkin, 2008) and time out from positive reinforcement (TO; Hagopian, Bruzek, Bowman, & Jennett, 2007) have been demonstrated to be effective in the treatment of severe problem behavior. Their effects are likely improved when the stimuli removed during RC, or limited during TO, are functionally related to problem behavior.

It may also be helpful to incorporate antecedent strategies into treatments designed to reduce problem behavior. A number of these procedures have been demonstrated to be effective, and one (NCR) has been described in this chapter. Other examples of antecedent-based treatments include stimulus control procedures (e.g., Anglesea, Hoch, & Taylor, 2008), various prompting procedures (e.g., Shabani et al., 2002), and choice procedures (e.g., Thompson, Fisher, & Contrucci, 1998).

Finally, treatment strategies can be combined to develop comprehensive treatment packages. For example, Reed, Ringdahl, Wacker, Barretto, and Andelman (2005) combined NCR and DR (compliance) in the successful treatment of two individuals' escape-maintained problem behavior. The NCR component was used to decrease motivation to engage in the escape-maintained problem behavior, and the DR component was used to establish and increase compliance with the delivered instructions.

Care Provider Training

Once treatment strategies have been demonstrated to be effective, and clinicians are confident in their applicability, care providers can be trained to implement them. When care providers have been included in the entirety of the intensive outpatient process, training needs will likely be reduced. However, in situations that preclude ongoing participation on the part of specific care providers, as is often the case with educational or vocational setting staff members, time should be set aside to explicitly teach the procedures. One approach in such situations is to follow a progression from a verbal description of the evaluation to in vivo practice implementing the treatment strategies. This progression includes:

Step 1: Discuss the findings of the functional analysis and treatment evaluation with the care provider. Of particular importance is pointing out the relevance between the findings of the functional analysis and the development of the treatment strategies. One strategy to follow during this step is a careful review of graphed data. Often, the picture provided by the graph will make the functional relation clear to the care provider, and enhance their understanding of the treatment rationale.

Step 2: Describe the treatment procedures step-by-step to the care provider. This description should be accompanied by a written description of the treatment and include an opportunity for questions and clarifications, as needed.

Step 3: Require that the clinic therapist (or, whoever has been implementing treatment to that point) demonstrate the treatment strategies in vivo with the patient while allowing the care provider to observe and ask questions.

Step 4: Require the care provider participate in the in vivo demonstration of the treatment procedures. This step can be further broken down into three smaller steps. First, have the clinic therapist conduct the treatment with the care provider in the therapy room shadowing the therapist (one option is to have the care provider deliver the reinforcers at this stage). Second, have the clinic therapist and

the care provider take turn implementing trials. For example, during instructional situations, the clinic therapist delivers the first instruction and delivers the first reinforcer. The care provider delivers the next instruction and the next reinforcer. The therapist and care provider alternate implementing the procedure, with therapist feedback to the care provider, for the remainder of the treatment sessions. Third, have the care provider conduct the procedures with clinic staff watching from across the therapy room, or in an adjacent observation area, and providing feedback to the care provider.

These steps approximate the steps involved in many behavioral skills training (BST) programs. Such programs have been demonstrated to be successful in teaching children particular skills (e.g., Himle, Miltenberger, Flessner, & Gatheridge, 2004), teaching staff members how to conduct behavioral assessments (e.g., Lavie & Sturmey, 2002), and teaching adults to implement FCT systems (Rosales, Stone, & Rehfeldt, 2009). Certainly, other strategies for training care providers exist, and should be used depending on clinical variables and constraints. See Chap. 5 of this handbook for descriptions of various training techniques.

Case Examples

This section of the chapter provides two examples of clinical cases completed by an intensive outpatient service. Case 1, Farah, was a 16-year-old girl diagnosed with autism, moderate intellectual disability, and disruptive behavior disorder not otherwise specified (NOS). Farah was referred by her school district for assessment and treatment of problem behavior, specifically aggression. Several attempts had been made by Farah's school and district to conduct a functional assessment and implement function-based treatment. However, at the time of referral, Farah continued to engage in aggression and, due to the disruptive nature of the problem behavior, was receiving educational services at a district building with district personnel, as opposed to in her assigned school building with assigned teachers.

Prior to beginning the intensive outpatient services, an interview was conducted with educational service providers. This interview suggested that Farah's problem behavior was occasioned by delivery of academic instructions. They further indicated that Farah sometimes attempted to avoid any type of interaction, not just academic. They reported no identifiable preferred items, and Farah did not appear to be interested in interacting with leisure stimuli in the education setting.

Upon initiation of the intensive outpatient services, a free-operant preference assessment (Roane et al., 1998) was conducted using stimuli available in the therapy room (e.g., leisure items such as tactile, auditory, as visual stimuli, games, puzzles). Farah did not approach these items during the assessment.

A functional analysis of aggression was then conducted. Conditions included in the functional analysis consisted of free play, ignore, academic escape, attention, and social escape. During the *free play* condition, the therapist allowed Farah to do what she wanted in the room (e.g., interact with available activities, sit at the table, or walk around the room). No instructions were presented. Additionally, no interaction was provided unless Farah initiated interaction by coming into close proximity with the therapist. There were no programmed contingencies for aggression. During the *ignore* condition, Farah and the therapist were alone in the room with no alternative items. The therapist sat by the door to the room, no instructions were delivered, and no interaction took place. There were no programmed contingencies for aggression. The therapist delivered instructions using a three-prompt, graduated-guidance (verbal, model, physical) procedure every 30 s during the *academic escape* condition. Instructional materials included those currently being used in Farah's academic environment. Contingent on aggression, the therapist would remove instructional materials for 30 s and immediately terminate the prompt sequence. No alternative items and no attention were delivered during the 30-s breaks. During the *attention* condition, the therapist began the session by removing attention and directing Farah to an activity (e.g., "I'm busy, you can play with the puzzle."). Contingent on aggression, the therapist

provided 30 s of attention in the form of redirection or mild reprimands. The *social escape* condition consisted of the therapist providing ongoing attention to Farah in the form of conversation and close proximity. Contingent on aggression, the therapist would cease the interaction for 30 s and move a few steps away from Farah. No instructions were presented during this condition. Sessions lasted 5 min and the functional analysis of aggression was completed in 44 sessions (3 h and 40 min spread over the course of 5 days).

Figure 24.1 displays the results of the Farah's functional analysis of aggression. Aggression occurred at some level in each of the conditions. However, elevations in responding relative to the free play and ignore conditions were noted in the academic escape, attention, and social escape conditions. These conditions were then targeted for treatment.

Farah's treatment consisted of FCT. Specifically, in each of the conditions functionally related to problem behavior, the same establishing operations were put in place (e.g., academic instruction, close proximity and interaction, or diverted attention, depending on the condition). However, the contingency was altered such that aggression resulted in extinction (i.e., continued presentation of the academic task, continued interaction of the therapist, or diverted attention, depending on the condition). The therapist prompted a simple, appropriate communicative response (touching a laminated card that specified "break," "leave me alone," or "talk to me"), and Farah's exhibition of the response resulted in a 30-s presentation of the programmed reinforcer (e.g., break from demand, cessation of social interaction, or attention).

Figure 24.2 displays treatment results in a multiple baseline across functions arrangement. Implementation of FCT resulted in decreases in aggression for each of the identified functions. It should be noted that behavior was more variable during the social escape FCT and attention FCT conditions, relative to the academic escape FCT condition. This variability may have been a by-product of the dichotomous nature of these two conditions. We could not control when Farah was motivated for isolation or attention.

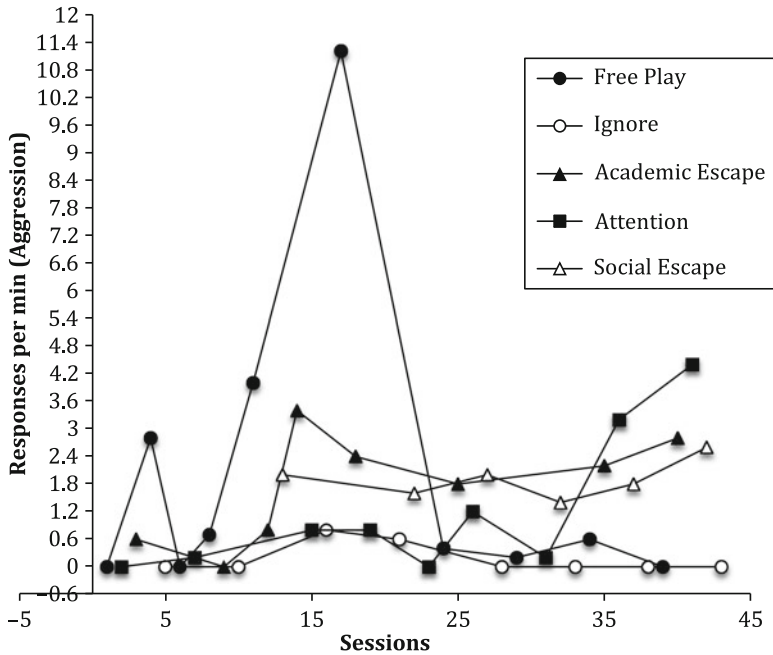


Fig. 24.1 Responses per min of aggression exhibited by Farah during the free play (closed circles), ignore (open circles), academic escape (closed triangles), attention (closed squares), and social escape (open triangles) conditions of her functional analysis

We contrived the establishing operation (EO) at the outset of the session (by either providing or diverting attention) and indicated to Farah verbally and through the presence of the unique communication card what reinforcer was available. It is possible that the available consequence did not match the specific EO Farah was experiencing when the sessions were conducted.

Following several days of implementation of the treatment strategies, Farah’s education team attended sessions to learn the various strategies. The education team was first shown the data from both the functional analysis and treatment evaluations. Next, the education team observed a clinic therapist implement the treatment. Members of the education team responsible for implementation of academic and behavioral programs then joined the therapist with Farah. The clinic therapist implemented the treatments with the team member present then faded out participation. Fading was conducted by first alternating presentations of the relevant EOs and reinforcers. Next, the education team member conducted the sessions with the clinic therapist in close proximity

to provide direct feedback. Finally, the education team member conducted the sessions with the clinic therapist either at the far side of the room, or watching from an adjacent observation room. Educational team members attended sessions across a 2-day period at the end of the intensive outpatient process, and were included in the wrap-up meeting during which time they could ask questions regarding clarification and implementation of the treatment strategies. Farah’s behavior remained appropriate during care provider training. However, it is not uncommon to observe increases in problem behavior during care provider training, particularly when care providers are attending sessions for the first time at the conclusion of the intensive outpatient process. In fact, we commonly alerted care providers to this distinct possibility.

Case 2, Nancy, was a 19-year-old young woman diagnosed with autism, moderate intellectual disability, stereotyped movement disorder with SIB, and disruptive behavior disorder NOS. Nancy had a lengthy history of services from the behavioral clinic, having previously been seen to address

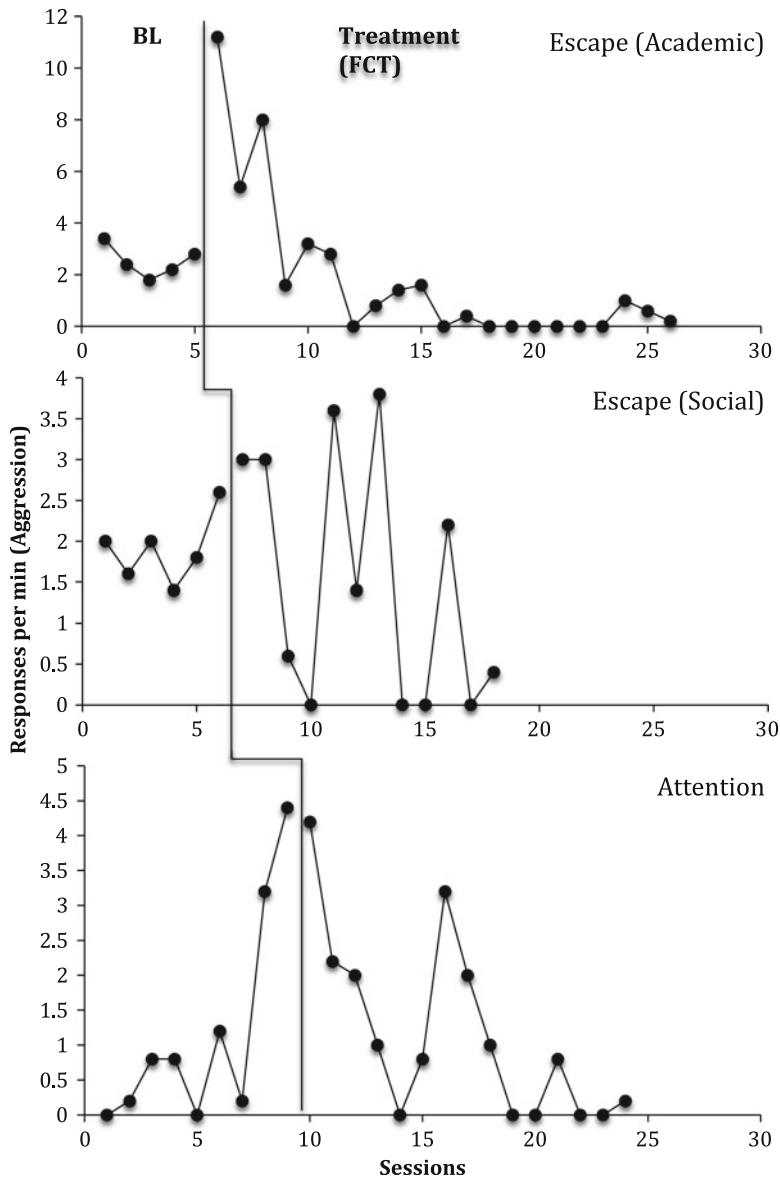


Fig. 24.2 Responses per min of aggression exhibited by Farah during baseline (BL; taken from the functional analysis) and FCT phases of her treatment evaluation for each identified behavioral function

attention-maintained SIB in both the home and school settings. Nancy’s parents initiated the referral after the function of her SIB appeared to change. In particular, Nancy’s parents indicated that SIB was occurring frequently during instructional situations. Antecedent-based approaches to addressing the SIB (e.g., structured picture schedule) had not helped decrease the behavior. Thus, Nancy

was scheduled for evaluation with our intensive outpatient service. Upon initiation of the intensive outpatient services, a free-operant preference assessment (Roane et al., 1998) was conducted to identify preferred items for inclusion in the various assessment sessions. Music, puzzles, and cars were identified as highly preferred, whereas a koosh

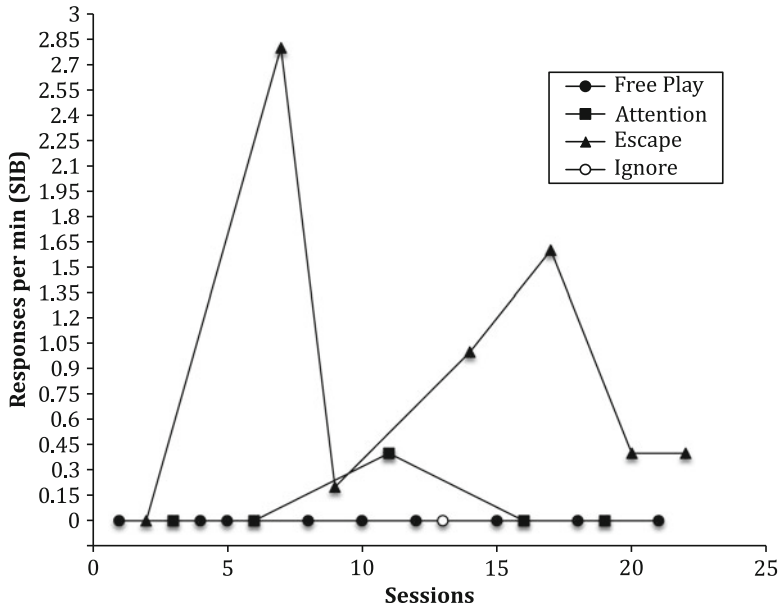


Fig. 24.3 Responses per min of self-injurious behavior (SIB) exhibited by Nancy during the free play (closed circles), attention (closed squares), escape (closed triangles), and ignore (open circle) conditions of her functional analysis

ball and pin toy was identified as low-preferred items.

A functional analysis of SIB (elbow banging; striking either elbow against a hard surface) was conducted. Conditions included free play, ignore, escape, and attention. The procedures were similar to those described for Farah. However, during the *free play* condition, the therapist engaged with Nancy on a response-independent, ongoing basis. Highly preferred items were included in the free play condition, while low-preferred items were available during the *attention* condition. Tasks included in the *escape* condition were those identified by Nancy’s parents and school as relevant.

Figure 24.3 displays the results of Nancy’s functional analysis. Problem behavior was consistently exhibited during the escape condition, while rarely or never exhibited during the remaining conditions. Thus, treatment was developed to address the negative reinforcement function of Nancy’s SIB.

Treatment consisted of several components. First, instructions were presented as they were during the functional analysis escape condition. Contingent on compliance, Nancy was presented

with a choice of requesting a break (using either the manual sign “break” or touching a “break” card) or requesting another instruction using the manual sign “more.” Extinction was in place for SIB throughout treatment.

Figure 24.4 displays the results of Nancy’s treatment evaluation. An immediate decrease in SIB was observed following the implementation of the treatment procedures. In addition, Nancy exhibited elevated and steady rates of appropriate requests for break. Requests for more work were not exhibited.

Nancy’s parents participated in all sessions, including the functional analysis and treatment implementation. They were responsible for implementation of all sessions with coaching from a clinic therapist, and could do so with good procedural fidelity. The overall length of the parents’ availability was limited due to work schedules and home responsibilities. This limitation highlights one of the challenges to providing such short-term services. Ideally, evaluation of the treatment effects would take place within the context of some type of single-subject experimental design. However, the parents felt convinced

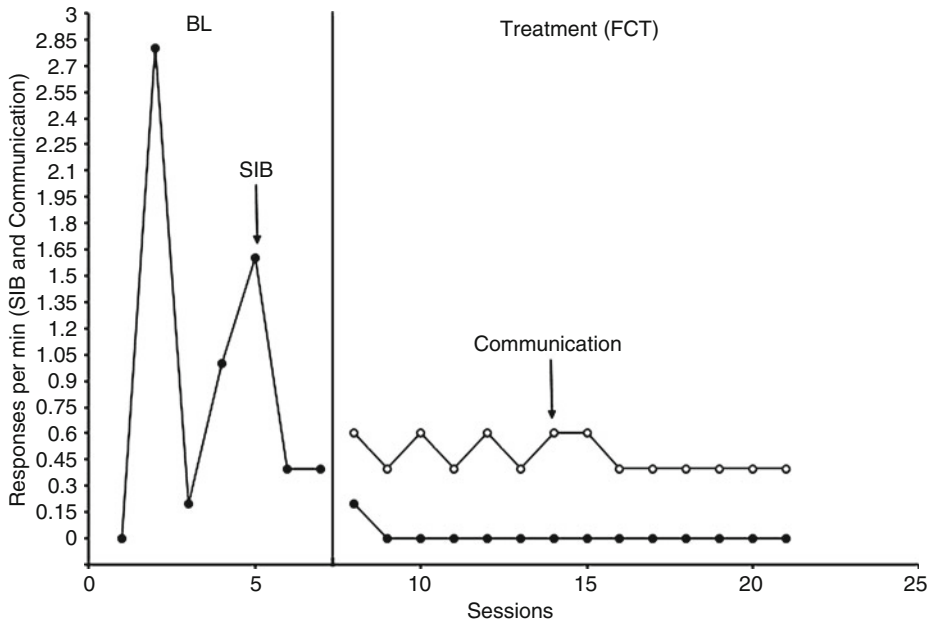


Fig. 24.4 Responses per min SIB (*closed circles*) and appropriate communication (*open circles*) exhibited by Nancy during baseline (BL; taken from the functional analysis) and Treatment (FCT) phases of her treatment evaluation

regarding the effects of the treatment evaluation, having participated in similar evaluations with Nancy in the past, and wanted to end the intensive outpatient services as soon as possible. Given that clear results were obtained in the functional analysis of SIB, clinic staff agreed that Nancy's treatment should continue in the home environment with parents implementing the procedures learned during the course of the evaluation.

Summary

The assessment and treatment of problem behavior continues to be an important clinical endeavor, particularly for individuals with developmental disabilities (Matson et al., 2010). There are a number of different service options available that range in intensity from outpatient visits to inpatient admissions. Sitting in the middle of this continuum is the intensive outpatient service model. This model has proven useful for individuals who have not benefitted from, or are unlikely to benefit from, outpatient services, but whose problem behavior does not warrant the intensive

observation available during inpatient admissions, or for whom an inpatient admission is not an available option.

A model related to clinical progression was provided. However, there are any number of specific assessment strategies, treatment evaluation methods, and care provider training procedures that could be employed in such a setting. What is of greatest importance is that the approach taken related to the delivery of intensive outpatient services is based on a functional approach to the assessment and treatment of problem behavior: an approach that carries with it almost 30 years of empirical evidence of its utility.

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Do Good, Take Data, Get a Life, and Make a Meaningful Difference in Providing Residential Services!

25

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An Introduction to Dragon-Wrestling 101

Giving Due

The chapter title and the introduction title are tributes to the four publications that may best describe the principles and beliefs blended into the development of best-practice community services (i.e., Hart & Risley, 1995; Risley, 1996, 2001; Wolf, Kirigin, Fixsen, & Blasé, 1995). They are essential reading directly from the masters of their craft for those who wish to attempt to build an effective community support program. Much has come from their work and much is owed to the quality of life they have made possible by their achievements. Each reading unpacks a clearer vision for what may need to be done and why.

With these publications as a backdrop, this chapter will focus on important program design components of effective community living models that support people with a wide range of developmental disabilities. The models that we describe

may not be familiar to most readers; as a result, this chapter will provide a brief historical overview of our partnership before highlighting the current and ever-evolving services we offer such as the Family Teaching Model (FTM), Extended Family Teaching Model (EFTM), and HomeLink Support Technologies (HomeLink).

About the CLO/KU Applied Behavioral Partnership

Community Living Opportunities (CLO) was founded in 1977 by professors from the Department of Human Development and Family Life (now Applied Behavioral Science) at the University of Kansas (KU) and a group of families who had family members with multiple severe developmental disabilities. From these very small beginnings, CLO has grown to become a sizable and highly regarded service provider, meeting the needs of over 485 adults and children on an annual budget of approximately \$22 million dollars. Additionally, CLO has helped develop over \$65 million dollars of annual budgeted community living services by creating sister organizations in multiple states, primarily to help develop community living opportunities for people leaving state-operated institutions that were closed or downsized.

The CLO/KU partnership has spanned over three decades of research and development activities that have contributed to the development,

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use, revision, and dissemination of CLO's service models. CLO has many programs, services, and support models, which are described in detail at www.clokan.org and www.homelinksupport.com. Space does not permit us to describe all of these in the present manuscript.

A Brief Overview of CLO's Family Teaching Model and HomeLink Support Technologies

The roots of CLO's FTM and EFTM models are buried deep in its KU partnership. The FTM began as an adaptation of the Teaching-Family Model, created by the Achievement Place Training Project at KU (Wolf, Phillips, & Fixsen, 1972). From these beginnings and with the help and mentoring of the founders of the Teaching-Family Model at Achievement Place, CLO's version took form and has been adapted and revised for over three decades and across multiple agency disseminations.

Before discussing what we believe are some of the important factors for providing high-quality and effective community services, it may be best to very briefly describe CLO's FTM, EFTM, and HomeLink program. Details and examples of these programs will be increasingly provided as important components of a program design are discussed.

Family Teaching Model

With the FTM, a family teaching couple (FTC) and their family live adjacent to three or four people with developmental disabilities in an adjoining home and provide support. The homes are typically duplexes with two separate living arrangements, often connected by a door to allow the FTC access to the home of persons receiving support (herein, clients). We require the FTC to live in the adjoining home; as a result, their only job is to serve the clients as a live-in FTC. The FTCs have four general responsibilities: (1) they are the on-site manager of the home; (2) they coordinate, arrange, access, and provide community living, health, adaptive, and behavioral care for the clients; (3) they are the primary liaison

with families and guardians; and (4) they supervise all support and relief staff providing services on evenings and weekends. As a requirement of employment, the FTCs must be certified annually by CLO/KU. This certification includes workshop and seminar didactic training; monthly in-home coaching and mentoring by an experienced "coach"; practice evaluations of the implementation of key processes and achievement of important person-centered outcomes; and achieving high expectations on in-depth, independently conducted professional and consumer evaluations.

Extended Family Teaching Model

The EFTM is essentially a very specialized adult foster care program (CLO has a children's foster version of this program, too). It functions and operates almost identically to the FTM program as described above, with the following exceptions: (1) only one or two clients are typically supported in an EFTM home; (2) the clients live with the extended family teachers (EFTs) and their family in one home (often owned or leased by the EFTs); (3) although the EFTs complete the same training, coaching, and annual certification requirements as the FTCs, the EFTs participate in additional training and meet additional requirements for foster placements; and (4) EFTs are paid as independent contractors rather than as employees of the organization. This program was called the EFTM simply because it was viewed as an extension of the FTM previously described. The majority of EFTs were previously FTCs, direct care employees, home coaches, or clinicians at CLO who had long-term relationships with one or possibly two persons they helped to support. For an EFTM placement to occur, the family/guardian, the client, CLO, and the prospective EFT must agree to the placement. Additionally, the prospective EFT must participate in pre-placement home studies, additional extended family background checks, and other training beyond what is required of FTCs.

HomeLink Support Technologies

HomeLink is an amazing breakthrough use of technology that creatively combines advanced security and smart-home technologies with specially trained

professionals to provide remote and deployed support. HomeLink can deliver health and behavioral support, home security, in-home care, or emergency support to an individual in the home when and where it is needed. It can be used to remotely supervise the provision of care, simply answer a question, or offer remote assistance or training. At CLO, HomeLink is used to connect our supports to one or many homes in need, “virtually” anywhere.

HomeLink is *individually designed* to meet the needs for supporting a client’s independence. An application may involve the use of a variety of sensors, including security, health, or behavioral sensors. It can also involve low or no light cameras or interactive speakers/microphones in a home. It might involve installing innovative technology that leverages home television systems to become teleconferencing systems that connect the right people to offer training, support, or advice personally and interactively to a person or support staff in need.

And while this all sounds very “technical,” perhaps the “art” of HomeLink is that it doesn’t require any technical abilities by the person in need. At the heart of this technology is its state-of-the-art monitoring and virtual support center, located in Lawrence, Kansas. From there, a professionally trained support team monitors homes under individually designed support agreements, provides in-home remote help, and/or dispatches and monitors local networks of care as needed. CLO’s HomeLink program offers support to its FTM homes, and is developing additional grant-funded technology to offer this support to its EFTM homes and to private homes.

Defining and Measuring Service and Person-Centered Expectations

Quality of Life Outcomes

The first step to implementing a best-practice community service program is to define service expectations and the outcomes to be produced. CLO/KU began developing its service expectations and critical program outcomes in the early 1990s and it is a process that is in continuous refinement. We began with a review of the literature that focused on

efforts to define a successful community placement or a high-quality community lifestyle (Strouse, 1995). Most studies on successful community placements, however, were post-institutional studies of successful and non-successful community placements. Most studies were correlational in nature, and there was very little agreement as to what exactly constituted a successful community placement other than remaining in the community placement for long periods of time and avoiding institutional or in-patient placement. Measures of community success commonly reported in literature, included improved adaptive skills (Borthwick, Meyers, & Eyman, 1981; Kleinberg & Galligan, 1983; Willer & Intagliata, 1982), perceived quality of life from the viewpoint of family and friends (Landesman, 1986; Schalock, Keith, Hoffman, & Karan, 1989; Seltzer, 1981), the absence of problem behavior (Bruininks, Chen, Lakin, & McGrew, 1992; Thiel, 1981; Willer & Intagliata, 1982), successful employment (Haring & Lovett, 1990), and various descriptive measures and/or conclusions based upon direct observation (Edgerton, 1967; Edgerton & Bercovici, 1976; Landesman-Dwyer, 1981; Seltzer, 1981). Although there were many attempts to measure some aspects of a good community life, this information fell far short of defining quality of life or the components that need to be in place to achieve it.

When our review fell short, we queried community providers who provided best-practice community programs, respected professionals in the field, and families and guardians about the important aspects of a high-quality community lifestyle. It seemed as if everyone had a different view of what comprised “a good life” and no one (to our knowledge) had yet achieved it. A good community life seems to involve a collection of daily experiences, which often vary for different people. However, we also found certain characteristics of a good life that are generally agreed upon by most people. For example, nearly everyone we queried expressed a desire to be healthy, safe, and treated with respect; to engage in purposeful, interacting activities; and to spend time with people they like while enjoying activities they prefer. In addition, individuals appear to want some control over their lives, learn and try new activities,

live in a nice home in a good community, and to surround themselves with good people they trust to help them when help is needed.

In the end, the CLO/KU team identified 11 outcome areas that describe many of the areas identified by those we queried and created indicators to assess the achievement of each outcome (available at www.clokan.org). Over time, we essentially conducted an ongoing social validity assessment of CLO's outcome measures (Wolf, 1978) by simply discovering that the ratings by consumer groups (outcome 11) were often associated with similar ratings of homes on the first 10 outcome areas (which we occasionally refined to reflect consumer preferences). These quality of life outcomes have been modified across the years and are presented below.

1. Pleasant and safe surroundings
2. Observance of legal and personal rights
3. Positive relationships with others
4. Living healthy lifestyles
5. Opportunities for choice and control
6. Effective learning opportunities
7. High level of participation in daily experiences
8. Community involvements
9. Effective communication
10. Pleasant social environment
11. Satisfied consumers

Person-Centered Measures of a Quality Lifestyle

In addition to CLO's measures of a high-quality of life, each client has his or her own idea about how he or she might want to live. This more personal definition of life quality is typically described with a person-centered plan (Smull, 2002). A person-centered plan is one based upon detailed assessments of interests, skills, and needs from various perspectives; interviews and input from those who know and care about the person; and feedback from the client. The end product is a clear description of the kind of lifestyle reasonably desired, the most important skills and opportunities needed to realize this lifestyle, as well as the supports that might be needed to be successful. Goals and objectives are developed from this

plan, which serve as a measurable guidepost for assessing individualized life quality.

Home Quality Evaluations

All homes within CLO are evaluated at least once a year based on 11 quality-of-life outcomes and individually identified person-centered outcomes. These multicomponent evaluations include (1) a professional evaluation or review; (2) consumer evaluations of satisfaction; (3) CLO's At-A-Glance evaluation; (4) care reviews; and (5) clinical reviews. Each of these components individually contribute to the overall assessment of quality of life for persons served by CLO, and will be briefly described in the following paragraphs.

Professional Evaluations

The professional evaluation is a detailed in-home review lasting 2–3 days conducted by an evaluator with specialized training in reliably assessing CLO's outcomes (and who is not associated with the home being evaluated). Professional evaluators meet with the home staff to discuss what they can expect to happen during the evaluation, arrange a time to review records, and schedule a lengthy meeting to interview home staff and observe the home and community activities and interactions. The interview and observation activities typically last 8 h. The professional evaluators review the quality of life indicators, complete the assessment tools, and calculate outcome scores.

Consumer Evaluations

In addition to an in-home professional evaluation, consumer satisfaction evaluations are distributed to consumers and their guardians to solicit feedback about program quality and determine areas in need of improvement. These measures ask consumers to evaluate, rate, and provide comments on items designed to assess the home performance in the outcome areas previously described. To supplement these ratings, guardians are also personally interviewed on a quarterly basis to determine if there are issues or concerns they may have about the home where their family member resides. Results of the consumer evaluations and

guardian interviews are instrumental in determining whether stakeholders are satisfied.

At-A-Glance Evaluations

The CLO/KU team also wanted to capture quality information from planned and unplanned visits to homes by families, clinicians, managers, advocates, or others. The At-A-Glance evaluation was developed for this purpose. This evaluation asks fairly simple, general rating questions that can be easily completed by persons with little training. Moreover, this evaluation can be easily completed after a 15–20-min home visit. The At-A-Glance evaluation tool allows CLO/KU to collect multiple samples of home performance across a month, with some samples of unannounced visits.

Care Reviews

Another component to the CLO/KU home evaluation process is a review conducted by CLO's advocacy and protection specialist. Any report of a care concern or unexplained event or incident is reviewed by an advocacy and protection specialist who is administratively independent of the provision of services and reports directly to CLO's Quality Assurance department. A care review might include reviews of a fall, an unexplained injury, property damage, a concern of poor care, a safety concern, or any other similar issue.

Clinical Reviews

The final "internal" review of quality that contributes to the overall evaluation of CLO's services is its clinical review process. This process is completed semiannually or quarterly (or more often, if needed) for clients who exhibit very challenging behaviors or have significant health concerns. A skilled behavior analyst (often faculty from the University of Kansas, Department of Applied Behavioral Science) leads a CLO team review where information on progress and concerns are presented and recommendations are made to ensure progress. A key expectation of this clinical review team is to review the progress of clients who may be taking medications for behavioral control. A liaison from this group

works closely with physician specialists (e.g., psychiatrists and neurologists) to organize and present data for their consideration and use.

Establishing Criteria for Success

The quality assessment process described above gathers information about the performance of CLO's community living support services and examines outcome measures that are considered important indicators of quality. The job of quality assessment, however, is not complete until decisions are made to determine if overall performance on various measures/indicators meets (or does not meet) our quality expectations in each of the outcome areas. To determine this, measures/indicators within and across outcome areas are examined and rated on a 5-point scale, from 1 (*unacceptable*) to 5 (*exceeds standards*). Average outcome ratings of 4 (*meets standards*) or greater, tabulated across each of the outcome areas, are required for a home and/or FTC to receive certification. While there are many measures of performance based upon observational and other verifiable data, ratings are used to determine if performance data meets or exceeds expectations (the criterion performance). Evaluators are expected to obtain 90 % or higher agreement (i.e., inter-rater reliability) on critical decisions regarding whether an outcome area is considered "passing" (averages 4 or greater) or "not passing" (averages less than 4).

Creating a Service Model to Achieve Expected Outcomes

It is nearly impossible to create a best-practice community living program without developing a reliable and valid measure of quality of life and service expectations. That said, measuring outcomes is not the service model. The service model (i.e., the intervention) includes the collective strategies for delivering services. The following pages will describe some factors that may be important in the development of a best-practice service model. We will provide examples on our attempts to implement these factors in the FTM or EFTM services.

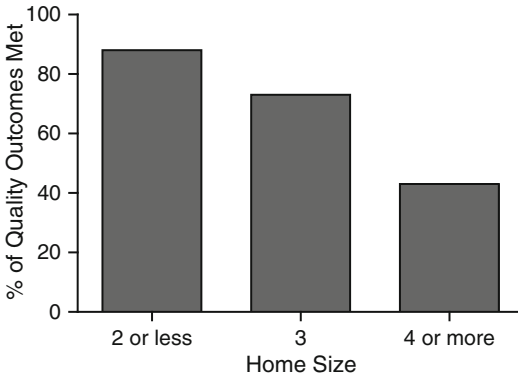


Fig. 25.1 The percent of quality outcomes met by size of CLO home in 2011

The Home, its Size, and its Location

Home Size

Most studies on home size and quality are correlational, but they generally show that home size is inversely related to quality (Heller, 1982). We have found the same result in our own homes, where our smaller homes reliably achieve greater measured outcomes than do larger homes. It isn't clear why small homes out-perform larger homes, since only correlational or descriptive research has focused on this issue. That said, we believe that small homes are critically related to good care because they can allow greater flexibility in meeting needs, have fewer different people involved in care, and provide an opportunity for deeper relationships to develop between clients and caregivers. Figure 25.1 compares outcomes achieved at CLO in 2011 from a selection of homes of different sizes. While this figure shows differences by home size, it also should be noted that at CLO larger homes (group homes) are supported exclusively by shift staff, while three-person and two- or less person homes are typically Family Teaching and Extended Family Teaching homes, respectively.

Home Design Requirements

The design of the home needs to be appropriate to meet the needs of the clients residing in the home. Persons with ambulation and accessibility needs must have accessible accommodations to

promote independence. In general, universal design concepts (Frailey, 2005; Nunn, Sweaney, Cude, & Hathcote, 2009) are preferred and most collectively meet the needs of multiple populations. Universal design is a design concept where accessibility friendly features are embedded into typical home designs that are created for the general public so that they meet current and future needs for accessibility of occupants. Communities have very different zoning and building code requirements, and it is critical to ensure that these requirements are met. We find it helpful to visit with the planning, zoning, and codes department in the community in which we wish to provide services in order to understand local code expectations. It is also important to consult with your state fire marshal's office to obtain any information that might impact housing choices. The greater the number of people living together and/or the greater the needs, the more stringent (and costly) the building and fire safety codes. As a general rule, homes that house three or fewer unrelated persons have fewer code requirements, as do homes that house families or foster families with a member with a developmental disability. Homes that are leased or owned directly by the clients are also more likely to have less stringent code requirements than homes owned by a provider of services.

CLO supports persons with developmental disabilities in a variety of different kinds of homes. As much as possible, CLO avoids multi-level homes in favor of single-level homes. Even when clients are ambulatory, one-level living is generally safer and easier for evacuation. CLO's foster homes are typical residential houses with the same code requirements that exist for typical families. CLO's Family Teaching homes are three bedroom typical duplexes where the family lives on one side and three clients live on the other (which is considered a separate home). The codes are identical to those in place for regular tenants of duplex-style homes because only three people with developmental disabilities live on one side (one home), and they typically lease the home directly from a community landlord (not from CLO). In contrast, CLO owns some eight person group homes that have significantly more stringent

building requirements, and are built to the most stringent life-safety codes, which include automatic sprinkling systems and fire rated doors and corridors.

Location, Location, Location

The amenities and resources of a well-selected community and neighborhood can have a tremendous impact on the quality of life for clients. Safety, availability and types of jobs, independence, food, health care, recreation and interesting activities, transportation, zoning, and most importantly the people who provide support are important considerations when determining home location. Wolf Wolfensberger was one of the pioneers of creating normalized lifestyles for people with developmental disabilities, and he created one of the first assessments of important community attributes of a well-selected home and community (Flynn, 1999). Fifty years later this assessment still prompts the asking of very relevant questions about home location. Is the home in a safe and attractive neighborhood, away from busy streets? Are there green spaces close or parks for enjoyment? Are shopping, medical care, restaurants, possible job or volunteer opportunities, family and friends, and other amenities that are important to the person served close? Is public transportation or specialized transportation available for access? Will the desired location offer affordable and appropriate housing choices for the population's needs? Some neighborhoods, home associations, and city planning requirements can make it very challenging and expensive for homes to be located in certain areas, especially if the home size is too large or out of character relative to the neighboring homes.

Finally, are sufficient staff support resources close to the home and will the home and location be highly desired by good support staff? The proximity and attractiveness of the neighborhood to talented employees may well be the most overlooked and understudied consideration for home selection. It might be helpful to examine the businesses and services in the location of a proposed home. What industries are there? What is the crime rate? How reputable are the schools? Is

there a college or junior college nearby? How much do service agencies pay workers in the community closest to the neighborhood selected? What is the unemployment rate? Are there resources, activities, and amenities in this area that will be attractive for support staff? Will the neighborhood and community location offer affordable and talented staffing supports?

With CLO, the FTCs and EFTs and their family members *live in* the same neighborhood as the clients they support. Therefore, their needs and preferences can play a very large part in the selection of a home location. CLO's FTM homes are generally located in duplex-home developments and this can narrow options for some locations. EFTM homes, which are specialized foster-care homes, can be located almost anywhere. Group homes can be specially constructed and larger than typical housing, and consequently, it can be challenging to find the right place that fits everyone's needs.

Roommate Considerations

Roommates must be compatible, and their collective needs must be ones that can be reasonably, reliably, and willingly met by the available direct support staff. The right roommates may even reduce the need of support because of complementary skill sets for everyday living. Similarly, incompatible roommates can cause the need for additional staff support. There are assessments that attempt to identify the intensity of support needs for individuals. In many states, these assessments are linked to funding tiers, which make sense, since cost is partly related to support needs. There are several assessments that might be helpful in evaluating support needs, including the Supports Intensity Scale (Bossaert et al., 2009), the Inventory for Client and Agency Planning (Hennike, Myers, Realon, & Thompson, 2006), and the Developmental Disabilities Profile (Hennike et al.).

While assessments can be helpful to look at individual needs, we have found none that look at the collective needs and/or the complementary skills of proposed roommates as a group.

This, however, is a necessary activity to determine if and how a small group can be best served with the support available. To evaluate the support needs for roommates, consider the daily and weekly routines that will be required to collectively support persons proposed to be living together in a home. Then consider the available staff supports to meet these routine needs across various times of the day. Are there too many needs of the same type or occurring at the same time? Are there too many elopement risks given the available staff? Are there too many challenging behaviors or loud behaviors? Do persons served require more assistance than can be reasonably provided by available staff? Or do some persons exhibit behaviors that might provoke challenging behaviors of others? Will it be challenging to access the community with available staff if too many persons need help with ambulation or too many people need specialized transportation? Are there too many up-at-night needs relative to the available support? On the other hand, do roommates have some complementary skills that could be a benefit or even reduce staffing needs, like cooking or cleaning skills or home safety or stranger safety skills?

Helping create effective roommate strategies is a balancing act of pairing clients who enjoy each other's company, while also assuring that there are appropriate staffing resources for care across daily routines. The best advice is to consider all aspects in resolving roommate groups, especially the relationships of people. Perhaps the most important consideration is to ensure that decisions have input from people who know the clients well, accurately understand the staffing resources and limitations, and are very familiar with the availability of community services. Finally, regardless of the work that goes into selection, it is critical to recognize that roommates often do not work out for many reasons, and while roommate moves need to be minimized, they will most certainly need to occur and should be expected. One of the biggest mistakes is to resist making changes to incompatible roommate situations or when clients present too many needs for available staff.

Direct Service Workforce Stability

While there are many considerations to the provision of best-practice community services, none are more important or challenging than providing a client the support of a stable workforce of talented and caring people. Unfortunately, numerous comprehensive national studies of the developmental disabilities (DD) community workforce reliably show very high turnover rates that exceed 70 % per year (Braddock & Mitchell, 1992; Larson & Lakin, 1997). This instability will surely worsen as baby boomers become seniors and as nationalized healthcare begins to offer services to 49 million uninsured persons.

There has been a considerable amount of research attempting to determine factors related to instability in the DD workforce. Most of this research, however, attempts to correlate various factors with turnover (Braddock & Mitchell, 1992). Turnover is generally defined as an annual percent, which is based upon the number of staff it takes in a year to fill the number of positions scheduled to provide care. Factors significantly correlated with turnover include poor pay, difficult working conditions in increasingly dispersed settings, reduced supervision, inadequate training, undesirable work schedules, rapid expansion of community services, difficult-to-serve populations, high competition for service employees, and other factors (Braddock & Mitchell; Larson & Lakin, 1997). While correlational research has helped to potentially identify some factors that may be related to turnover, this kind of research has apparently not fostered many useful strategies for creating a more stable model of staff support.

Strouse, Carroll-Hernandez, Sherman, and Sheldon (2003) proposed looking at staffing stability differently in order to gain more insight on how to develop strategies that may provide more consistent care. Instead of focusing on turnover, Strouse and colleagues examined payroll data by home within CLO to account for why there were far more caregivers involved in care across time than there were positions. This involved examining pay records and standard schedules of positions and determining

why, for each instance, a different person worked who was not permanently scheduled to work in that specific schedule. Looking deeply in one home across time to examine these reasons can generate much more insight into solutions to improve staff consistency. Vacancies (caused by turnover) was a significant reason for more people to be involved in care. There were, however, other reasons for the staffing situation. Once these “causes” are identified, strategies can be developed (organizational and individual interventions) to improve performance in and across homes and programs. Causes of instability measured by too many people involved in care might include: (1) inefficiently designed work schedules that require more people (e.g., overlapping, working wrong time, or part time workers) than necessary to provide care for the ratios of staff needed; (2) loss of staff (e.g., turnover); (3) inability to efficiently and quickly hire staff for vacant positions; (4) training strategies that remove people from work schedules; (5) non-preferred work schedules or poorly conceived differential pay strategies that cause people to move into more preferred schedules that may be in other homes or programs (when they become vacant); (6) poor substitute strategies where many different substitutes are used across many different homes; and (7) absenteeism, family medical leave, vacation, and other leave-related issues.

The causes and interventions used at CLO are beyond the scope of this chapter, but they are partially discussed by Strouse et al. (2003) who empirically evaluated an intervention package developed at CLO that significantly improved the stability of its shift staffing program by implementing a new scheduling strategy that reduced the number of people needed to provide care and turnover, without decreasing care ratios. While this research produced significant (and meaningful) improvement, researchers concluded that CLO’s FTM and EFTM services provided a much more stable workforce (i.e., over 350 % less turnover) than possible under the best of shift-staffing conditions, and this is still the case at CLO. Figure 25.2 depicts the differences in annual staff turnover by the type of home (shift, FTM, and EFTM) in 2010. These data suggest that the EFTM homes are the most stable of all homes.

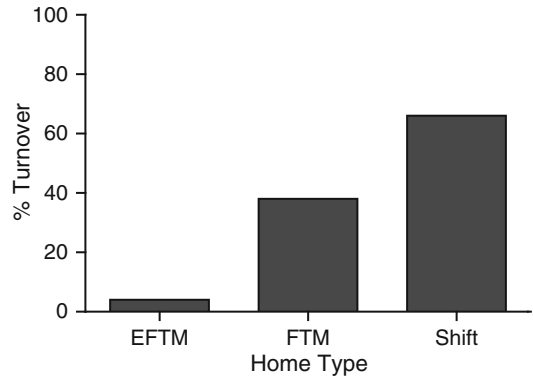


Fig. 25.2 The percent annual staff turnover by home type in 2010

Staff Selection

Goals for Selection

To help provide the best supports, it is important to hire and match talent to the lifestyle needs of clients. This process, however, would be much easier if there was a large pool of people interested in working for the agency. If the pool is small, then a best-practice selection process is pointless. Consequently, the hiring process has two primary goals: (1) to recruit as many caring people to apply as possible; and (2) to make sure that the “best” people from this pool are hired as quickly as possible. Goal 1 is essentially marketing and sales (yes, sales). Goal 2 requires the implementation of an applicant-friendly hiring process that ensures that the best people are selected quickly. Agencies that experience challenges with hiring staff often spend too little time on goal 1 and/or their strategies for addressing goal 2 are not applicant friendly or timely.

Recruitment Strategies for Direct Service Employees

Recruitment strategies are multifaceted strategies that include advertising, marketing, eMarketing, referral programs, recruitment fairs, and many personal visits to places and communities from which employees are sought. For many reasons, the best recruitment effort begins in the neighborhoods and surrounding communities of the home or program

needing support staff. If staff can be found close to where support is needed, then support will be available more flexibly and it is far more likely that the employee will be vested in both the home and the neighborhood, which benefits the clients. In our experience, the best way to accomplish this is to focus upon neighborhood activities, clubs, churches, grocery stores, community boards, local community centers, billboards, bus route advertising, sign (or van sign) advertising by industries in the area, neighborhood flyers, local newsletters, local radio, and targeted eStrategies that provide geographical targeted advertising. As was mentioned previously, the availability of affordable talent is a major consideration to home location.

The best recruitment source, however, is a network-driven referral strategy that includes asking recently hired candidates, employees, past employees, parents, advocates, friends, and even vendors for employee referrals. "Asking" people to help should be a formal and regular part of normal operations and should involve all parts of the provider company. We recommend that this strategy (i.e., asking) be embedded into routines such as annual planning conferences, reviews of care, tours of services, home visits, conferences, neighborhood gatherings, trips to the grocery store, and other activities. The request (or ask) should be accompanied by a presentation of a simple business card with contact information on one side and a small description of employment opportunities on the other. We recommend designing the card so that there is a space to note the name of the person referring a potential applicant. All recruitment efforts might best be held together by social networking strategies, such as Facebook, twitter, and Google+. It certainly is possible to pay for referrals, but it is not yet clear that this presents any more participation than could be obtained by asking regularly. A final point is to consistently ask candidates where and/or from whom they learned about an employment opportunity. If they learned from a referral source, make sure that there are formal and informal efforts for recognizing the contribution of this source. We also recommend that agencies gather data about the frequency of referrals from a particular source so that the agency can adjust future strategies accordingly.

A Customer Friendly Selection Process

Engerman, Strouse, Sherman, and Sheldon (1997) developed and evaluated a hiring strategy that was designed to make informed employment decisions (both on the agency's and applicant's parts). This strategy includes a screening process, an interview and detailed application, a home visit, and a background check, all of which cumulated into a hiring decision. This package intended to provide both CLO and the applicant the information needed to make a good decision. It also attempted to include research-supported components that are important to making an informed hiring decision, such as screening, realistic job previews, and other selection strategies (see Caldwell & O'Reilly, 1985; McEvoy & Cascio, 1985; Premack & Wanous, 1985). The applicant was evaluated at the screening, interview, and home visit and rated on dimensions that CLO identified as important in hiring an employee. An overall rating on a 4-point scale was computed for each candidate. Similarly, the candidate rated the hiring process before and after a hiring decision was made so that we could learn from their perspective how to improve the process. Candidates who were rated highest (3+) at each step (i.e., screening, interview, and home visit) were prioritized to proceed through the process more quickly for a hiring decision. Candidates who were rated a 1 at any step were not selected to complete the next step and sent a regret letter. We attempted to reduce the number of trips, amount of time, and response effort of each candidate during this process.

Family Teacher Selection

The process for selecting CLO's FTCs is somewhat different and needs to be separately discussed. FTCs are live-in or live-near positions that provide care and support. The recruitment process for FTCs includes all the marketing components discussed above, but there are also regional and national marketing strategies for finding people who want this lifestyle. These strategies include foster care (or house-parent) websites or newsletters, as well as mission-oriented entities like the Peace Corps. The greatest recruitment source, however, is from within

CLO's own program where shift caregivers who support Family Teachers learn about this lifestyle and decide that it is something they want to pursue.

The hiring process for FTCs is also different. This process often takes longer and involves more time spent with existing Family Teachers, who help mentor them in learning about their lifestyle. This normally includes an extended home visit with one or two experienced FTCs, and includes an opportunity to dine with an experienced FTC. These activities are accomplished in the absence of recruitment professionals who arrange the visits, so that discussions can be honest and personal. Additionally, CLO provides a website to learn about life as a Family Teacher, including video interviews of FTCs who discuss the merits and challenges of this lifestyle. Files of interested Family Teachers are maintained until a suitable matching placement is found. Of course, this process may be different and abbreviated if the candidate is already a CLO employee. Hiring decisions are team-based and stipends may be offered for relocation, depending upon distance, agency need, and other circumstances.

Extended Family Teacher Selection

The process for selecting EFTs is also different and even more detailed because it is essentially a foster placement within the EFTs home. The great majority of all EFT home placements are generated from long-term standing relationships that are generally formed between Family Teachers and one or two persons they support. Consequently, most EFTs fully understand the expectations and lifestyle they are considering before they begin. Occasionally, EFT placements are considered from outside of CLO's network of employees, but generally these placements involve an EFT candidate and a placement (and family) who have known each other for an extended period of time (e.g., a paraprofessional in the school or an employee from another provider or closing institution and a person with whom they have worked for years). Regardless, CLO requires that the EFT family spend considerable time with a possible placement and their family prior to making a placement decision. Additionally, a comprehensive home study is

conducted to make sure that the home environment and interests are all aligned prior to making a placement decision. All placement decisions must be agreeable to CLO, the EFT and their family, the client, and the family/guardian of the person to be placed. It is a long process that can be made more efficient when the EFT candidate already works with a client (e.g., a direct support staff, clinician, manager, or family teacher). For all of these reasons, EFTs are essentially "home grown" and are considered a logical extension of other placements or long-term relationships.

Staff Development, Performance Coaching, and Certification

Overview

All good programs will have a great staff development program to ensure that those individuals who provide support have the skills and detailed knowledge they need. Readers are encouraged to see Chap. 5 for more information. Harchik, Sherman, Sheldon, and Strouse (1992) evaluated a process developed and used at CLO that includes formal workshop/seminar training, regular in-home opportunities for practice and ongoing coaching from an experienced consultant, and structured evaluations and feedback. Wolf et al. (1995) details a process of training, coaching, practice evaluations, and formal evaluations that result in certification used in the Teaching-Family Model for programs providing homes for adjudicated youth. Sherman, Sheldon, Morris, Strouse, and Reese (1984) details an adapted version of this process used within programs that provide supports for persons with developmental disabilities. These processes are essentially embedded into CLO's FTM and EFTM programs, and have been refined across three decades of evidence-based use.

Certification

The primary goal of CLO's training process for all FTCs and EFTs is to meet annual certification requirements through an independent evaluation process by meeting or exceeding requirements of CLO's outcome expectations (described previously). The certification process involves work-

shop training, ongoing coaching and feedback, independent “practice” evaluations, and finally the formal certification evaluation where key processes and outcomes are independently evaluated to ensure that employees are performing to high standards. FTCs and EFTs who become certified are recognized and rewarded in many ways, including a bonus program that encourages participation and demonstration of skills during and after this certification process. Certification is also a requirement for ongoing employment or placement. Consequently, the goal of “certification” helps align the agency’s goals of high performance of those who are asked to achieve these goals.

Workshop Training

Workshop training is the first step in the certification process. A primary goal of workshop training is to teach standardized and person-centered techniques designed to increase rated outcomes and consumer satisfaction. Additional important goals, however, are to ensure that there is a good match between the philosophy and expectations of the agency and the FTC and EFT participants, and to develop relationships between participants and with persons responsible for training and mentoring them through the certification process (coaches). Training includes two weeklong workshops. The first workshop occurs prior to working in a home, and is followed by a structured in-home orientation to learn the specific needs and teaching strategies of the clients they will support. A second workshop typically occurs between 90 and 120 days after the first workshop and describes more detailed strategies for achieving CLO’s service and individual outcomes. All training workshops are skill-based, and competency in learning is assessed by written test and by role-play. In recent years, CLO has worked to incorporate eLearning strategies to improve its training for its curriculum topics. Its eLearning modules are available online and complements CLO’s workshop training program by providing online resources available in the home to assist support staff who are learning skills to implement various components of CLO’s service model.

On-Going Coaching

Perhaps the most essential component of the certification process is monthly in-home, coaching and mentoring. FTCs and EFTs participate in an ongoing home-coaching process where an experienced coach helps them adapt and implement strategies they learned in workshop training in their home for clients (Harchik et al., 1992). This process involves biweekly in-home visits; reviews of strategies and techniques to be implemented (often using online instruction and video training for discussion); help with adaptation and implementation; observation and feedback; and mini-outcome evaluations. The time spent on various learning modules is individualized to the couple, persons served, and needs of the home. This process is implemented to systematically and positively prepare for a successful certification evaluation. The consulting modules covered as part of monthly coaching visits in the first year generally revisit topics presented in workshop training and focus on adapting and implementing strategies that we feel best achieve our service and person-centered outcomes.

Independent Evaluations

A private “trial” evaluation is conducted by an independent professional evaluator sometime between the sixth and eighth month of the FTC or EFT’s first year of providing support. Feedback from this evaluation is presented by the evaluator to the coach and the FTC/EFT, and will result in additional coaching during the final months prior to the certification evaluation. Because this is a trial evaluation, the findings do not impact ratings or scores on the annual certification evaluation. Finally, the annual certification evaluation is conducted with the expectation that FTCs and EFTs will achieve and/or maintain their certification. While every effort is made to ensure that couples are successful in achieving certification, instances where couples do not meet all standards typically result in a revisit conducted within 4 months from the original evaluation. Revisits are often done more quickly if areas in need of attention are minor. It is a requirement of employment (FTC) or contractual requirement

(EFT) that they are certified within 18 months from beginning training. While it is possible that FTCs or EFTs might not achieve this goal, it is rare that this would happen simply because the coaching process would work through these issues earlier. It is also possible that the FTC or EFT would realize that the position was not a good match and select out of this service-delivery option sooner.

Intervention Considerations

In a review of implementation and generalization, Stolz (1981) concluded that many useful interventions were not used widely or at all. Several explanations may account for this observation including a lack of understanding by the individuals who are expected to implement the intervention, a belief that the intervention will not work, and that the interventions are not reinforcing to use (Fixsen, Blasé, Timbers, & Wolf, 2001). Thus, it is important to consider using interventions that are positive, straightforward and simple, potentially effective, and are motivating to use and implement by the support staff charged with the responsibility of implementing them.

This is a challenging goal for community support programs where staff are often highly decentralized in the community, unsupervised, and “on their own.” To improve the probability that teaching interventions are implemented (and potentially effective), efforts must be made to make teaching moments natural, functional, non-stigmatizing, and convenient to implement during a typically busy day.

At CLO, we work to create a teaching culture among FTCs, EFTs, and support staff. Components of this somewhat “standardized” approach include: (1) an enriched and active lifestyle filled with natural opportunities for learning; (2) daily and weekly routines for essential activities of daily living; (3) an incidental and planned teaching style that include specific praise, meaningful rationales, regular and frequent opportunities for practicing new and alternative skills, and rewards for good effort; (4) frequent opportunities for self-

government, problem-solving, choice and control; and (5) the use of effective communication strategies. The effectiveness of these components is then amplified by good mutual relationships between “teachers” and clients.

An Enriched Lifestyle

Nothing can serve as a substitute for interesting things to do, both for improving the lives (and behaviors) of persons with developmental disabilities as well as those who support them. The best way to consistently offer interesting activities is to embrace the naturally occurring resources of an enriched community and engage in activities considered to be interesting and meaningful as determined by person-centered support plans. FTCs and EFTs help clients they support to “get a life” (Risley, 1996) partly by successfully involving clients in their busy family life of soccer games, school events, weekend excursions, and other family necessary and/or fun activities. One of the most challenging tasks is ensuring that there aren’t unnecessarily long gaps of low or no activities where clients fill voids by engaging in behaviors that are often designed to enrich a bored existence (e.g., gaining attention inappropriately or engaging in nonfunctional or maladaptive behaviors). Few teaching strategies can be effective unless they are delivered in front of a backdrop of interesting, engaging activities.

Routines

Carefully planned, organized, and reasonably consistent daily and weekly routines are essential for creating greater independence in daily living. With consistent and logical routines, persons with intellectual disabilities learn how to navigate their day timely and efficiently and with less assistance from teachers instructing them about what needs to be done and by when. Over time and with consistent teaching, many clients will require progressively less support and will feel more pride in the independent completion of daily living chores. Weekly routines like laundry, banking, shopping, and other routine activities help persons better plan their week and budget their time so that they can engage in recreational, family, and other preferred activities. Conversely,

the absence of routines creates needless prompting by support staff about what to do next, and consequently a dependency on staff for direction, which can become less positive and frustrating for clients who may want more independence.

Incidental and Planned Teaching

Wolf (1978) described a social validation process used to first develop components of a generally standardized, effective teaching style for use by teachers using the Teaching-Family Model for adjudicated youth populations. This study identified the teaching components that were most liked and believed to be most effective and then incorporated these components into standardized teaching interactions. Sherman et al. (1984) discuss adaptations of these teaching components for use in teaching persons with intellectual disabilities. Hart and Risley (1975) discuss the components of incidental teaching, which focus on noticing and creating ongoing, natural opportunities for learning (and teaching) skills. CLO/KU has worked hard to encourage a teaching culture that adapts and includes these strategies into its generally standardized “teaching interactions.” Three general teaching interactions are taught for use by its staff including (1) rewarding appropriate behavior or approximations of appropriate behavior; (2) teaching new skills; and (3) teaching replacement skills for maladaptive behavior. Specific praise, rationales for appropriate behavior, specific descriptions (steps) for new or expected behavior, opportunities to practice, and rewards for good effort are all steps that are embedded as appropriate in these three teaching techniques. Although the teaching techniques are generally standardized, they are natural, positive, and generally effective for most learning opportunities. Additionally, as much as possible CLO teachers are encouraged to orchestrate, recognize, and take advantage of naturally occurring opportunities for learning or applying learned skills regularly and frequently across typical daily activities. Planned and preventative teaching is encouraged for persons who need more preparation to exhibit a skill when natural opportunities occur, and often just precede the occurrence of these opportunities.

Self-Government, Problem-Solving, and Choice and Control

A primary goal of a best-practice community support program is the promotion of independence and self-control empowering those persons that they support (Bannerman, Sheldon, Sherman, & Harchik, 1990). Thus, a key component of effective intervention programs must be teaching persons with intellectual disabilities to learn how to solve everyday problems effectively and learn skills that will allow them to take more control over their daily lives. Teaching self-government and problem solving is a continuous process, which is often embedded within incidental and planned teaching interactions where steps of appropriate skills and rationales for using them are “problem solved,” and every day opportunities for choice and control are recognized and taught as they arise. This might include discussing and selecting items for menu planning, activities to do, shows to watch, clothes to wear, how to handle a disappointment, and countless everyday choices that can be easily missed simply by not offering these opportunities. If 20 or 30 incidental and planned choices are taught across a day, or simple problems are solved (occasionally with deeper discussions that might include rationales or weighing advantages and disadvantages of various options), then choice, decision-making, and problem-solving skills will most likely be increasingly learned and independently used.

Decision-making and problem-solving skills can also be improved when more formal systems of self-government are used (Bannerman et al., 1990). Sherman et al. (1984) describe how daily family conferences can be used to make decisions and solve problems while also teaching and practicing the steps for mastering these skills. At these meetings, persons living in a home or community meet, decide upon group activities, determine house jobs or discuss how to fairly divide daily or weekly responsibilities, and raise or propose solutions for problems and concerns. Decision-making skills include: (1) specifying the decision to be made; (2) generating options; (3) discussing the advantages and disadvantages of the options; (4) making a decision; and (5) discussing how and when to implement the decision.

Problem-solving skills include two more initial steps, including: (1) specifying the problem, and (2) discussing why it is a problem (followed by the five steps previously presented).

Effective Communication Strategies

Many persons with developmental disabilities have communication challenges expressing their wants, needs, or emotions (Sigafos, 1997). Similarly, receptive language skills are often lacking, making it difficult to learn skills or to rely on fewer prompts. The lack of expressive and receptive communication skills can lead to misunderstandings, frustrations, and can often result in challenging behaviors that could be avoided with better communication strategies. Much work and teaching must be done to communicate expectations, requests, and choices in a way that is individually understandable (Bannerman et al., 1990). Picture boards, picture schedules, gestures and signs, or communication technology are all used to help persons express wants, needs, and emotions effectively or used by staff to help communicate expectations or options. There are many good systems for assisting with communication, but the Picture Exchange Communication System (PECS) is one of the most widely used (Sulzer-Azaroff, Hoffman, Horton, Bondy, & Frost, 2009).

Relationship Development

While little empirical research exists on the role of good staff relationships on effective teaching persons with intellectual disabilities, it is widely considered both necessary and preferred (Risley, 1996; Sherman et al., 1984; Wolf, 1978; Wolf et al., 1995). Good relationships, however, do not happen by accident. Great relationships are created when caring people spend significant amounts of quality time together and learn about, help, teach, and positively support each other. The presence of good relationships might potentially be assessed by observing mutual statements of caring and regard, the use of personal rationales, frequent instances of positive reinforcement and encouragement, reciprocal smiles, and frequent close proximity (including appropriate physical contact). Presumably too, these same strategies might be used to facilitate or develop

relationships across time. It seems to us that a positive relationship with a family teacher or support staff exists if a person they support works hard repeatedly across time to gain their attention or avoid losing it. Once this is achieved, the artful contingent application of attention can build strong skills, while corrective feedback or withholding attention for brief periods of time can effectively reduce inappropriate behavior. The importance of a good relationship—while hard to define and challenging to produce—cannot be overstated. The most critical dimension for the development of deep personal relationships, however, is simply spending substantial time together, a task only possible by the presence of very stable, vested, tenured teachers consistently supporting only a few people across time.

Clinical Supports for People with Significant Needs

To serve people with significant health, adaptive, or behavioral needs it is essential to develop a strong and highly coordinated clinical team that closely connects the FTC/EFT or key support staff and agency clinicians with professional clinical support and specialists. CLO's collective clinical services offer wellness care, technical support and training, as well as home-based behavioral, health, and adaptive services to support FTCs and EFTs. CLO's HomeLink Technologies (to be discussed later) is beginning to offer opportunities for FTCs and EFTs to receive remote health and behavioral support that will allow better and more frequent support in the home for persons they serve.

To coordinate health, adaptive, and behavioral support with quality of life support, CLO conducts regular clinical reviews of care (described earlier in this chapter). A skilled clinician (often times faculty from the KU Department of Applied Behavioral Science) leads this review, with the goal of integrating health, adaptive, behavioral, and other professional support to help improve the quality of life of persons served. When specialists (e.g., psychiatrists or neurologists) are consulted for challenging behaviors or concerning medical

conditions (e.g., uncontrolled seizures, serious aberrant behavior possibly related to a psychiatric diagnosis), data are organized and questions are considered (in these reviews) prior to a specialist visit. During the visit, a liaison from the clinical team presents data and discusses conditions that may be a concern. Recommendations are gathered from the specialist along with treatment risks and benefits for various treatment approaches. It is critical to point out that specialists such as psychiatrists or neurologists have only a limited amount of time to consider data and recommend or make a treatment decision, so it is important to be organized and concise. We find it especially helpful to organize progress on various dependent measures around the various treatment approaches (or medications) or to define treatments in effect when behavioral/medical outcomes are particularly good or bad. This helps the specialist see the impact of various past treatments at a glance. Anecdotal information is rarely helpful unless it is supported by data. The goal of the clinical review team at CLO is to ensure that data are properly taken and arranged so that the right treatment conclusions can be made based upon reliable data.

Organizational Considerations

Three decades of community services has embedded some beliefs about several management strategies that we feel are important from an organizational viewpoint. We expect our FTCs and EFTs to be situated to effectively manage and orchestrate high-quality community lifestyles for the people they support. We work hard to ensure these teachers have all of the tools and training required to make everyday life decisions that push forward a good life for each client. This is inherently different from divisional approaches where experts know part of people while “paraprofessionals” are there to keep people busy until the expert arrives. Instead, we believe in what Fixsen et al. (2001) describe as the triadic model, which is a strategy where professionals develop general intervention skills of teachers and/or caregivers, who in turn use these skills to positively impact the lives of those persons they support. Organizationally, we build our services around this principle.

Decentralized, Whole Person Management

There are many benefits for multidisciplinary involvement in the provision of services for persons with intellectual disabilities living in the community. That said, these different perspectives and services must be seamlessly integrated into an enriched, preferred, teaching-oriented lifestyle. At CLO, interdisciplinary input and support services are integrated by a management structure where one manager is responsible for the provision of services for a caseload of people. At the direct implementation level, the FTC or EFT is charged with putting integrating services and supports to serve a small caseload of one to three persons living in their home. This model extends upward in the organizational chain. At CLO, those individuals who directly supervise FTCs or EFTs are called “coaches” and are similarly charged to integrate services across disciplines into an enriched community lifestyle with a larger caseload (10–16 people served). Individuals who supervise coaches are called “site directors” and they also oversee and integrate services for a caseload of approximately 50 clients (or 4–5 coaches). Thus, at the FTC/EFT, coach, and site director level we expect this “whole person” approach to management where ultimately one person is in charge of seamlessly integrating various services for a person or a caseload of people. There are many support services, such as clinical supports (e.g., health, behavioral, or OT/PT), vocational supports, human resources, finance, and other services, but there is always a manager (an FTC/EFT, coach, and site director) who is responsible for ensuring that these parts are integrated into services that matter and work seamlessly to create an enriched community life for the whole person. When possible, support services (e.g., nurses, behavior analyst, case managers, or vocational professional) are aligned so that these professional’s caseloads are as consistent as possible with FTCs/EFTs, coaches, and site directors. An important organizational goal at CLO is to reduce the number of different professionals involved in care within a home or program to its minimum number. The “team” for a home or program must include the right people, but it does not include

more than is necessary. This can mean that caseloads of, say, a nurse, behavior analyst, or a case manager, might change so that three different support professionals (e.g., three nurses) are not needed for one home that serves three different people. Ultimately, we want our FTC/EFTs to work with a small core group of professionals to access the help they need so that their life is less complicated and focused on care.

Continuous Support Verses Day and Residential Programs

The traditional service dichotomy within the community is residential and day services. Day services are typically offered during business hours (i.e., 9 AM to 4 PM, Monday through Friday) and often consist of teaching-oriented activities of daily living, prevocational, or vocational activities (including supported employment). Residential services, ironically, do not refer to “home” services, but rather this term refers to “not day services.” As a result, residential services provide supplemental support to serve a client when day services are not in session or the client is unable to receive day services for adaptive, behavioral, or health reasons. At CLO, “day” services have become “community inclusion” support services where health, therapeutic, community enrichment, volunteer, and work activities are offered to support enriched “out of home” lifestyles. CLO’s day services space is generally small, and includes activity spaces, space for a health and wellness clinic, space for occupational therapy/physical therapy support, and other essential services space. The remaining space needed for services is provided naturally in the community. Community opportunities are generally provided through an individual schedule developed and coordinated by the FTC/EFT and coach who work across hours and days, not confined to typical 9 AM to 4 PM time limits of traditional day services. Nonresidential community services at CLO are viewed more like class offerings of a community college. Persons might have “class” or activity opportunities in the morning, afternoon, evening, weekdays, or weekends, depending upon the needs, interests, and opportunities of persons served.

This philosophy is a paradigm shift which may help open the door to possibilities that jobs, activities, and lifestyles are available at any time

and any place. If a person needs to have opportunities available in 2-h out-of-home intervals of activities, then we attempt to make arrangements for this particular need. If a job is better available on a Saturday, then we ensure the client has the opportunity to participate if he or she has an interest. CLO’s general strategy replaces traditional day services with community opportunities that are not confined by the hours of operation of a more traditional day services program. There certainly are people (managers) who coordinate “outside the home” activities at CLO but these opportunities are essentially “zones” of opportunities or “themes” of opportunities, and often occur outside of normal time expectations offered by many programs.

Virtual Offices, Information Management, and Learning Management

At CLO there is progressively less and less of a “place” for management. EFTs, coaches, site directors, and support staff must be mobile and accessible to the home and community. The “office” has become the laptop, wireless access points, and web-based information management systems that can be collaboratively accessed by anyone anywhere. Experience has taught us that offices are where managers and clinicians are, but not necessarily where you want them to be. If you want professional and support staff to spend time in a person’s home or in the community then that is where their office needs to be located. To accomplish this, we must eliminate barriers of where people keep the “stuff” they need and want to do their job and provide access to information and resources virtually. Very good information systems are available that are “web-based,” secure (HIPAA), and accessible from any location. One system that deserves special mention is “Therap” (see www.therapservices.net) which is a web-based system that combines all facets of information (clinical, management, service coordination, financial, and more) and integrates this information around a “whole person.” This system is highly customizable for most every local use and is nationally used and developed collaboratively across a large provider network. Because it is web-based there is no handcuff to local servers or technology expertise.

Another web-based software (also called “software as-a-services”) that deserves special mention is “Google Business Apps for Non-Profits.” This service provides user-friendly business web-based applications that include word processing, spreadsheets, presentation, contact management, document management, and “closed” and “open” social network solutions that are available anywhere. Google offers these secure applications free for nonprofits for up to 3,000 users. Additionally, Google allows third party integration for many useful add-on programs that improve collaboration and networking for teams focused around client “circles.”

One last technology innovation (also cloud-based) that deserves special mention for best-practice community services is eLearning. Learning needs to occur at places and times that are convenient for the FTC/EFT and coach. While there are places and uses for “traditional” training workshops (described earlier), there is a need for training and retraining opportunities to be made virtual and available when and where they are needed. The very best cloud-based eLearning system for our use has been “Elsevier’s College of Direct Supports.” This is a highly developed national curriculum of community learning developed by Elsevier in collaboration with the University of Minnesota. Community programs, like CLO, can adopt and use these eLearning classes as mix and match modules with an agency’s own curriculum supplements (including videos if desired) uploaded to the Elsevier hosted website. This strategy allows endlessly flexible curriculum combining both the best that a program has with great coursework developed by national experts who are associated with the College of Direct Supports. Online tests are embedded within the web-based software to ensure that knowledge is acquired, while data on covered modules and test performance is always accessible to the learner. Many automated features exist to assist agencies in maintaining records and reports of learning compliance. It is a great, flexible, and cost-effective system for providing and tracking learning, and the existence of a flexible but nationally developed curriculum makes this choice a simple one.

Pay Strategies and Performance

Pay strategies are critically important for best-practice supports. CLO’s overriding goal is to pay as much as it realistically can to those who deliver care and pay this amount in the best way possible to push forward the goals of providing a highly vested, stable, workforce. To accomplish this, several important considerations are worthy of discussion.

Take Home Pay

Most direct service staff want to maximize their take home pay. Unfortunately, they are often the lowest paid agency employees. Shift workers are typically paid hourly and are often required to pay for benefits they do not want or cannot afford. Many of these benefits (those they do not want) are desired and used by managers and clinicians who make considerably more money. A major consideration for hourly staff is not just how much they are paid, but rather how much money they take home (after deductions and taxes). Agencies that provide direct support using hourly paid staff would benefit by carefully examining what must be deducted from their pay check and ask themselves if it is a benefit for which the staff want to pay. In some cases, because of the federal Uniform Reciprocal Enforcement of Support Act (URESA), benefits provided for managers must be provided for all staff whether they want them or not. This, of course, takes limited resources away from what is available for pay. One potentially useful alternative strategy is to consider using a Professional Employment Organization (PEO) to separate the hourly workforce in ways that allow different workforces to receive the benefits they desire without paying for benefits they do not desire. This strategy can be used to move hourly workers to a new corporation and then lease them back to the service corporation. It is called “co-employment.” Using a PEO requires much consideration and is well beyond the scope of this chapter, but it can be a very useful strategy so that different workforces can receive the benefits and pay they want.

Another way to maximize take home pay is the provision of living accommodations that are a

requirement of work. Family teachers **MUST** live in an adjoining space to provide “as needed” care. While the FTCs certainly benefit from a free home and living accommodations, these costs are not taxable under the right conditions. As a result, live-in FTCs can maximize their pay (presuming that they must pay for housing regardless of where they work). EFT’s compensation, again under the right circumstances (that are also beyond the scope of this chapter), is largely non-taxable if they meet requirements for foster care (adult or children). These requirements became more accessible for adult developmental disabilities populations in with the passage of the Job Creation and Worker Assistance Act of 2002, which includes the Bunning/Lewis Foster Care Tax Bill. There are many considerations for adult and children foster care, but under the right conditions it can be highly effective for maximizing funding for care (and lowering provider costs in non-care areas).

Pay Schedule

Another way to maximize funding to benefit caregivers is to pay weekly or bimonthly, but not biweekly. In our experience, most caregivers prefer more frequent pay, so weekly pay is most preferred. CLO has administrated many surveys of its caregivers and most prefer weekly pay and do not like to wait long periods of time to receive compensation. Additionally, weekly pay makes pay differentials and bonuses (to be discussed later) more effective, because these contingencies are not delayed and are more immediate. Another issue, though, is that typical household bills are either weekly or monthly but rarely every 2 weeks (biweekly). Car payments, house payments, and utilities are typically monthly. If your annual earnings are divided into monthly equal amounts, then your maximum earnings are available by month. If, on the other hand, your annual earnings are divided by 26 weeks (biweekly pay), then you are not getting the maximum amount of pay per month. Instead, there are two extra pay periods per year and this effectively reduces the amount of money available for typical monthly bills by a little over 12 %. If an organization is trying to provide the most money possible for their staff to pay

their bills, then it is best to provide pay in ways that maximizes the money available within a month. Weekly pay essentially allows this because monthly bills often have a small window of flexibility as to when they are due, which will fit well within a weekly pay system. While this may sound like splitting hairs, we encourage readers to ask an hourly worker if she would like to have 12 % more money a month for bills and readers will learn that this is an important issue.

Schedule Migration and Differential Pay

Schedule migration can happen if some work schedules are more preferred than other schedules. If schedules are differently preferred then as more preferred schedules become available, caregivers leave their position and migrate to these preferred schedules and homes. This process causes needless turbulence in care and leaves the least preferred (and hardest to fill) schedules open to recruit new employees to fill, which can cause chronic vacancies and overtime. At CLO, schedules are designed to be as equal as possible while data are collected on schedule openings to ensure that certain types of schedules do not have excessive openings with long latencies for filling positions. Additionally, we regularly examine transfer requests to ensure that schedule migration is minimized. We use two strategies to equate the desirability of schedules. One strategy is to design the schedules so they are equally desirable (e.g., the schedules have an equal share of hours, days off, and weekend work—there are very few Monday to Friday positions). The second is to add compensation to certain days, times, and schedules to equate their desirability (i.e., a shift differential). There has been a considerable amount of research on CLO’s scheduling strategy for direct service hourly staff and relief staff positions. It is possible to pay more money per hour, have less staff turnover, and improve care, all without paying more (overall) for employment costs. For more information, please see Strouse et al. (2003).

Overtime

There are many causes for overtime and just as many remedies. Overtime is an essential measure for successful community providers and is most

typically worked by only a small percent of the workforce who want more hours. If overtime is forced, it is our experience that excessive required work may lead to additional turnover. Overtime certainly leads to overwork, which can lead to poor care. As overtime increases so do costs and turnover. We employ multiple strategies to limit overtime (many already described). Three strategies, which work in concert, deserve discussion: (1) scheduling, (2) superimposed positions (additional positions beyond what is needed for a home or program), and (3) differential pay for hard-to-fill hours. We cannot predict vacancies and openings in any given home for any given day. Since CLO is a fairly large provider, however, we can predict fairly accurately how many openings we will fill *by schedule type across homes and programs*. To address this known number, we then “over hire” staff to work superimposed schedules with expectations that they will move to these openings (wherever they are) to provide relief. We developed a position of “scheduling coordinator” whose primary job (and incentive pay) centers on effectively managing the replacement of open positions and keeping overtime low. Additionally, this “superimposed” replacement process allows new staff to sample vacant positions to make sure that they like the home and position before agreeing to become a permanent staff of that home or program. This process has become a standard placement process at CLO so that staff can have some experience in sampling homes before a decision is made about where to work. A goal of this sampling strategy is to better match new employees to a home and program that they will enjoy. Our hope is that this strategy will contribute to reduced turnover, but we are still examining its impact. Of course, lower turnover equals fewer openings and lower overtime.

The third leg of the overtime stool is paying differentials for various days and times of day. At CLO the workweek is Monday through Sunday (the weekends are the last of each workweek). We pay a \$2.00 per hour differential for weekend work, *providing that the staff worked their full schedule during the week (prior to the weekend beginning)*. Thus, if a staff person worked his or her required weekday hours he or she would receive \$2.00 per hour additional pay for week-

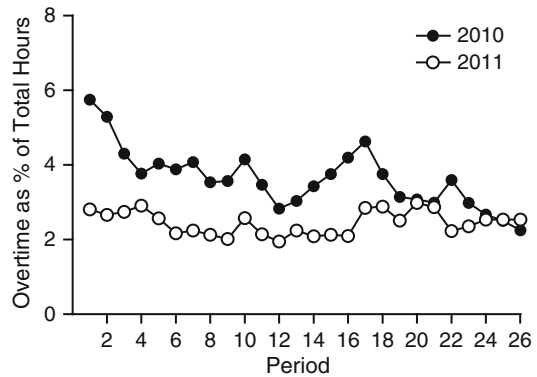


Fig. 25.3 Overtime as a percent of total hours in 2010 (before contingency) and 2011 (after contingency)

end hours worked. This contingency significantly reduces call-offs in the week and on the weekend, and encourages staff to work their assigned schedule. This, of course, improves care, decreases call-off vacancies, and makes life more livable for managers who must ensure that staffing is consistent across time. Figure 25.3 displays the overtime hours before and after the full package of these contingencies were in force.

Performance Bonuses

If you are a behavior analyst, it is hard *not* to consider performance bonuses to improve services. We certainly use them at CLO. They must be, however, carefully considered. Bonus pay must comply with labor law requirements (be sure to consult a good labor attorney) and they must align employee/clinical/manager goals so that programs and departments are not competing with each other. The latter outcome can easily happen if performance is assessed only by department, if the goal is not related to the agency’s overall performance, or if the goal is not the same for all staff. We recommend a resource entitled *The Goal: A Process of Ongoing Improvement* (Goldratt & Cox, 1984), which is a simple and well-written book that is important reading for promoting strategies for achieving agency performance in ways where various interests do not compete against each other. This book examines how various groups can either work in harmony or at odds with each other all in the name of agency performance.

CLO essentially pays bonuses to FTCs, EFTs, coaches, and site directors for achieving the same critical home outcomes, implementing important processes, and for providing appropriate supports (that are necessary for the success of the first two performance expectations). A bonus is provided to FTCs or EFTs for key practices and outcomes being present within an assigned home. A coach is provided a bonus for the same key practices and outcomes being present to a high degree in assigned homes. Similarly, a site director is provided a bonus for the same practices and outcomes being present in a larger caseload of homes. Bonuses are paid monthly and everyone is generally interdependent upon each other for joint success.

HomeLink Support Technologies

On-Demand Labor

We believe budgets would go farther and services would be less costly if labor could be provided only when a need arose and only for as long as a need existed. Costs are driven upward primarily based upon the cost of “just in case” labor. Many programs pay an overnight staff person “in case” a client awakens and requires assistance. Depending on the needs of the clients, some programs have two staff available in the home in case situations intensify due to problem behavior escalation. If not for intermittent and unpredictable needs most agencies could provide less coverage (lower staffing ratios) if there was a way to know when additional support was needed and a way to deliver it immediately. Historically, we have been unable to predict with certainty when help is needed and then provide extra help only when that need arises and only for as long as that need exists. But if we make this prediction, two outcomes are possible. First, we could save money or at least spend our money on more enriching supports. Second, we could provide supports in smaller homes, because one of the reasons group homes exist is to pool staffing resources to address the intermittent needs of the clients who live in the home.

Cutting edge technology, however, is now changing what is possible from a care perspective. Like no other innovation, technology offers the

ability to “know” when a need exists and provides a deployment methodology that can allow programs to meet a need “on demand.” The technology must be effective and highly reliable. Additionally, there must be a new model of services that are highly deployable. Great technology combined with a new service model will become the next paradigm in care fueled by high growth in dependent populations and flat resources, and pushed forward further by a very high desire of people to receive care in their own home.

The Development of HomeLink Support Technologies

CLO has been pioneering remote support technology since 2000, and has invested considerable resources in pursuing its next phase of service options. Because CLO uses “live in” or “live near” supports in its service models, it already had the ability to allow support to ebb and flow around the needs of our clients because help was available in, next to, or near the home if we only knew when those needs were to happen. CLO began its HomeLink support program by remotely monitoring homes at night, using its technology to deploy support (either from live in Family Teachers or people who roved across a neighborhood supporting multiple homes at night). This strategy allowed CLO to save hundreds of thousands of dollars a year in paying for nightly staffing costs, which was reinvested in quality of life supports during the day. Additionally, it allowed CLO to promote nighttime environments that resulted in improved sleeping conditions for persons we supported because we could better assure an environment where people could sleep (low lights, quiet, and free from distractions and the presence of staff who might inadvertently reward attention-seeking clients for not sleeping at night).

From these beginnings (and a dozen years of work and investment in technology and on-demand support models of care), HomeLink, combined with new deployment models of support, offers many more options and services 24-h-a-day 7 days a week to improve the lives of persons with developmental disabilities. A client may now live in a small apartment alone or with one roommate (with or without a disability) and receive staffing support tailored to

his or her need. Service models are still being regularly shaped to meet the new rules of on-demand support. The focus of these new service models is the creation of a community of support. In this approach, the resources of a neighborhood are gathered to support persons (potentially across dependent populations) who live in that neighborhood. Our goal at CLO is that those who live in the neighborhood would largely support its neighbors. This can happen by recruiting people from within the neighborhood to help or by encouraging (via live-in stipends) people who want to provide on-demand support to live in the neighborhood where clients in need of intermittent help reside. This model has many financial and quality of life advantages for those who need support and those who provide support. Social networking sites combined with technology, virtual communication technology, and contracting and pay strategies can offer new ways for reliably making a meaningful difference in the everyday lives of people with significant needs. HomeLink technologies and CLO's deployment systems continue to evolve to fit hand-in-hand.

HomeLink Behavioral and Health Support and Treatment Integrity

HomeLink is increasingly used to improve the behavioral and health services provided for CLO's homes and better ensure the integrity of treatment during times when managers or clinicians are not present in the homes. HomeLink Technologies can record activities (video/sound) from multiple angles and locations in a home simultaneously. These simultaneous recordings can be reviewed anytime remotely by clinicians (health or behavioral clinicians) or home/program managers (coaches or site directors). Additionally, devices (alert pendants) can be worn by home staff and used to "mark" instances of a behavior occurring in a home to allow clinicians or managers an easy way to later locate these. Clinicians can search a video database for these marked videos to see what occurred before, during, and after a particular behavior. This essentially allows for a remotely gathered collection of video/audio "firsthand" data to help in a functional assessment of a problem behavior. Additionally, by examining samples of archived

video/audio in a home it is also possible to determine if interventions are implemented as they were intended and are having the intended results. Further, it is possible to remotely watch staff members interact live with clients of a home and remotely coach them using a mobile phone with ear buds to provide private assistance on how to interact. Courtemanche et al. (2012) demonstrated that it is possible to ensure that effective procedures were implemented when the clinician was not present by using an incentive bonus strategy based upon reviewing archived video made possible by HomeLink. More recently, grants are in process to utilize HomeLink to provide remote house calls by RNs and Physician's Assistants and to collect remote health data (e.g., seizure and vitals data). With HomeLink, it is unnecessary to watch hours and hours of video footage to observe the low rate, high intensity behavior a clinician wanted to see firsthand. Additionally, since the clinician isn't in the home it is unlikely that he or she is impacting a client behavior. Since data are firsthand recordings or live instances, much more information is available compared to traditional data collection. These uses of technology are rapidly changing the quality and cost of behavioral and health support, and will likely help enormously with treatment integrity over time. To learn more about what is presently possible and under development (as well as HomeLink's privacy protocols) see www.homelinksupport.com.

A Retrospective Analysis

Nearly 7 years ago, a group comprised clinicians from CLO and faculty from KU evaluated approximately 15 years of data on agency performance (Sherman et al., 2007). We were familiar that better outcomes (described previously) were achieved in our FTM and EFTM programs compared to our shift and group home programs. Our clinical review team also knew (from numerous years of clinical reviews of care) that many individuals experienced tremendous improvements in important personal outcomes when they moved from our group homes and shift homes to our FTM and

Table 25.1 Average incidence per month by home type

Client	Group home	FTM	EFT
<i>Weight (average pounds per month)</i>			
Harriet	NA	199	201
Joe	285	240	230
Tammy	146	NA	135
<i>Aggression (average instances per month)</i>			
Bob	NA	31	1
Brad	16	0	0
Christy	72	35	2
Doris	266	46	NA
Harriet	NA	8	4
Joe	867	300	200
Troy	NA	27	4
<i>Self-injury (average instances per month)</i>			
Christy	26	13	5
Dana	112	66	10
Tammy	28	NA	3

EFT homes. From these experiences and beliefs, this group examined the behavioral and medical outcomes for a selected sample of persons we had served in multiple homes across 15 years. The purpose of the review was to compare progress on long-term managed behaviors and medical conditions across types of residential home.

Our review clearly confirmed what our clinicians already knew, which was that the FTM and EFT homes made a reliable and meaningful difference in the quality of life of persons they supported who have very challenging behavioral and medical conditions, including elopement, self-injurious behavior, pica, aggression, obesity, and many other conditions. What the data showed is that when persons lived in shift homes, behavioral and medical challenges were generally higher than when they lived in FTM and EFTMs. We also learned that progress often reversed if they moved back to shift homes. Table 25.1 contains data generated from this retrospective review.

Dragon Wrestling 101, Putting it All Together

The goal of this chapter is to discuss strategies for providing cost-effective, best-practice services to support people with developmental disabilities

(and perhaps other populations) to live enriched community lifestyles in the community. It was not by accident that CLO has shifted towards its FTM and EFT models as preferred models of care. They provide much more stable staffing supports and allow a starting point for “on-demand” support to be cost-effectively leveraged by high technology. Live-in, Live-with, and Live-by models of care combined with HomeLink-like technology may become the *quality and cost* “X factor” for providing high quality and affordable services by offering a way to leverage a caring community to benefit the needs of dependent populations within a small neighborhood.

Providing best-practice services, however, is as much about doing many, many small things correctly as it is about doing very big things well. This chapter presents many considerations, large and small, that work together to push forward service quality and best-practice community living supports. In all likelihood, the suggestions or considerations might raise more questions than they solved simply because they would need more explanation than would be possible within the scope of a book chapter. Our hope is that this chapter helps construct a list of strategies to be explored and offers a road map for community providers to systematically evaluate and implement systems-level supports. Most, if not, all providers lack sufficient resources to leverage service quality in ways that provide what they want for people in need. Our belief, though, is that much more is possible if the doors of best practice are fully open. We are in very challenging, fast moving, tight, and exciting times. It is times like these, however, that fuel important innovations.

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