

The National Autism Center's

# Evidence-Based Practice and Autism in the Schools



A GUIDE TO PROVIDING APPROPRIATE  
INTERVENTIONS TO STUDENTS WITH  
AUTISM SPECTRUM DISORDERS





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Text Revision (pp. 23)

ISBN 978-0-9836494-1-0

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## Acknowledgements

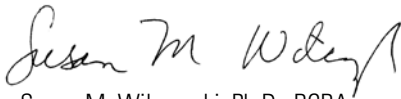
We are grateful to the many individuals and organizations who supported the development of this manual.

Production and distribution have been made possible through a generous gift from the American Legion Child Welfare Foundation, Inc. Thanks to their support, the National Autism Center has delivered thousands of free copies of the manual to educators across the country serving students with Autism Spectrum Disorders.

We also wish to express our gratitude to the Niel M. Wreidt 2003 Revocable Trust for the financial support that allowed us to develop this manual.

This manual could not have been developed without the contributions of its primary authors. We thank: Laura Fisher, Psy.D., for her comprehensive examination of Autism Spectrum Disorders (Chapter 1); Dipti Mudgal, Ph.D., BCBA, for her extensive review of interventions that have solid research support (Chapter 2); Hanna Rue, Ph.D., for her thoughtful examination of professional judgment and data-based decision making (Chapter 3); Melissa Hunter, Ph.D., for her sensitive consideration of strategies for incorporating family input into decision making (Chapter 4); and Susan Wilczynski, Ph.D., BCBA, for her analysis of methods of producing systemic change to enhance evidence-based practice in the schools (Chapter 5). Dr. Wilczynski also served as a secondary author for Chapters 1–4.

Finally, we appreciate the in-kind support provided by May Institute. Without the support of its talented communications team, this manual would be visually unappealing and hard to read!



Susan M. Wilczynski, Ph.D., BCBA  
Executive Director  
National Autism Center  
*Editor*



Eileen G. Pollack, M.A.  
Director of Publications and Media Relations  
National Autism Center  
*Editor*



## **Forward**

The National Autism Center is dedicated to serving children and adolescents with Autism Spectrum Disorders (ASD) by providing reliable information, promoting best practices, and offering comprehensive resources for families, practitioners, and communities. The National Autism Center initiated the National Standards Project to conduct a comprehensive review and evaluation of existing research into treatments for children and adolescents with ASD. The resulting National Standards Project Report was published in 2009 to share these findings. (See Appendix for the *Findings and Conclusions* report.)

We offer this educator manual to help fulfill the National Autism Center's mission to advocate for evidence-based practice, and to assist front-line interventionists as they select and implement the most effective research-supported treatments for ASD.

# Introduction

## The Importance of Evidence-based Practice

The evidence-based practice movement began in medicine in the 1990s.

While research had led to advancements in the medical treatment of patients, physicians were not always aware of these advancements. In some cases, physicians continued to use medications or medical procedures that were no longer considered appropriate. In other cases, physicians were unaware of newer medications or medical procedures that would lead to better outcomes for their patients.

Physicians are not alone in their need to stay current with advances in research and best practices in their fields of expertise. A broad range of health and school professionals also face this problem. While keeping up with research is challenging, we are all obligated to do so in order to provide the most appropriate and effective services to the students we serve. In fact, federal legislation regulating the provision of services in schools is filled with references about the need to employ research-supported treatments (Individuals with Disabilities Education Improvement Act, 2004; No Child Left Behind, 2002).

The National Autism Center has developed this manual as a means of promoting evidence-based practice for Autism Spectrum Disorders (ASD) in the schools. Why? Because we know that evidence-based practice is in the best interest of the student and that it is most likely to produce positive outcomes with this population. The information presented herein is meant for all “front-line” interventionists who work in school settings.

Although research findings are essential, they are not the only component of evidence-based practice. Evidence-based practice requires the integration of research findings with other critical factors.

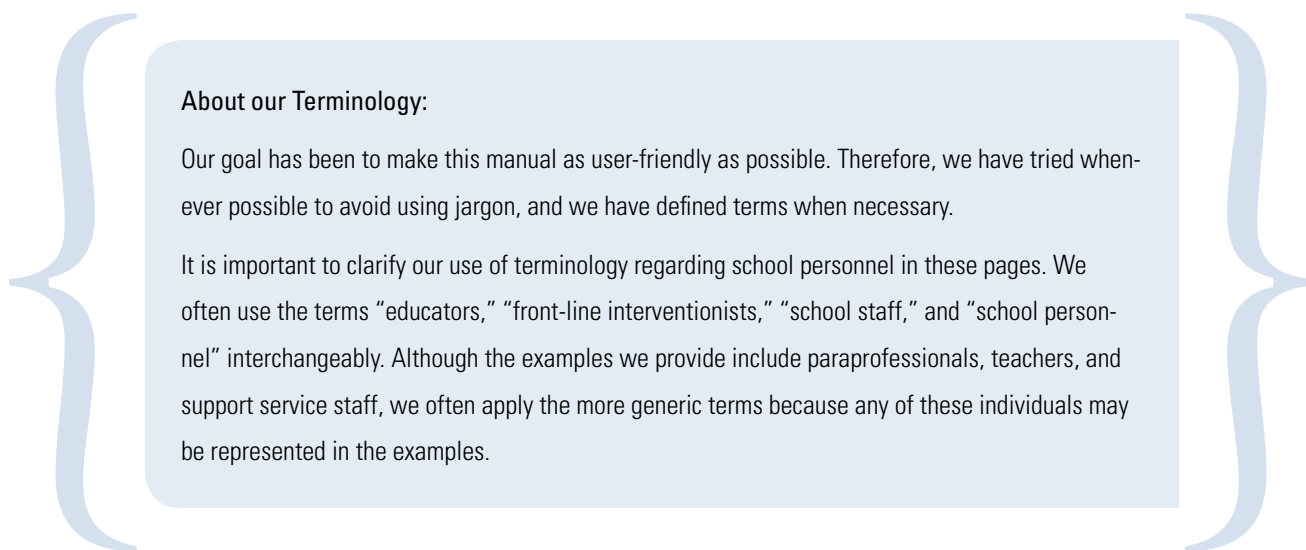


**These factors include:**

- Professional judgment and data-based decision making
- Values and preferences of families, including the student on the autism spectrum whenever feasible
- Capacity to accurately implement interventions

This definition of evidence-based practice is applied to school settings throughout this document. Evidence-based practice is complex and requires both ongoing communication and respectful interactions among all stakeholders. Even when a list of effective treatments is identified, collaboration is the key to achieving the best outcomes. To that end, we have provided examples involving a broad range of professionals and support staff throughout the manual to illustrate the points we make.

We have organized this manual in a progressive fashion. We recommend beginning with the chapter describing ASD and ending with the chapter on building capacity. Although some chapters may be perceived as more relevant to some school personnel (e.g., an administrator may be drawn to the chapter on building capacity), we believe it is important for all school personnel to be familiar with all factors that contribute to evidence-based practice for ASD. For example, we anticipate that even experienced professionals will benefit from the discussion about complex diagnostic concerns for this population.



**About our Terminology:**

Our goal has been to make this manual as user-friendly as possible. Therefore, we have tried whenever possible to avoid using jargon, and we have defined terms when necessary.

It is important to clarify our use of terminology regarding school personnel in these pages. We often use the terms “educators,” “front-line interventionists,” “school staff,” and “school personnel” interchangeably. Although the examples we provide include paraprofessionals, teachers, and support service staff, we often apply the more generic terms because any of these individuals may be represented in the examples.



## Outline of Chapters

### Chapter 1} Autism Spectrum Disorders

Most readers of this manual will already have some understanding of Autism Spectrum Disorders (ASD). But autism and related disorders are complex, and we all benefit from considering just how broad the spectrum can be. Experience with young students with severe autism is not the same as understanding adolescents with Asperger’s Disorder. Further, an alarming number of students with ASD are misdiagnosed with alternate disorders for years before receiving the correct diagnosis. Finally, some students on the autism spectrum should also be diagnosed with one or more additional disorders. Correct diagnosis is essential for developing interventions that will help your students reach their potential.

We begin our manual on Evidence-based Practice and Autism in the Schools by reviewing the defining and associated features of ASD. In Chapter 1, we also consider variables that should be examined when making differential diagnoses for individuals demonstrating symptoms often associated with ASD.

### Chapter 2} Research Findings

Everyone wants to use treatments that work. Yet identifying effective interventions can be challenging. Consider this: treatments for which no well-controlled research has been published are often described as “evidence-based practice.” This can make it extremely difficult to know which treatments have research showing they are effective, and which do not.

We recognize that translating research into practice is complicated. That is why we have created this manual as a tool to help you know which interventions have strong evidence of effectiveness. The National Autism Center’s National Standards Project identifies the level of research support available for treatments often used with school-aged individuals on the autism spectrum.

In the *Findings and Conclusions* report of the National Standards Project, the term “Established Treatments” is applied to any interventions with sufficient research to show they are effective. Eleven Established Treatments are identified in Chapter 2. We describe each one detail and provide illustrative examples to clarify the uses of these interventions.

## Chapter 3} Professional Judgment

Evidence-based practice is a complex process that requires the knowledge and skills of well-trained professionals. Therefore, your professional judgment is extremely important in this process. In your work, you are presented with a broad array of treatment options available to support students on the autism spectrum. Even if you restrict your choices exclusively to treatments that have produced favorable outcomes in research, you will need to select among the field of 11 identified in the *Findings and Conclusions* report.

Your experience working with a specific child with ASD, your understanding of interventions that have been effective in the past, and your awareness of the environment in which the treatment would be implemented are all critical to helping you identify which of these 11 Established Treatments might be most useful.

Since research is ongoing and best practices evolve, your professional judgment extends to your awareness of additional research support beyond those studies reviewed in the *Findings and Conclusions* report.

### For example:

- The National Standards Project reviewed articles published before the fall of 2007. We are happy to report that additional research has been conducted and published since that date. As a result, you may be aware of more recent, well-controlled studies that strongly suggest more research support for an intervention identified as an “Emerging Treatment” in the *Findings and Conclusions* report. Armed with this knowledge, your judgment may lead you to place that treatment under consideration along with any of the Established Treatments.
- There may be some symptoms that co-occur with ASD that are not associated with any Established Treatments. For example, some adolescents with Asperger’s Disorder may experience co-morbid psychiatric disorders (e.g., anxiety disorders or depression). There are no treatments specifically addressing anxiety and depression that fall into the Established Treatments category in the *Findings and Conclusions* report. However, there *are* treatments for anxiety and depression for individuals who are not diagnosed with ASD. Your awareness of this important literature should absolutely assist in treatment selection.

Like other evidence-based practice guidelines, the National Standards Project followed strict inclusionary and exclusionary criteria. How did this affect the outcomes? Perhaps Facilitated Communication can serve as an example. The National Standards Project excluded a large number of studies on the treatment of Facilitated Communication because they involved {a} adults 22 years of age or older, or {b} individuals with infrequently occurring co-morbid conditions, or {c} adult facilitators (as opposed to the individuals with ASD). Although Facilitated Communication was classified as an “Unestablished Treatment” in the *Findings and Conclusions* report, as a professional, you may be aware that a large number of professional organizations have developed resolutions advising against the use of Facilitated Communication. These resolutions are often related to concerns regarding “immediate threats to the individual civil and human rights of the person with autism...” (American Psychological Association, 1994). Your professional judgment is likely to play a role in treatment selection in this case, as one example.

Professional judgment can also be important when considering an intervention identified as an Established Treatment in the *Findings and Conclusions* report. You may

seek out more detailed information in the literature to help guide appropriate treatment selection.

For example, let’s say a young boy with ASD has a history of becoming prompt dependent. You might select “Schedules” to help him independently move from one task to another. Then you might select prompts that are easier to fade as opposed to prompts that are more difficult to fade. Although schedules and prompting procedures are each identified as an Established Treatment in the *Findings and Conclusions* report, your professional judgment as a front-line interventionist is essential in structuring environments that best promote independent learning.

Initial treatment selection is only one part of the process of engaging in evidence-based practice. In order to be confident that an intervention is effective with a specific student, it is necessary to collect data. These data should be collected in a way that allows you to determine if the intervention is effective. Data will also let you quickly make changes to treatments if an intervention is not producing desired improvements for your students.

Chapter 3 offers a more complete discussion of the importance of professional judgment and the role data collection plays in this process.

## Chapter 4} Values and Preferences of Families

Family members and/or the individual with ASD should participate in intervention selection to maximize outcomes. The annual review of the Individualized Educational Plan (IEP) serves as one opportunity to discuss the comprehensive goals to be met so that the student with ASD can reach his academic potential and participate in meaningful ways in the community. But setting these goals is only the starting point in the conversation that should occur between family members, the student with ASD, and school professionals. To achieve the best outcomes, efforts should be made to build consensus about the treatment approaches used to meet the IEP goals.

There are several ways in which treatment selection is undermined if the input of family members and/or the individual with ASD is not sought, or is ignored. For example, family members often seek additional supports beyond those offered within school systems. Behavior specialists, speech-language pathologists, occupational or physical therapists, and other professionals may provide therapeutic services outside the school setting. These professionals may have already attempted to implement any number of treatments that did not produce favorable outcomes. Without seeking the family's input, school professionals may select treatments that have already been shown to be ineffective with a specific child. (See Chapter 5 for discussion of the importance of data-based decision making as a component of professional judgment.)

It is also important to understand how the cultural values and preferences of a family may conflict with the implementation of one treatment or another. For example, in certain cultures, it is not appropriate for children to make direct eye contact with adults. Despite the fact that teaching a child to make and maintain eye contact is often one of the first skills addressed in Comprehensive Behavioral Treatment for Young Children, family members may object to this skill being taught. Often, a compromise might be reached if an open and honest dialogue occurs. (For example, the child will make eye contact with adults in the school setting, but no efforts will be made to teach her to make eye contact in other settings.) Conversely, the team may make the decision to

begin the intervention without directly teaching eye contact and then set a date to reconsider the issue if the data show the child is making little progress.

There are many barriers that could undermine parental participation in the educational process. These barriers do not have to be insurmountable if schools seek to identify and address them. For example, additional supports should be provided for families facing challenges associated with transportation, child care, language barriers, or difficult work schedules. We offer strategies for gathering information from families that will allow you to create a positive and inclusive environment for the entire family.

The individual with ASD is a member of the family, and his values and preferences must also be taken into consideration whenever feasible. For example, an adolescent boy who would benefit from an improvement in his social relationships might select a less intrusive intervention (such as Social Stories™) over a more intrusive procedure that sets him apart (such as Peer Training Package). Certainly, his opinion is relevant in selecting between these two treatments, and will likely have an impact on outcome.

To expand your use of strategies for incorporating the values and preferences of families, we encourage you to read Chapter 4.

## Chapter 5} Capacity

Let's say your school makes the decision to implement one of the interventions identified as an Established Treatment in the *Findings and Conclusions* report. Does this automatically mean you are about to engage in evidence-based practice for ASD? We would argue that you are not—that is, not until you have built the capacity to implement the intervention with a high degree of treatment integrity. Further, even after you have begun to implement the intervention correctly, you must ensure the intervention is sustainable.

We already know that selecting treatments should involve {a} an understanding of research findings, {b} input from qualified professionals, and {c} input from families, including the student whenever possible. However, when your school makes decisions about implementing an intervention, it's important to ask, "If we feel strongly enough that this intervention should be implemented with one child, should it also be



implemented with more children with ASD who exhibit similar needs?” When selecting one of the Established Treatments, the answer will almost always be “yes.”

Selecting treatments for more than one child often involves making systemic changes within the school system. This typically begins with problem clarification. You need to answer three questions: What do we need to accomplish? Who is responsible for planning for the new treatment? Who will evaluate the effectiveness of the new treatment?

When decisions are made for a specific child, these questions are often answered by a small team of individuals who work with or care for the child. When decisions are made for a school system, it is important to include a broader range of professionals, as well as families, into the decision-making process. Paraprofessionals, other support staff, psychological services, allied health professionals, and administration—in addition to teachers—should all be included in the planning and evaluation of any new treatment that is being adopted broadly (across students and settings).


The planning and evaluation team will also need to make decisions about the scale of the change (e.g., a classroom, a grade level,

or a school) and the groups for which the new treatment should be considered (e.g., All children? All children with ASD? Children in a particular age group or developmental level?). Next, the team must consider all aspects of the system that may be affected by this change. For example, will the curriculum need to be changed? What are the settings in which the treatment will be delivered? Who will deliver the treatment?

**Before beginning training, a needs assessment should be conducted to identify the following barriers:**

- Differences between the existing and proposed interventions
- Additional time required to implement new treatments
- Treatment acceptability
- History of treatment delivery
- Organizational climate

The planning and evaluation team’s responsibilities do not end with the needs assessment. They must also operationally define the intended outcomes. This may involve specifying the goals for a classroom, grade level, and/or school system. In addition to clearly defining the goals for the affected system, the goals for the target population

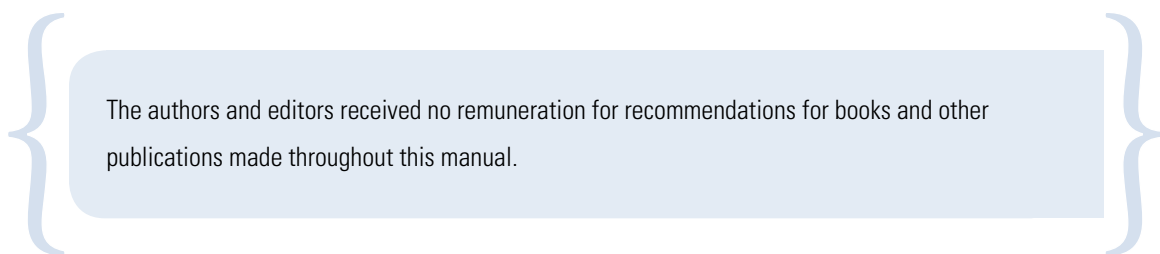


must be defined so that they are specific, observable, and measurable. Both immediate and long-term goals must be considered.

Finally, the planning and evaluation team must develop a written plan for implementing the intervention. That plan will clearly specify the roles and responsibilities of both the team and the professionals responsible for implementing the new treatment. Developing the plan is an extensive process that is outlined in Chapter 5.

## **Appendix} *Findings and Conclusions of the National Standards Project***

The *Findings and Conclusions* report of the National Standards Project is published in the appendix of this manual. We hope you will find this to be a valuable resource.



The authors and editors received no remuneration for recommendations for books and other publications made throughout this manual.

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# 1

# Understanding Autism Spectrum Disorders

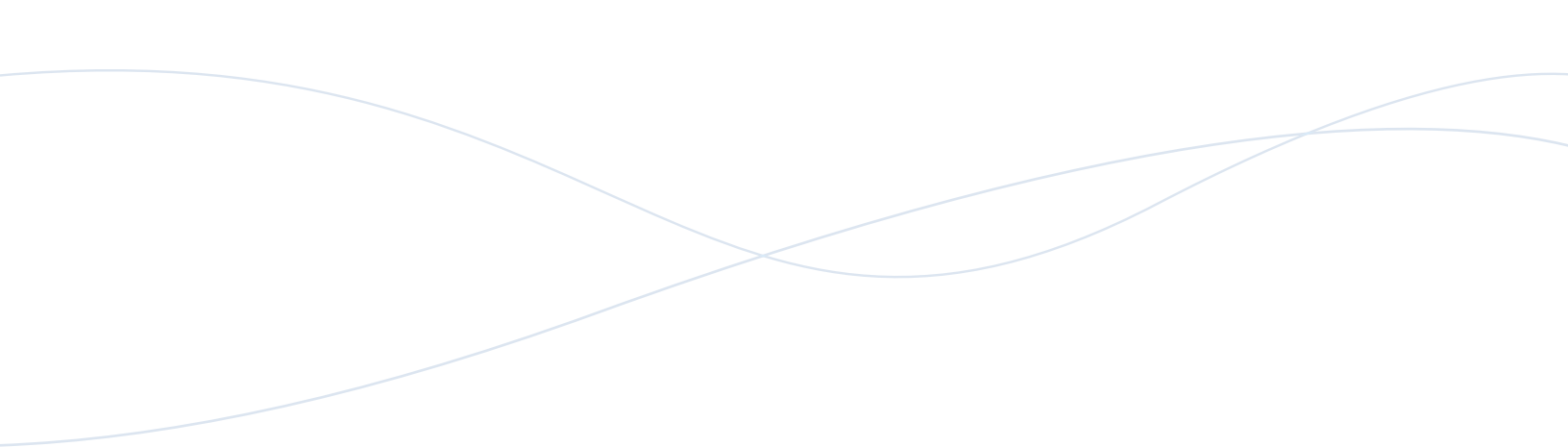
## Historical Perspective

There has been tremendous progress made in the field of autism over the last 50 years. While it was once a syndrome that was rarely discussed in public, we find information about Autism Spectrum Disorders (ASD) all around us—on television and radio, websites and Internet searches, public service announcements, and in the views of celebrities sharing their stories. Even the President of the United States is now discussing the importance of autism diagnosis, cause, and cure, and he has earmarked federal dollars for research and treatment initiatives that will be instrumental in furthering the field in the years to come.

Before discussing the current state of autism, however, let's briefly review the history of this disorder and what we have learned over the years.

In 1943, a doctor named Leo Kanner began observing a group of children who were previously thought to have mental retardation. He noticed that these children had difficulty developing speech, and did not socially interact with their peers. He also noted that these children engaged in ritualized and/or repetitive behaviors to the exclusion of other activities. These children had difficulties with transitions, and did not like changes in their routines or schedules. Some of them experienced regressions in their functioning over time, losing skills that had been established previously. We know Kanner's description will be familiar to you if you serve children on the autism spectrum.

At the time, treatment for autism was very limited. Most of these children were placed in institutions, far from the public eye, to live out their lives. Professionals



commonly held the view that “refrigerator mothers” were responsible for the symptoms observed in these children. Deficits in the children’s functioning were assumed to be linked to poor attachment and/or absentee parenting (Bettleheim, 1967). Because parents were often blamed for their children’s disorders, many experienced great shame for having a child with ASD.

Much has changed in the last five decades. We now know that autism is most likely caused by a combination of genetic and environmental factors. Although we would like to think that parents are no longer blamed, all-too-frequent examples demonstrate how autism is still widely misunderstood. One example is a nationally known radio personality who recently stated that autism was “a fraud, a racket” and that a child diagnosed with ASD is probably “a brat who hasn’t been told to cut the act out.” Let’s hope that some day parents will no longer face this kind of discrimination.

Around the same time that Kanner was identifying symptoms of autism, pediatrician Hans Asperger was studying another group of children (Wing & Gould, 1979). These boys and girls were also having problems in social interactions with their peers. Like their counterparts, they exhibited behavioral problems commonly seen in children with autism. However, this group of children did *not* have deficits in speech and language formation. In fact, these children often spoke early and frequently. They also did not display deficits in adaptive functioning. In other words, these children could feed themselves, dress themselves, participate in their personal care, and function independently in the community. Unlike the group that Kanner observed, most of these children did not have lowered cognitive abilities. They were often very bright and had specific areas of interest in which they could amass large amounts of information.

Unfortunately, Asperger’s research was not discovered until three decades later. It was reintroduced to the field when other individuals interested in ASD began questioning the diagnostic criteria that were used at the time. His work has made a tremendous difference in the way we have come to view and understand the autism spectrum.

## Defining and Diagnosing Autism Spectrum Disorders

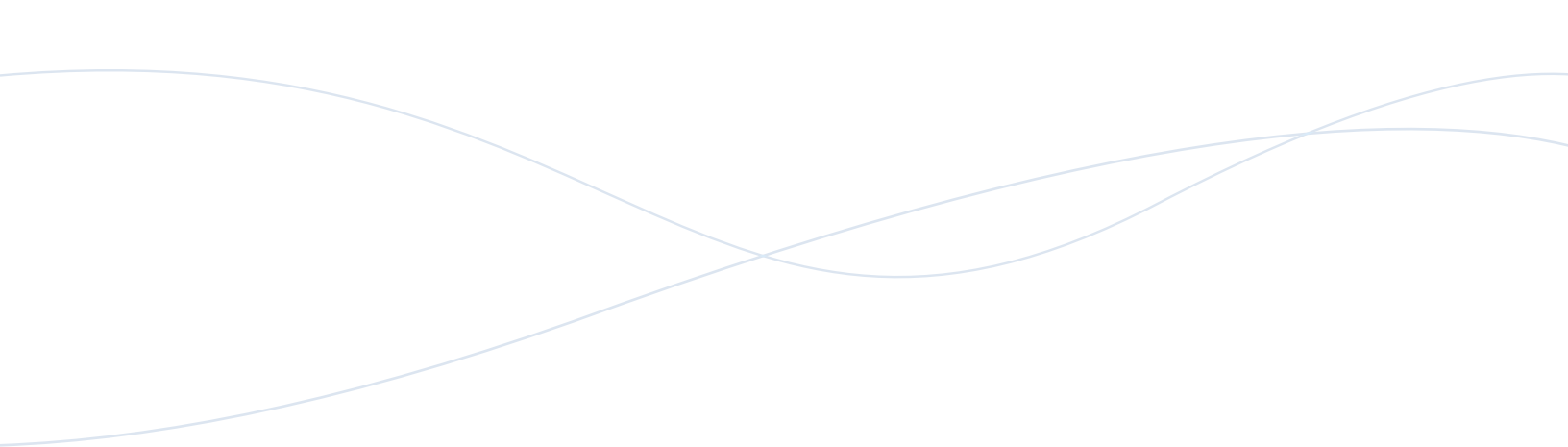
In 1994, the *Diagnostic and Statistical Manual of Psychiatric Disorders* (DSM-IV) went through a complete overhaul (American Psychiatric Association). The diagnostic criteria for Pervasive Developmental Disorders (PDD), commonly referred to as Autism Spectrum Disorders (ASD), were reviewed and revised to include aspects of both Kanner's and Asperger's work.

There was also additional research on another group of children who seemingly met strict criteria for autism, but did not have severe deficits in cognitive functioning. As a result, these children were labeled as having "high functioning" autism (Ozonoff, Dawson, & McPartland, 2002). Steps were then taken to establish new diagnostic criteria which considered the changes and variability observed in children with ASD.

**The current version of the DSM (DSM-IV-TR, 2000) includes five major diagnoses that fall under the Pervasive Developmental Disorder (or ASD) umbrella:**

1. Autistic Disorder
2. Asperger's Disorder
3. Pervasive Developmental Disorder–Not Otherwise Specified (PDD-NOS)
4. Rett's Disorder
5. Childhood Disintegrative Disorder

Of the five, two of these disorders (Rett's Disorder and Childhood Disintegrative Disorder) are extremely rare, and you are unlikely to see these cases in schools. In fact, they are sufficiently different from the other three disorders that there is disagreement in the field about whether or not they actually belong on the autism spectrum.



The other three diagnoses are more common, and you are very likely to come in contact with children and adolescents who meet criteria for one of the three disorders in your daily school interactions with students.

As our understanding of ASD has evolved over the years, so too has the way we diagnose and treat children with ASD. It can be viewed as a lifelong syndrome that is usually diagnosed in early childhood and continues through adulthood. Although there is currently no cure for ASD, impressive and long-term life outcomes can occur when children receive early and intensive behavioral interventions.

In fact, a percentage of children “fall off” the spectrum following intensive intervention and re-evaluation by autism specialists (*USA Today, May 8, 2009*, “Some kids with autism can recover, study suggests”). These kinds of improvements reinforce the critical importance of early identification and treatment. As a field, we are continually improving the way we identify children so we can streamline them into specialty services (Gupta et al., 2006; Kabot, Masi, & Segal, 2003; Sigman, Dijamco, Gratier, & Rozga, 2004).

## Misperceptions About ASD

When people think of ASD, they often conjure up images of individuals with severely impaired language who are living in institutions, similar to Dustin Hoffman’s character in the movie *Rainman*. Working in the schools, however, you know this is typically not the case. While it is true that some children remain nonverbal, many children with ASD have some form of verbal communication skills. They often develop these skills as a result of treatment provided by school and allied health professionals who are committed to evidence-based practice.

Another commonly held assumption that has evolved over time is that all children with ASD have intellectual disabilities. It is true that, in the past, over 80% of children diagnosed with ASD also met criteria for mental retardation. However, with early diagnosis and access to effective treatment, these numbers are decreasing (Chakrabarti & Fombonne, 2005).

## Autism Today

There has been much discussion as to why the rate of autism has been steadily increasing since the 1990s. One reason is linked to the change in diagnostic nomenclature in 1994. At that time, the diagnostic criteria for autism expanded to include children who were not previously considered “on the spectrum.”

Studies have shown that, despite this change in diagnostic criteria, the number of diagnosed cases of ASD is much higher than expected (Johnson & Myers, 2007). Many researchers believe the increase in the number of cases of autism worldwide is due to a combination of genetic and environmental factors (Folstein & Rosen-Sheidley, 2001).

Researchers are working diligently to seek answers for families about the cause of autism.

### *Current facts about autism:*

- It affects 1:150 children nationwide (Centers for Disease Control and Prevention).
- It can be found in all cultures of the world, and does not discriminate based on race, socio-economic status, education of parents, or other demographic variables (Wong, Hui, & Lee, 2004; Howlin & Asgharian, 1999).
- It is three to four times more common in boys than in girls.
- It currently has no known cause or cure.



## What Does Autism Look Like?

This section describes each of the five diagnoses for ASD in greater detail. As you study the different features and characteristics associated with these diagnoses, you will be able to more clearly identify the similarities and differences between autism and its related disorders.


### Autistic Disorder

As many front-line interventionists know, autism is characterized by severe difficulties in communication, socialization, and behavior (Klinger, Dawson, & Renner, 2003). What this means for individual children varies based on each one's cognitive ability, communication skills, and adaptive functioning. When a child is diagnosed with Autistic Disorder, or autism, he or she has met at least six out of 12 criteria, with at least two criteria in the social domain, based on the DSM-IV-TR (APA, 2000).

In addition, symptoms must be present before the age of three, and must affect the child's functioning in more than one area of concern (i.e., home, school, or community). Moreover, symptoms cannot be better accounted for by other disorders associated with attention, behavior, thought processes, medical concerns, or mood.

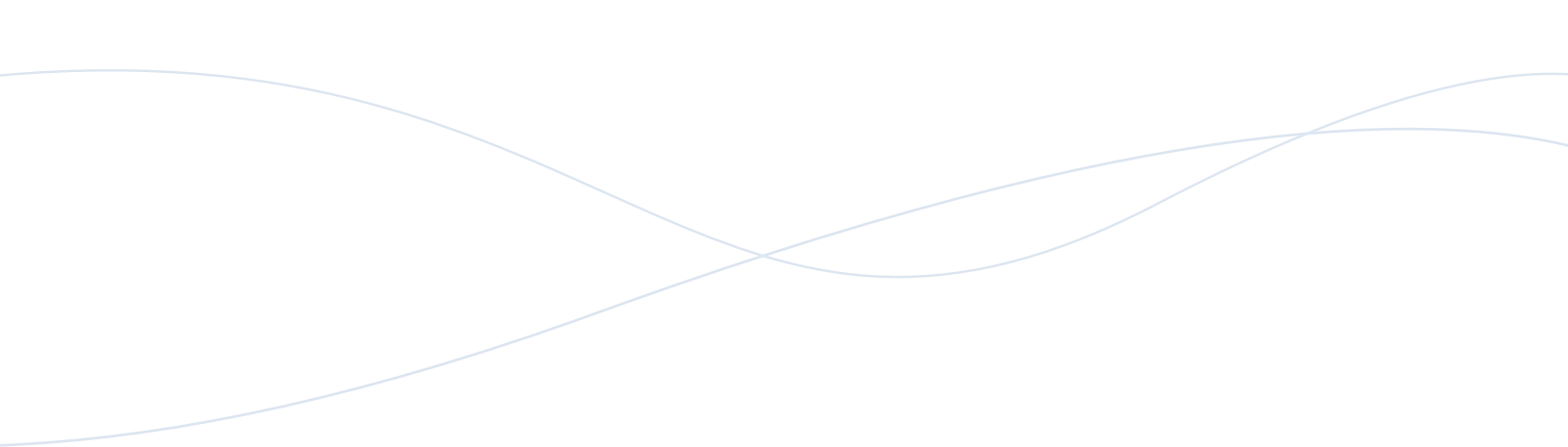
#### Examples of symptoms of Autistic Disorder in the *communication* domain include:

- The child must have a delay in language.
- The child does not compensate for a delay in language by using strategies like gestures to communicate.
- The child may exhibit problems with language, once language starts to develop. For instance, he may engage in repetitive language, or scripts, to communicate. He may repeat phrases he has heard on television or from his parents or friends.
- The child may immediately echo the speech of another individual.
- The child often has trouble initiating and maintaining conversations with peers. It may seem like she is talking *at* someone instead of *with* someone. She may also find it difficult to start and stop conversations.
- The child often has significant difficulty with, or cannot respond to, open-ended questions.

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- The child may exhibit significant delays in play skills. Typically, as a child ages, he should move from basic imitation to more complex make-believe play (Lifter, 2008). However, he also needs to be able to interact with peers when they play—something which children on the spectrum often do not do spontaneously.

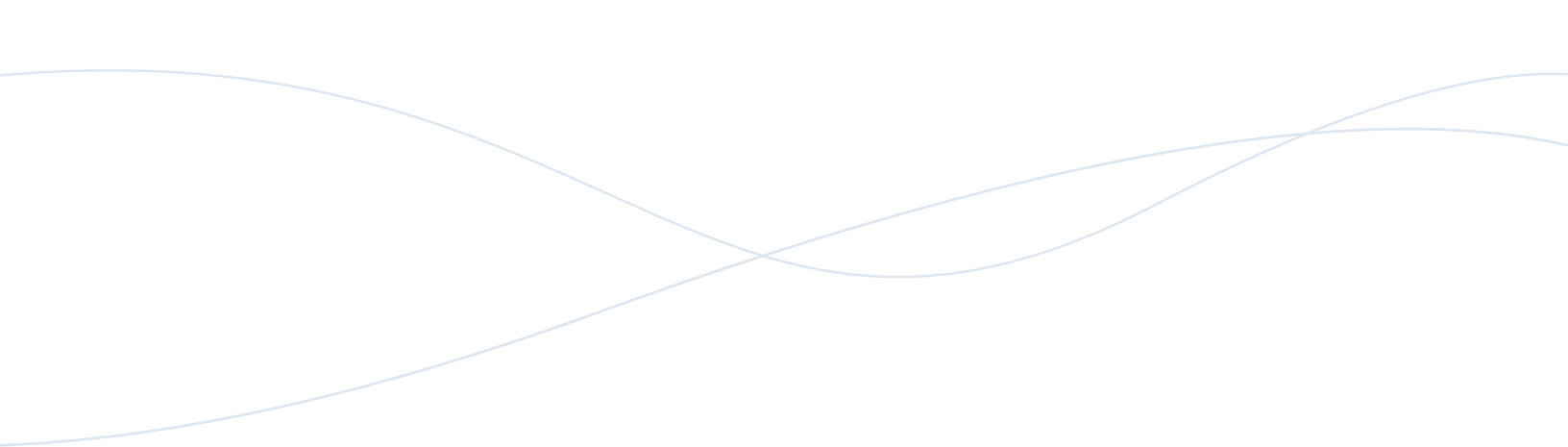
**Examples of symptoms of Autistic Disorder in the *social* domain include:**

- The child may poorly modulate eye contact. She may be able to look at family members, but not at peers. Or she may be able to make eye contact, but only fleetingly or under certain conditions.
- The child may have a blank expression, or difficulty expressing a range of facial expressions. Some children with autism appear to be happy and smiling all the time. While this may seem to be a positive attribute, it can be misleading or confusing when a child who has a happy expression kicks or bites out of anger or frustration.
- The child may be capable of displaying many different facial expressions, but still fails to convey his emotional state to others. For example, a child may not physically orient to another person to communicate his mood. He may then become frustrated that others are not picking up on his moods (even though he is not directing his facial expressions to help other children and adults understand his point of view). In extreme cases, children may actually turn their bodies away from you when interacting. This can be quite confusing for the conversational partner.
- The child may have difficulty incorporating *nonverbal* communication in his speech or social interactions. Most people talk with their hands, make subtle movements with their eyes and head to indicate the conversations should continue or end, and engage in other slight nonverbal gestures as a way of communicating. In fact, 80% of communication is nonverbal in nature! Most children with autism do not know how to use gestures effectively. These children may not realize the significance of specific gestures, and may therefore use them inappropriately. Unfortunately, many children with autism have a difficult time reading nonverbal cues. As a result, they may be ostracized by peers due to their inability to manage social interactions.

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- The child may have significant problems making and maintaining friendships. A younger child with autism will often play alone or have difficulty joining group activities. She may also engage in earlier stages of play, such as parallel play, when her peers engage in more interactive play. An older child may not have a “best friend” or social group. He may prefer solitary activities such as playing video games all day, or setting up elaborate play schemes with action figures that cannot be altered by others.
  - The older child with autism may not understand personal boundaries, and will either stand too close or too far away from peers. Overall, establishing friendships is difficult.
  - The child may have difficulty with “social or emotional reciprocity,” which can be loosely translated as the give and take of an interaction. She may be more successful when she can set up the interaction to accommodate her needs. Some common challenges with reciprocity for children with autism include:
    - ▶ Turn-taking activities, particularly for younger children.
    - ▶ Expressing empathy when others are upset or distressed. This becomes more problematic as children age and emotional and social concerns move to the forefront.
    - ▶ Offering comfort when another person is crying, or joining in when someone is extremely happy.
    - ▶ Sharing accomplishments or seeking praise.
    - ▶ Understanding their role in relationships. This can be the biggest challenge for children on the spectrum, as they often do not realize how their behaviors affect those around them.
    - ▶ Knowing how to alter their behavior to better meet the needs of others.

**Examples of symptoms of Autistic Disorder in the restricted, repetitive, nonfunctional patterns of *behavior, interests, or activities* include:**


- The child may exhibit strong interests in a specific topic or toy. Children with autism have been known to have extreme interests, such as memorizing train schedules or dates in history, or categorizing all aspects of aquatic life. They may have extremely well-developed memory skills, and be able to easily recall things that occurred many years ago. Many children gravitate to numbers, letters, and colors in their play and communication with others. Some children become fixated on videos such as *Thomas the Tank Engine*, watching segments of the movie over and over.
- The child may have extremely rigid ideas about time, travel, and daily routines. He might become highly agitated if his routine is altered. It is not uncommon for parents to report that their child becomes very upset when the family drives a different route home from school one day.
- The child often thrives on structure, and can have difficulty adjusting when school vacation starts, or the family moves to a new home. This rigidity can be seen in a child's play as well. Some children insist that play sequences unfold in a certain manner, and become annoyed or withdrawn if the play sequence is altered by peers or adults. Parents also report rigidity around feeding, dressing routines, and placement of objects around the home.
- Probably one of the most obvious symptoms of Autistic Disorder includes the atypical body movements that are sometimes associated with this disorder. Although not always indicative of autism, these symptoms are often the first things people notice in terms of unusual behavior. For instance, some children really enjoy spinning their bodies in circles for much longer than their peers could sustain. Other children engage in full or partial body rocking, and may position their bodies in unusual ways. Children will sometimes run in ritualized patterns on the playground or in the home. They may walk on their toes or flap their hands. At times, they may flick their fingers or cross them in unusual ways.

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- The child may experience sensory challenges, and will be either over- or under-sensitive to temperature, texture, smell, or sound. It is not uncommon for the child to refuse to wear specific types of clothing or sleep on sheets that are not made of a specific material.
  - The child often engages in unusual play-based behaviors. She will line up her toys, categorize them, or place them in various positions that cannot be altered. Some children enjoy watching objects fall, and will repetitively drop objects such as balls, water, sand, etc. Other children enjoy spinning items, and will spin toys, plates, forks, lids, or other things that are not meant to be spun.
  - The child may visually examine his toys or objects in their environments. He may peer at objects out of the corner of his eye, but also may place them directly in his field of vision, moving them in and out of that field. Often, a child will flip over a toy car and flick the wheels while watching them spin, or lie on the floor and watch the wheels move as he pushes the car.

## **Asperger's Disorder**

In many ways, Asperger's Disorder (also called Asperger's Syndrome) is very similar to Autistic Disorder. Like the child with Autistic Disorder, the child with Asperger's Disorder has problems with multiple areas of critical life functioning which appear in a variety of situations. Whereas Autistic Disorder is characterized by deficits in *all* three domains (communication, socialization, and behavior), to qualify for a diagnosis of Asperger's Disorder, a child does not have an identified history of communication difficulties early in life. That is, basic receptive and expressive skills do not appear impaired in children under age five. By definition, children with Asperger's Disorder do not have a language delay. In fact, they often have a history of speaking early, and can be quite hypervocal in their toddler years. They may learn to read words early as well (i.e., hyperlexia), and may have awed their parents with their ability to recite things like labels and highway signs.

Although language delays are not identified in young children with Asperger's Disorder, this does not mean they will not experience significant communication challenges. As we have already described, communication is complex and involves



not only speech, but nonverbal strategies and social pragmatic skills. Social pragmatics involves the use of language for a wide variety of functions (e.g., requesting, informing, promising, etc.). It also involves the ability to alter language based on the needs of the listener. Students with Asperger's Disorder may not provide the context for a story they are telling, or may not understand that the quality and content of speech should be modified across settings (e.g., classroom, lunch room, library, etc.).

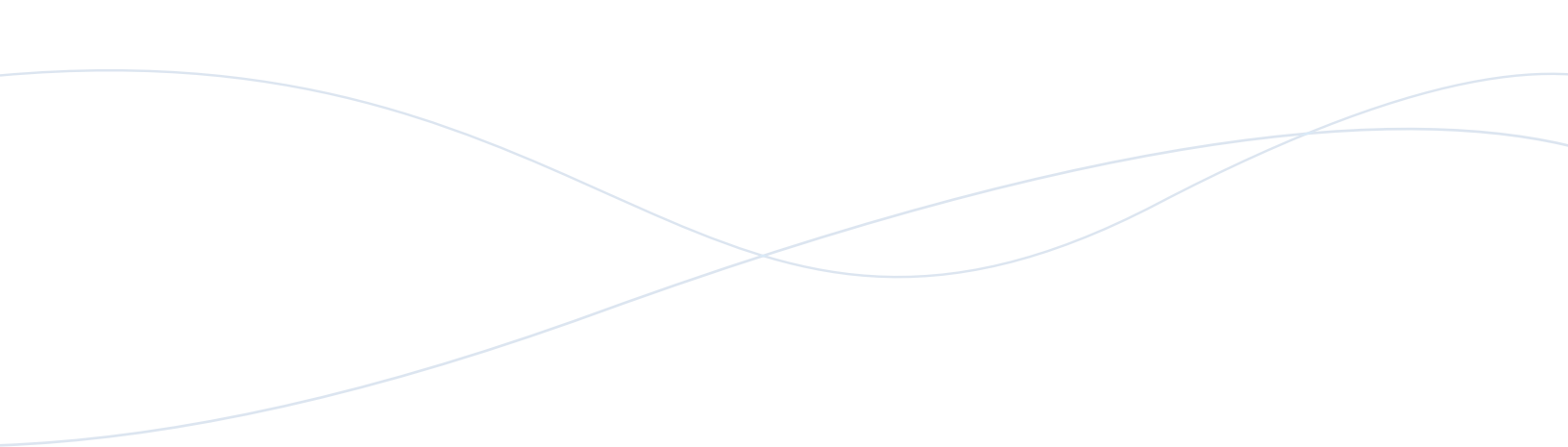
Finally, most people independently learn certain conventions about holding conversations. They probably read cues suggesting the person with whom they are communicating has become confused or bored. They read the expressions of others and change their own expressions based on the tone of the conversation. Students with Asperger's Disorder often have difficulty learning and applying these rules regulating conversations.

Similar to their counterparts with Autistic Disorder, some children with Asperger's Disorder have incredible memories and can amass large amounts of data about a topic of interest. Usually, these interests are atypical for the age of the child and can impede his ability to socially connect with other children. Unfortunately, most 7-year-olds do not want to hear all about the

sinking of the Titanic, the great horned owl of Minnesota, or how tectonic plates shift in the geothermal layer of the earth!

Like children with Autistic Disorder, children with Asperger's Disorder are likely to be challenged by social situations. However, they often appear more sophisticated than their counterparts with autism. As a result, people with whom they come in contact assume these individuals will follow the social rules that guide us through a complex social world. However, children with Asperger's Disorder will likely miss social cues provided by peers. Their timing may be off when they initiate an interaction, and the quality of the interaction is usually different from that of their peers. They may find awkward ways to interject their agenda into a social activity. Because many individuals with Asperger's Disorder have reduced interest in interacting with others, they unfortunately get even less experience developing these social skills.

Children with Asperger's Disorder differ from children with Autistic Disorder in two other fundamental ways. First, they do not have cognitive delays. In some cases, they may even be intellectually gifted, and may receive high scores on standardized tests of intelligence. These children often display higher verbal skills as compared to nonverbal skills. (Often, the reverse is true in Autistic Disorder.)



Despite their cognitive strengths, students with Asperger’s Disorder often require accommodations in the classroom in order to successfully manage the same academic coursework and materials as their peers. They may have difficulties understanding the abstract nature of some instructions, or may be challenged by the lack of structure involved in some tasks (e.g., self-directed group activities).

Secondly, children with Asperger’s Disorder do not exhibit delays in adaptive functioning. This means they can bathe, feed, and dress themselves without assistance. They generally do not have difficulty with skills such as making purchases, using computers, or applying basic rules of safety in public places. They often attend regular classrooms and can be involved in peer-driven activities.

## **Pervasive Developmental Disorder–Not Otherwise Specified**

Pervasive Developmental Disorder–Not Otherwise Specified (PDD-NOS) is an umbrella term assigned to children who do not meet criteria for either Asperger’s Disorder or Autistic Disorder (Walker et al., 2004). Psychologists diagnose PDD-NOS when a child has *some* symptoms of ASD (4-5 versus 6 or more). In addition, children who do not have the typical profile but meet a sufficient number of characteristics of ASD (e.g., a child who starts to show symptoms after age 3) would receive a diagnosis of PDD-NOS.

The most common misconception about a diagnosis of PDD-NOS is that it is equivalent to a very mild form of autism. Nothing could be further from the truth! For instance, a child can have 4-5 extremely severe symptoms and meet criteria for PDD-NOS. In comparison, a child with Autistic Disorder (six or more symptoms) can display more mild symptoms, and have fewer deficits overall. Therefore, when formulating plans for students with PDD-NOS, it is often beneficial to think of these children as having similar levels of difficulties as seen in other ASD diagnoses.

Researchers have increased their focus on the diagnosis of PDD-NOS. They speculate that PDD-NOS includes a number of different sub-groups that explain and account for unique clusters of symptoms. Until this issue is resolved, however, a greater percentage of the students you encounter may carry this diagnosis, as compared to either Asperger’s Disorder or Autistic Disorder.

## Rett's Disorder

Rett's Disorder is also considered a Pervasive Developmental Disorder, or an ASD. However, this disorder is much more severe and life-altering than the previous three discussed.

The research-supported treatments described in this manual may be implemented with students with Rett's Disorder. However, the "findings and conclusions" were not based on a review of literature involving individuals with Rett's Disorder. Studies involving children with Rett's Disorder and Childhood Disintegrative Disorder were not included in the National Standards Project because these disorders are not on the autism spectrum, according to the Centers for Disease Control and Prevention. Also, the developmental trajectories are so different for these disorders that there is controversy in the field about whether or not they should continue to be included in the DSM as Autism Spectrum Disorders. We provide the following description in the event you encounter a student who seems to show some characteristics of autism, but who also seems very different to you.

### Facts about Rett's Disorder:

- It is characterized by repetitive hand movements, such as clapping or wringing of hands, which affect the purposeful use of the hands. The hand-to-hand contact occurs persistently throughout the day and involves the meeting of the hands in the middle of the body.
- It is caused by a mutation on the MeCP2 gene in 80% of diagnosed cases.
- It is a very rare disorder, affecting one in every 10,000 births.
- It is more commonly seen in females, although we now know that males can also have this genetic abnormality.
- Children with Rett's Disorder may have intellectual disabilities. However, IQ scores may not always be accurate because problems with motor coordination can interfere with performance on verbal and nonverbal tests.
- Children with Rett's Disorder are often nonverbal, with significant delays in all forms of communication (e.g., speech, use of gestures, and other nonverbal communication strategies).



- Children with Rett’s Disorder have multiple systemic issues such as gastrointestinal problems, motor problems, and bone density abnormalities.
- Seizures are common in children with Rett’s Disorder. As with all seizure disorders, additional loss of skills may occur if seizure activity is not well-controlled.
- Many children with Rett’s Disorder exhibit air swallowing and sleep apnea, and have choking responses to food. Because of these multi-system concerns, it is important that you are well-informed about how to address these issues. When working with children with Rett’s Disorder, you may have contact with professionals such as neurologists, gastroenterologists, psychiatrists, developmental pediatricians, orthopedic specialists, feeding specialists, breathing specialists, and behavioral specialists.
- Increasing motor problems may be evident after the age of 10.

## **Childhood Disintegrative Disorder**

The final disorder on the Pervasive Developmental Disorder continuum is Childhood Disintegrative Disorder (CDD). As noted previously, the research-supported treatments we describe in this manual were not based on a review of literature involving individuals with CDD. We provide the following description of CDD in the event you encounter a student who seems to show some characteristics of autism, but whose history seems very different to you.

### **Facts about Childhood Disintegrative Disorder:**

- It is an extremely rare disorder—even more rare than Rett’s Disorder.
- Children with this disorder develop normally during the first two years of life. At around age 3 or 4 (but up to age 10), these children begin to regress in their communication, social, and behavioral skills. Children who were verbal lose the ability to speak; those who were social and outgoing appear to become more withdrawn and isolated; and adaptive functioning skills such as walking or toilet training disappear.
- The outcome for many of these children is poor, and treatment, although congruent with treatments for autism, is not as effective over time.



## Autism Across the Lifespan

The symptoms exhibited by a student with ASD may change over time. A child who receives speech services at age 3 may face very different communication challenges by the time she reaches her high school years.

Each developmental stage brings its own challenges for all children, and this holds true for students on the spectrum. You are more likely to see certain symptoms in the toddler years, but these symptoms may be extremely subtle or non-existent by the time the student reaches adolescence.

This pattern of development can be very confusing for individuals unfamiliar with the autism spectrum because they expect the same symptoms to remain fairly constant over time. In fact, some of these individuals may doubt whether an ASD diagnosis is warranted due to preconceived notions about what a student with ASD should “look like” at certain ages.

Table 1 lists some of the various challenges that students with ASD may face across the years they are served in the schools. It includes an overview of symptoms commonly observed at different stages in a student’s life. We recommend sharing this information with colleagues who may have less experience working with students on the autism spectrum.

**Table 1}** Developmental Changes in Students with ASD Across the School Years

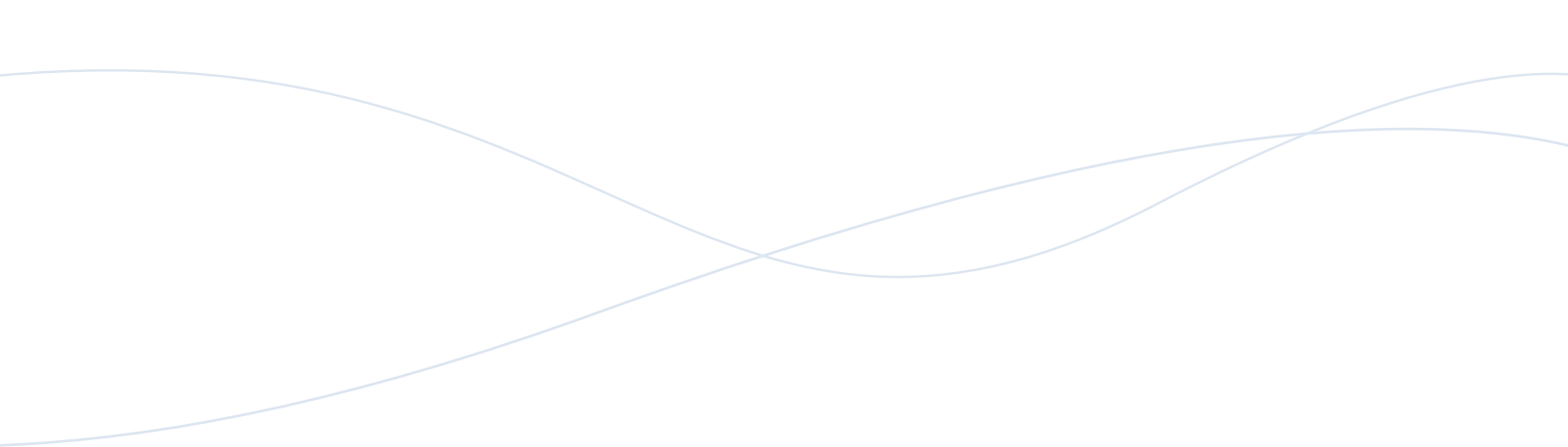
Domain	Age	Symptoms
<b>Social Development</b>	Infant/Toddler	<ul style="list-style-type: none"> <li>• May avoid touch</li> <li>• May isolate from groups</li> <li>• An infant may not imitate facial expressions</li> <li>• Toddlers may not laugh in response to parent's laughter</li> <li>• Failure to respond to the emotional needs of others</li> </ul>
	Early School Years	<ul style="list-style-type: none"> <li>• May not engage in social games</li> <li>• May prefer younger children</li> <li>• May appear "bossy" when playing with other children</li> </ul>
	Adolescence/ Early Adulthood	<ul style="list-style-type: none"> <li>• Gaps in social skills become even more apparent</li> <li>• Dating challenges</li> <li>• Social challenges sometimes related to issues such as poor hygiene (e.g., rigid adherence to rules regarding frequency of bathing)</li> </ul>
<b>Communication Development</b>	Infant/Toddler	<ul style="list-style-type: none"> <li>• May lack speech</li> <li>• Immediate or delayed echoing of other's words</li> <li>• Use of scripted phrases</li> <li>• May not respond to name</li> <li>• Unlikely to use gestures</li> </ul>
	Early School Years	<ul style="list-style-type: none"> <li>• May sound like "little professors" who are lecturing on a topic</li> <li>• Conversations are one-sided</li> <li>• May not see how their behavior hurts others</li> </ul>
	Adolescence/ Early Adulthood	<ul style="list-style-type: none"> <li>• Poor understanding of abstract concepts</li> <li>• Challenges in understanding jokes or slang</li> <li>• May mimic language from television or movies, placing them at risk for problems at schools (e.g., say "I'm going to get a gun and kill him" as a means of expressing anger or frustration)</li> </ul>
<b>Restricted, repetitive, nonfunctional patterns of behavior, interest, or activity</b>	Infant/Toddler	<ul style="list-style-type: none"> <li>• Repetitive motor movements like hand-flapping, finger flicking, rocking, etc.</li> <li>• May line up toys for visual examination</li> <li>• May categorize toys instead of playing functionally with them</li> <li>• Some rigidity in routines</li> </ul>
	Early School Years	<ul style="list-style-type: none"> <li>• Rule-bound</li> <li>• May create own rules to make sense of the world—then have a hard time managing when others violate these rules</li> </ul>
	Adolescence/ Early Adulthood	<ul style="list-style-type: none"> <li>• May engage in elaborate rituals to avoid motor tics</li> <li>• May obsess for hours about a brief encounter with a peer</li> </ul>
<b>Other</b>	Infant/Toddler	<ul style="list-style-type: none"> <li>• Tantrums</li> <li>• Sensitivity to light or sound</li> <li>• Feeding challenges (often associated with texture)</li> <li>• Safety concerns (e.g., may run outside in bare feet into the snow)</li> </ul>
	Early School Years	<ul style="list-style-type: none"> <li>• Academic concerns</li> <li>• Difficulties with concentration and irritability due to sleep or communication problems</li> <li>• May be disruptive during transitions</li> <li>• May be clumsy in sports activities</li> </ul>
	Adolescence/ Early Adulthood	<ul style="list-style-type: none"> <li>• Symptoms of depression or anxiety</li> <li>• Acting out</li> <li>• May not understand rules regarding sexual behavior (and may be set up by peers to violate these rules)</li> <li>• Increased risk for seizures (associated with onset of puberty)</li> </ul>



## Differential Diagnoses and Co-morbid Conditions

Our goal in this section is to provide background information on disorders that are related to ASD in two ways. These disorders can be similar to ASD in various ways (and may therefore be confused with ASD), or they often occur along with ASD.

- **Differential Diagnoses.** Some disorders share common characteristics with ASD. For example, children with ASD can have behavioral concerns, attention and concentration difficulties, mood dysregulation, and medical involvement—and all of these symptoms alter with age. It is not easy to diagnose these children or adolescents because they do not have “classic” autism. An ASD diagnosis must be differentiated from that of other disorders that are similar to ASD. When psychologists or psychiatrists make these decisions, it is called a differential diagnosis.
- **Co-morbid Diagnoses.** Some disorders may occur simultaneously with ASD. In these cases, students should appropriately be diagnosed with an ASD *and* be diagnosed with an additional disorder. When psychologists or psychiatrists make these decisions, the additional diagnosis is called a co-morbid condition.

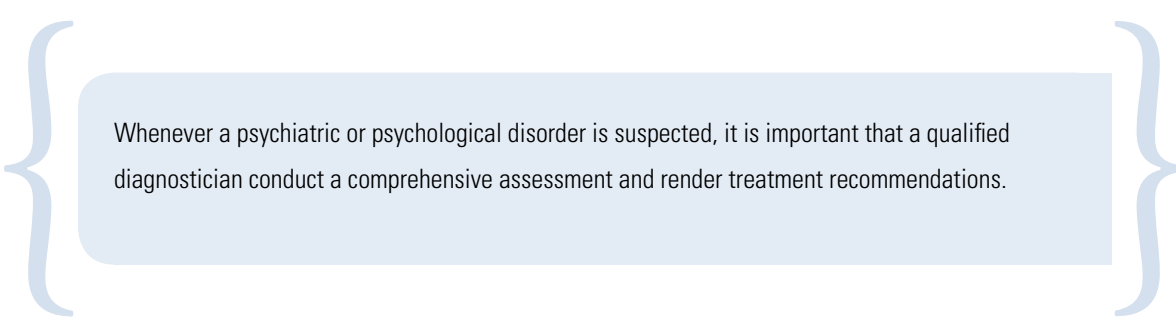


To confuse the matter further, some disorders may appear as a differential diagnosis for one child and as a co-morbid condition in another child. For example, consider a young boy who has the following challenges at school:

- Has social problems with other students
- Seems to violate social rules with adults, like talking when the teacher is talking
- Tends to look away from tasks that are presented to him
- Throws tantrums when things do not seem to go his way
- Misunderstands comments made by others
- Cannot seem to sit still

Does this child have an ASD? Attention Deficit Disorder? Both? Obtaining a clear and comprehensive evaluation from a qualified professional is the first step to clarifying whether a child has an ASD or requires a different or additional diagnosis.

School professionals often play an instrumental role in referring a child or adolescent whose correct diagnosis may have otherwise been missed by medical professionals or family members. We hope this information helps you make referrals for some of your students whose pattern of symptoms may be very complicated. After all, the sooner they get the proper diagnosis and support they need, the more quickly and fully they will achieve their potential.



Whenever a psychiatric or psychological disorder is suspected, it is important that a qualified diagnostician conduct a comprehensive assessment and render treatment recommendations.

## Frequently Occurring Diagnoses & Conditions

### Anxiety and Depression

Mood dysregulation and anxiety symptoms can be easily missed in children with ASD. On the other hand, a high-functioning teenager with undiagnosed ASD may only come to someone's attention specifically because of symptoms of depression or anxiety.

#### Consider the following diagnostic challenges related to depression:

- A teenager who is increasingly isolated, avoiding his peers more often or in different ways, and spending excessive amounts of time focused on a specific topic of interest may have symptoms of depression secondary to an ASD diagnosis.
- In teens with ASD, classic symptoms of depression may sometimes be masked. Their ability to effectively communicate their emotional states may be limited.

Therefore, mental health professionals may have to do some sleuthing to determine if behaviors observed are congruent with ASD in isolation, or ASD paired with a mood disorder. School professionals who have the opportunity to observe the student in a wide variety of circumstances may provide the information essential to making the correct diagnosis.

#### Anxiety symptoms can also be misleading. Consider the following diagnostic challenges:

- A child who is anxious about speaking in public may not only have a common phobia (e.g., public speaking), but may also be masking a tic disorder (a common symptom in ASD) that could be exacerbated by the activity.
- For many students, school refusal is linked with anxiety-based disorders. However, the student with ASD may also avoid school because the school day is too strenuous due to the high demand for social interaction and need to control stereotypic or self-stimulatory behavior (e.g., some children develop enough self-control to stop themselves from engaging in repetitive motor mannerisms at school but are exhausted at the end of the day as a result).

Anxiety levels should be regularly evaluated for students with ASD to make certain they are receiving appropriate services.

## Attention Deficit Hyperactivity Disorder

Children between the ages of 5-7 (or even younger) can be diagnosed with Attention Deficit Hyperactivity Disorder (ADHD). This disorder affects a child's ability to remain focused and to attend to tasks at hand. As noted previously, some children with ADHD may also be impulsive and explosive, and have extreme difficulties remaining seated or following simple classroom rules.

### Consider the following diagnostic challenges:

- Children with ASD may have difficulty with attention and concentration. They may experience the same behavioral challenges as a child with ADHD. However, the *reason* for the behavior is different. A child with ADHD may lose focus because he is thinking about recess. In contrast, a child with ASD may lose focus because he is fixating on the color of the teacher's sweater or watching the fan rotate. In addition, students with ASD may not be able to concentrate because instructions are too complicated given their communication difficulties.
- A child with ADHD may engage in problem behaviors due to pent-up energy. In contrast, a child with ASD may act out behaviorally due to a sensory interest or repetitive motor or vocal tic symptom. The same behaviors occur in both children, but there may be very different causes or triggers.

Carefully identifying the function or purpose of a behavior is often critical. The function of the behavior may influence both the diagnosis that is rendered and the treatment that is recommended.

## Obsessive-Compulsive Disorder

Children with ASD often display stereotypic or self-stimulatory behaviors. That is, they ritualistically repeat the same set of behaviors. Based on simple observation, it is often difficult to distinguish the compulsive behavior of an individual with obsessive-compulsive disorder (OCD) and the self-stimulatory behavior of an individual with ASD.

### Consider the following diagnostic challenges:

- Children with ASD *and* children with OCD might line up their toys, categorize things, insist on sameness in their routines or rituals, or have strange rules that they create to govern their actions with others. However, the children with OCD often have anxiety-based thinking that is intimately linked to their behaviors. For instance, a child with OCD may feel compelled to line up all of her shoes facing north and according to color. Usually, there is a thought associated with the behavior, such as “I need to line my shoes up, so the house won’t burn down while I am at school today.” In contrast, the child with ASD might identify a preference for sameness or, more likely, will be incapable of articulating why he engages in these behaviors.
- Repetitive hand-washing may be a self-stimulatory behavior for a student on the autism spectrum *or* it may be associated with intrusive fears of contamination and disease for the child with OCD.

It may be particularly difficult to make the distinction between compulsive and self-stimulatory behaviors with children who lack strong communication skills. Making the appropriate differential diagnosis may be based on the child’s ability to express whether or not intrusive thoughts and fears are present. Also, children with OCD often state that they wish they did not perform the compulsions. The appropriateness of specific medical treatments is clearly tied to the correct diagnosis.



## Psychotic Disorders

Some children with ASD are mislabeled as psychotic.

### Consider the following diagnostic challenges:

- A student with ASD may talk to himself and mumble under his breath in the classroom. When the teacher asks about this behavior, he states, “I was just talking to my friends.” It is clear to the front-line interventionists that this child was not speaking to any friends in the classroom! However, in the child’s mind, he was responding to actual conversations that had occurred around him in the lunch room earlier that day. It’s just that he does not understand the reciprocal nature of communication and social interaction. In his mind, he was talking to friends in the classroom.
- Asking children who are on the spectrum about “hearing voices” or “seeing strange things” is likely to elicit some unusual and misleading responses as well. For instance, a student with ASD may state she is always hearing voices

of people who are not in the room with her. However, she is referring to people downstairs, down the hall, or outside—not in her head. She is responding quite literally to the question that has been asked.

- Children with ASD may repeat fantasy-based activities that they have seen on television, or in video games or movies. They may or may not realize that what they are acting out is make-believe or pretend play. For instance, a boy with ASD may perfectly replicate every move made by Spiderman. If asked, he may insist that he is Spiderman and may have a tantrum when you challenge this statement. He is not truly psychotic, but he may benefit from some guidance in reality testing—mostly for his own safety and the safety of others.

Significant differences exist in the treatment of psychotic disorders and ASD. While these conditions may be co-morbid, you should consult a qualified professional with sufficient experience with both disorders if a psychotic disorder is suspected.

## Bipolar Disorder and Oppositional Defiant Disorder

The most confusing symptom we probably see in children with ASD is linked to behavioral outbursts. Many professionals who are not familiar with ASD assume a child's behavior is due to a mood disorder such as bipolar disorder, or a behaviorally driven diagnosis such as oppositional defiant disorder (ODD). The true cause of the behavior can be quite different.

### Consider the following diagnostic challenges:

- Children with bipolar disorder can be explosive, impulsive, and highly aggressive. Their symptoms are often cyclical and follow a pattern over time that can be tracked and monitored. However, most people do not regularly monitor these behaviors in a way that makes the pattern readily apparent.
- There is not typically an environmental stressor that is the primary trigger for the explosive, impulsive, and highly aggressive behavior for children with bipolar disorder. These behaviors are ruled by fluctuations of the chemicals in their brains that lead to (sometimes highly rapid) changes in their overall behavior. Although students with ASD may have these same symptoms, *their* problems are typically tied to environmental

stressors. It may not be readily apparent, however, what that environmental stressor might be (e.g., days in which math and music both appear in the afternoon may not be a pattern most people would easily recognize!).

- Children with ODD often act out for very specific reasons. They are often inadvertently taught to respond to limit-setting in a negative manner. When positive behavioral supports are provided, they are often able to restructure their responses in a positive and motivated way. In contrast, the child on the autism spectrum may act out because the noise in the next room is highly distressing even though it does not bother any of the other students in the classroom. He may rock back and forth, cover his ears in response to the "noise," and hit the girl next to him who tries to console him. He is unlikely to calm down until the sensory stressor is removed, or until he has become accustomed to the sound (this is not likely to happen quickly).

The *behaviors* may look the same for the student with ASD, the child with ODD, or the individual with bipolar disorder (e.g., Johnny hits Susie in the classroom), but the underlying *reasons* for the behavior are much different (i.e., chemical dysfunction, learned behavior, sensory-driven behavior, or rule-based behaviors). Determining what caused the behavior in the first place often leads to an accurate diagnosis.



## Final Considerations

Being aware of ASD diagnoses and their myriad presentations will be an important step in helping children with ASD in the school setting. Working closely with other educators, treatment providers, and diagnosticians in the field will help close the gaps between identification, intervention, and the best possible outcome for the child.

Even when outside professionals are involved, school personnel remain the “front line” in helping students with ASD reach their potential. This is most likely to occur when the needs of students with complicated school behavior and psychiatric histories are examined within their proper context.

Once a proper diagnosis is secured, treatment selection begins. It typically begins with identification of treatments that have been shown to be effective based on well-controlled research. Chapter 2 includes a discussion of research-supported treatments for ASD.

## Recommended Readings}

### Autism Specific:

- Attwood, T. (2007). *The complete guide to Asperger's syndrome*. Philadelphia, PA: Jessica Kingsley Publishers.
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- Geller, B., & DelBello, M. P. (2003). *Bipolar disorder in childhood and early adolescence*. New York, NY: Guilford Press.
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- Lifter, K. (2008, March). *Developmental play assessment and teaching: Theory to research and practice*. Presented at the May Institute, Randolph, MA.
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# 2

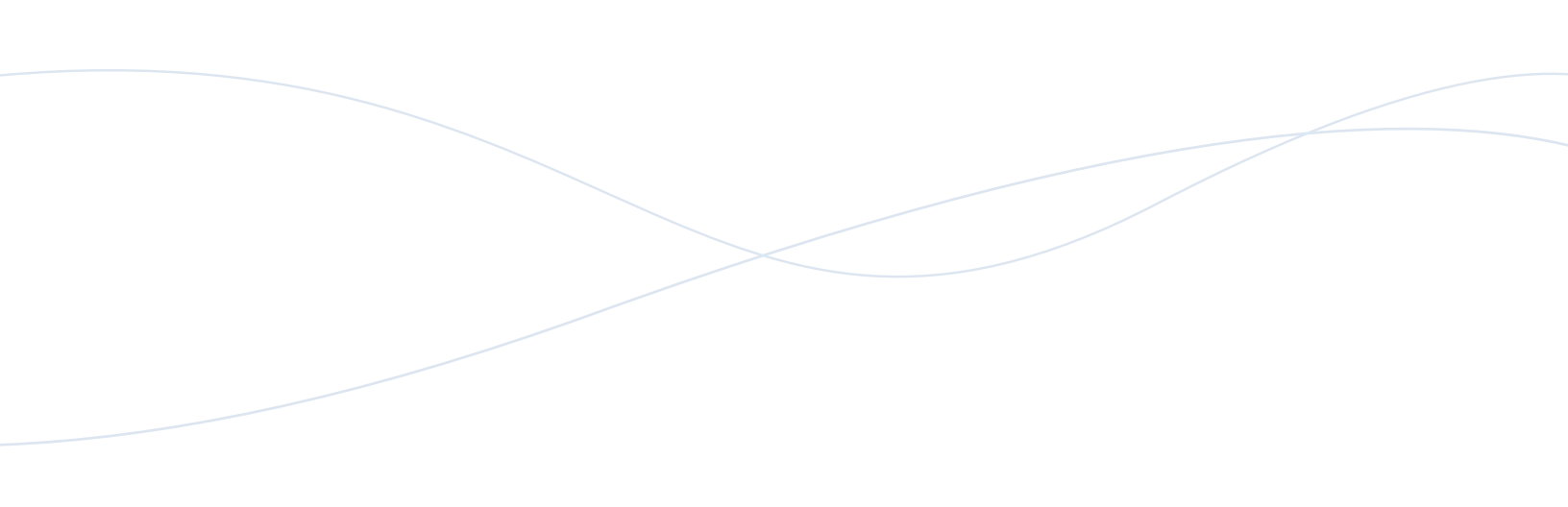
## Research Findings of the National Standards Project

Our understanding of Autism Spectrum Disorders (ASD) continues to evolve, bringing refinements in both diagnosis and treatment. More than 50 years of research have increased our knowledge of this complex developmental disability and led to a vast array of treatment options.

The need to evaluate and select from this long list of treatment options can be daunting for all of us—parents, educators, and health professionals. The good news is that information is available to help us focus on those interventions with evidence of effectiveness.

### Consider the following:

- We expect our health professionals to recommend medications or medical interventions that meet a high standard of evidence based on sufficient research findings. We should have equally high expectations for our educational and behavioral specialists who serve children with autism.
- The lifetime costs associated with ASD are high (\$3.2 million per individual (Ganz, 2007)). We can reduce these costs by choosing and providing treatments that have evidence of effectiveness (e.g., Behavioral Package, Modeling, Peer Training Package, Schedules, etc.).
- It is not possible to be experts in all available treatments. We *can*, however, focus our attention and resources on those treatments which research has shown to be effective.



In 2009, the National Autism Center completed a comprehensive, multi-year effort called the National Standards Project. Its goal was to identify the level of research support available for interventions for children and adolescents with ASD. The results of this effort are available in the *Findings and Conclusions of the National Standards Project* report which we have included in the appendix of this manual. We recommend that all front-line interventionists take the time to read these findings.

**Here are a few important points from the report:**

- A thorough and systematic review of the treatment literature is necessary to determine whether a treatment is effective.
- There are 11 “Established Treatments” that have been thoroughly researched and have *sufficient* evidence for us to confidently state that they are effective.
- There are 22 “Emerging Treatments” that have *some* evidence of effectiveness, but not enough for us to be confident that they are truly effective.
- There are “Unestablished Treatments” for which there is no sound evidence of effectiveness.

This chapter focuses on the 11 Established Treatments identified in the *Findings and Conclusions* report. Our goal is to familiarize you with these treatments and give you a place to begin—or continue—your exploration of available resources. Once you have decided which of these Established Treatments will be the best option(s) for your students and school, we recommend that you develop a collaborative and carefully planned strategy in order to build your school’s capacity to implement these interventions with a high degree of accuracy (see Chapter 5).

## Established Treatments

In the following pages, we provide a detailed definition and description for each of the 11 Established Treatments, or interventions, identified in the *Findings and Conclusions* report.

You may already be familiar with some of these options. Many volumes have been published on each of these interventions; we encourage you to learn more about those that might be most useful to you in your work. At the end of the chapter you will find a list of various sources that provide more in-depth discussion of these treatments.

### The 11 Established Treatments are:

- Antecedent Package
- Behavioral Package
- Comprehensive Behavioral Treatment for Young Children
- Joint Attention Intervention
- Modeling
- Naturalistic Teaching Strategies
- Peer Training Package
- Pivotal Response Treatment
- Schedules
- Self-management
- Story-based Intervention Package



## Antecedent Package

Antecedent interventions include a group of treatments designed to modify the environment *before* a target behavior occurs. These treatments have been shown to effectively reduce problem behavior and improve a broad range of developmentally appropriate skills. By concentrating on how we can modify the environment ahead of time, we can support a student's learning and decrease the likelihood of problem behaviors.

### Facts about Antecedent Package treatments:

- They have been shown to be effective with students aged 3-18 years
- They are associated with favorable outcomes for individuals diagnosed with autism
- They are effective with a wide range of target skills and behaviors, including:
  - Communication skills
  - Interpersonal (or social) skills
  - Learning readiness
  - Personal responsibility (e.g., daily living skills)
  - Play skills
  - Self-regulation
  - Problem behaviors
  - Sensory and emotional regulation


Most often, Antecedent Package interventions involve observing the student in

the setting where problem behaviors occur, then determining which of many possible environmental changes are appropriate. As you decide which environmental modifications to make, it is helpful to consult with an experienced behavior specialist about how to identify the events that lead to the behavior of concern (e.g., off-task behavior, self-injury, problems keeping hands and feet to self, etc.).

Treatments included in the Antecedent Package are often cost-effective and require minimal time. As you consult with a qualified behavior specialist, you can work collaboratively to develop simple-to-use strategies that are feasible in most settings.

Antecedent modification of staff, materials, tasks, and motivating variables should be considered alone or in conjunction with other treatments. Antecedent modifications are often made in combination with treatments in the category of Behavioral Package, another Established Treatment discussed below.

There are many treatments that fall into the category of Antecedent Package, including: choice; behavior chain interruption; cueing and prompting; stimuli manipulation; priming; high probability sequencing; noncontingent reinforcement; incorporating echolalia and an individual's obsessive behaviors; time delay; errorless learning; satiation; adult presence; contriving motivational operations; intertrial interval; and habit reversal.



It is beyond the scope of this manual to familiarize you with all of these treatments. Experienced specialists, as mentioned above, can provide invaluable information, feedback, and support in the use of antecedent (and other) strategies. We provide some examples below to help highlight the importance of Antecedent Package interventions.

**Consider the following examples of challenges you might encounter, along with their possible treatments:**

- **Example 1:** Cathy is a student in your classroom who often has problems with “talking out” around 2 p.m. The behavior specialist in your school collects data and notices a relationship between food intake and Cathy’s excessive talking out. He finds that Cathy tends to talk out in a disruptive way on days when she eats a small lunch. The behavior specialist consults with you about the possibility of giving Cathy a brief snack break at 1:30 p.m. Cathy’s parents are happy to provide a daily snack if it helps her stay focused in the afternoon. The behavior specialist reminds you that it is important to give the snack *before* the problem behavior starts to occur—otherwise Cathy may learn to talk out more in order to get a snack!
- **Example 2:** Your goal is to help your student, David, learn to ask to open the door (e.g., you want David to say “open door”). You know you will need to prompt him initially, but you want him to learn to initiate independently in naturally occurring situations. You decide to use the time delay prompt described below.

David receives weekly half-hour sessions with the occupational therapist. You know that he is motivated to go and responds positively to the activities included in the sessions. Therefore, when the occupational therapist comes to pick David up, she puts his hand on the door handle and looks expectantly at him. She then says “open” and encourages David to imitate her. When he does, she opens the door. Gradually, the occupational therapist will wait for a few seconds without saying “open,” and David will learn to say it himself. This same strategy is used by the speech-language pathologist and the paraprofessionals when it is time for David to leave the classroom.

- **Example 3:** As you know, echolalia (repeating back what someone else says) can interfere with instruction and learning. But school professionals have identified creative ways to incorporate echolalia into treatment for students with ASD.


Consider the case in which one teacher incorporates echolalia into an activity designed to increase receptive labeling (correctly identifying objects or pictures when told the name of the item). The teacher states the name of an object, and her student echoes the label. The teacher then places two objects (one of them the labeled object) in the student's hands. She holds out her own hand, and re-states the label. The student successfully responds by giving the correct object to the teacher. The study shows that this sequence of incorporating echolalia is effective in increasing student accuracy of receptive labels (Charlop, 1983).

- **Example 4:** Planned modification of the environment is also effective in decreasing challenging behaviors. Let's consider the case of a 19-year-old student with autism who had frequent problems with rumination (bringing up partially digested food, chewing, and re-swallowing the material). Assessments showed that when the young man consumed liquids during meals, he was more likely to ruminate. When the staff rescheduled his consumption of liquids to a time other than mealtime, his rumination decreased (Heering, Wilder, & Ladd, 2003).

## Behavioral Package

Treatments included in the Behavioral Package category are based on behavior principles. These treatments begin with an evaluation of what happens in the environment before *and* after a behavior you are targeting. Then, using the data that you've collected, you can begin to modify the environment accordingly. As with all treatments, your goal is to maximize a student's success.

Focusing on their areas of expertise, school professionals might use Behavioral Package treatments to target behaviors that appear on a student's Individualized Educational Plan (IEP). A speech-language pathologist might target speech, for example; a preschool teacher might target play; a high school teacher might target homework completion; and a psychologist might target problem behaviors.



Treatments in the Behavioral Package category are often based on both antecedents and consequences. We have already discussed a few antecedents that can be modified with the Antecedent Package. The key difference in the Behavioral Package category is that changing *consequences* to improve performance is always an essential component of the treatment.

**There are four fundamental consequences that explain most behavior:**

- 1.** When a positive consequence happens after a behavior occurs, that behavior is very likely to re-occur in the future. For example, Jane says “cookie” and her mom gives her a cookie. In the future, when Jane wants a cookie, she is highly likely to say “cookie.” Similarly, if Jane wants a cookie and throws a tantrum (e.g., pulls her mother’s arm and screams), and her mother gives her a cookie, the likelihood is high that Jane will pull her mother’s arm and scream the next time she wants a cookie.
- 2.** When a negative consequence happens after a behavior occurs, that behavior is very likely to decrease. Let’s say Jane wants a cookie. Jane screams and cries and her mother says, “No cookies for you.” Her mother doesn’t give in, and Jane doesn’t get a cookie. There is likely to be less crying and screaming in the future when Jane wants a cookie.
- 3.** When a positive consequence is removed after a behavior occurs, that behavior is less likely to occur again. For example, if Jane is playing with her dog and the dog eats her cookie, Jane will most likely decrease her future interaction with the dog—especially when she has a cookie in her hand!
- 4.** When a negative consequence is removed after a behavior occurs, that behavior is more likely to occur again in future. For example, let’s say Jane hates broccoli. She begins to scream and cry when her father serves her broccoli. He decides it is not worth all the fuss and takes the broccoli away. As a result, Jane’s screaming and crying is likely to re-occur when she is served broccoli.

Before the experienced behavior specialist proceeds to intervention, she knows it is important to identify the function of the child's behavior. She may observe, or ask the caregiver to observe, the consequences that follow the problem behavior. Consider George as an example. When George displays problem behavior in the classroom, his teacher frequently takes his work away. When she does so, George's problem behavior ends. A reasonable hypothesis is that the *function* of George's behavior is to escape or avoid the work.

Even though it seems counter-intuitive to take work away when a student is demonstrating problem behavior, this scene plays out quite frequently in classrooms everywhere. How often do students avoid or escape their work because they have been sent to time out? In this case it is important to test the hypothesis that George's behavior is continuing because it allows him to escape hard work. This can be done through a functional analysis. Once the hypothesis is confirmed, functional communication training (a Behavioral Package treatment strategy) may be appropriate.

### **Behavioral Package treatments:**

- Have been shown to be effective with individuals aged 0-21 years
- Are associated with favorable outcomes for individuals diagnosed with autism and

Pervasive Development Disorder-Not Otherwise Specified (PDD-NOS)

- Are effective with a wide range of target skills and behaviors, including:
  - Academic skills
  - Communication skills
  - Interpersonal (or social) skills
  - Learning readiness
  - Personal responsibility (e.g., daily living skills)
  - Play skills
  - Self-regulation
  - Problem behaviors
  - Restricted, repetitive, nonfunctional patterns of behavior, interest, or activity
  - Sensory and emotional regulation

There are many treatments that fall into the category of Behavioral Package, including: behavioral sleep package; behavioral toilet training/dry bed training; chaining; contingency contracting; contingency mapping; delayed contingencies; differential reinforcement strategies; discrete trial teaching; functional communication training; generalization training; mand training; noncontingent escape with instructional fading; progressive relaxation; reinforcement; scheduled awakenings; shaping; stimulus-stimulus pairing with reinforcement; successive approximation; task analysis; and token economy. These treatments involve a complex combination of behavioral procedures.

Consider the following examples of successful interventions using Behavioral Package strategies:

- **Example 1:** In our earlier example, Cathy started talking out around 2 p.m. on days when she did not eat enough lunch. The behavior specialist identified an antecedent intervention. He might have also implemented a treatment from the Behavioral Package category. For instance, Cathy could be taught to identify when she is getting hungry, and then to request food instead of engaging in disruptive behaviors. She would then be given food when she requests it.
- **Example 2:** An instructor is teaching a young boy to request preferred items. She asks the boy, “What do you want?” When the boy doesn’t respond, the instructor models the correct response (“bubbles”). If the boy still does not respond, the instructor models the initial phoneme of the response (“/bu/”). Over time, the boy’s ability to accurately make requests using the whole word increases (Bourrett, Vollmer, & Rapp, 2004).

The key at the start of this kind of training (known as mand training) is to choose a highly preferred item, so that the child will be motivated to gain access to that item. If a student is highly motivated by juice, for example, teaching him to request “juice” will likely produce more effective results than teaching him to ask for “water.”

- **Example 3:** Behavioral Package interventions may have multiple components. For example, students with ASD often benefit from interventions designed to increase their independence. But independent responding does not always result from a simple reinforcement schedule (although it is nice when it does!).

Pelios, MacDuff, and Axelrod (2003) used a multi-component treatment to target independent academic work skills of children with ASD. The treatment package included many different components including: reinforcement (contingent or delayed) for correct responding; fading teacher presence and prompts; response cost for incorrect responding; and unpredictable pattern of supervision. Following the intervention, students who were previously dependent on high levels of teacher supervision and prompts were able to complete these tasks with minimal teacher supervision.

## Comprehensive Behavioral Treatment for Young Children

Human beings learn at an astounding rate, especially during our early years. This is why early intervention is so important! When younger children with ASD receive effective early intervention, they are more likely to reach their potential across a range of skills (e.g., communication, social, pre-academic/academic, etc.). Comprehensive Behavioral Treatment for Young Children (CBTYC) programs are designed to meet this need.

### The treatment programs represented in the CBTYC category have various defining features, including:


- Intense service delivery based on applied behavior analysis (ABA), and measurement to assess the effectiveness of the program
- Provision of services in various settings, (e.g., home, community, inclusive classrooms, and self-contained classrooms)
- Rich student-to-teacher ratio
- Targeting the defining symptoms of ASD
- Using applied behavior analytic strategies (e.g., discrete trial teaching, incidental teaching, errorless learning, behavioral momentum, and shaping)
- Written guidance through treatment manuals and other materials

These comprehensive programs typically combine many of the behavioral interventions identified in this manual. CBTYC include strategies associated with each of the following treatments: Antecedent Package, Behavioral Package, Joint Attention Intervention, Modeling, Naturalistic Teaching Strategies, Peer Training Package, Schedules, and Self-management.

### CBTYC has been shown:

- To be effective with children aged 0-9 years (the age group to which it is usually applied)
- To be associated with favorable outcomes for individuals diagnosed with autism and PDD-NOS
- To be effective with a broad range of target skills and behaviors, including:
  - Communication skills
  - Higher cognitive functions
  - Interpersonal skills
  - Motor skills
  - Personal responsibility
  - Placement
  - Play skills
  - Problem behaviors
  - General symptoms associated with ASD

The intensive nature of this ABA-based instruction is achieved through a rich student-to-teacher ratio. That is, there are very few



students for every teacher (often there is a 1:1 ratio). Such a ratio is important to ensure the teacher is able to attend to the student completely, individualize the instruction, and provide immediate reinforcement. Intensity is also addressed by providing many hours of services weekly and extending service delivery over a long period of time. Often, these treatment programs provide services to children for two or three years.

There are a number of treatment programs that provide CBTYC. In the most well-known program, Lovaas (1987) first evaluated the effectiveness of CBTYC in a study of 19 children with ASD. They received services for 40 hours per week over a long period of time (2-3 years). These children showed significant gains in IQ scores. Most important was the fact that the treatment effects were maintained over time. By comparison, children who received 10 hours of special education per week did *not* show similar gains.

Other researchers questioned whether Lovaas' (1987) CBTYC was successful only because of the amount of time spent in instruction. So, they compared three different treatments: {a} 25-40 hours of CBTYC; {b} 15 hours of a traditional preschool program; and {c} 30 hours of eclectic intervention. In the end, treatment effectiveness was found to be related to the *type* of treatment. CBTYC *was* effective—it was not merely the length of time spent in treatment that led to gains for children receiving CBTYC services (Howard, Sparkman, Cohen, Green, & Stainslaw, 2005). Many additional studies have confirmed CBTYC is effective with many children on the autism spectrum.

Due to the complexity of CBTYC, it is difficult to develop an example that reflects all aspects of treatment. Most children received a minimum of 25 hours of services per week. Instruction varies depending on their communication, cognitive, social, and adaptive skills as well as problem behaviors that interfere with skill acquisition and success across important environments in the child's life. A student who first enters a CBTYC program may spend a large part of the day in discrete trial teaching, whereas a student further along in treatment may spend a good deal of time generalizing skills to new situations, materials, or people. CBTYC programs can be center-based or home-based (with some community activities). Center-based programs may involve a great deal of peer involvement or may focus almost exclusively on the student with ASD. Irrespective of these differences, the applied behavior analytic techniques produce important gains across a broad range of critical life skills.



## Joint Attention Intervention

Joint attention is a widely used term in the field of ASD. It refers to the behavior of two individuals focusing simultaneously on an object or activity and each other. The sharing of an activity is a fundamental skill in communication and social behavior, but it is not a skill that children with ASD automatically develop. Failure to develop joint attention skills may be one of the earliest indicators parents notice when they get the feeling that “something is not quite right.”

### Here are several examples of Joint Attention interactions:

- A child’s eye gaze follows the adult’s eye gaze (i.e., the parent looks at some object or event and the child follows the parent’s shift in eye gaze).
- A child prompts someone to look at an item. Joint attention also occurs when someone prompts a child to look at an item and the child responds to this bid.
- A child shows an object to another person, or responds when someone else shows the child an object.
- A child points to an object, or responds when an adult points to an object.
- A child and adult watch an activity together and look to the response of the other person.

Very often, joint attention is taught in a discrete trial teaching format. You begin by deciding which joint attention skill to target. In other words, it is important to clarify if the goal is to teach the child to *initiate* a joint attention interaction, or to *respond* to a bid from others.

Here is a sample joint attention interaction designed to teach a young child to *respond* by looking at an object when you point to it. Because you want to motivate the child, you begin by identifying something you know she wants to look at. Because you have observed her, you know that she is drawn to objects that light up. Therefore, you select a number of toys that light up. You decide where to teach this skill (e.g., the free play area, a table that has been set up to teach this skill, or an area of the floor that is near other children but won’t be distracting to your young student). Placing your hand close to the child’s face, you point at a light-up toy. When she sees your finger, you guide her to look at the toy. You then push the button so the toy lights up. You are now ready to repeat the exercise.

Along with the steps described above, teachers can use strategies such as choice, task interspersal, modeling, and reinforcement when teaching children to demonstrate joint attention.

#### **Joint Attention treatments:**

- Have been shown to be effective for children aged 0-5 years (the age group to which it is usually applied)
- Have shown favorable outcomes for children diagnosed with autism and PDD-NOS
- Have been shown to increase communication and interpersonal skills

#### **Consider the following cases of successful interventions using Joint Attention strategies:**

- **Example 1:** As noted in Chapter 1, using gestures is an early skill that many children use to communicate their interests to others. In one study, two other Established Treatments (discrete trial training and Pivotal Response Training) were combined to teach protodeclarative pointing (pointing with the intention of showing, not requesting) to children with ASD (Whalen & Schreibman, 2003). These strategies teach children essential joint attention skills.
- **Example 2:** Time-delay prompts can be used to supplement other behavioral strategies for improving joint attention. For example, three children with ASD (Martin & Harris, 2006) were taught to respond to increasingly difficult joint attention bids from adults. Eventually, the children learned to respond when an adult got their attention and then looked at an object of interest (i.e., no gestures or comments were required).
- **Example 3:** Children benefit from coordinated efforts across home and school environments (more on this subject in Chapter 4). Home environments provide additional and rich opportunities to generalize skills learned at school, to practice new skills, and to increase the number of positive interactions with family members. For all these reasons, school systems may want to provide joint attention training for parents. Parents can develop competence in using behavioral strategies to teach joint attention skills to their children with ASD. Joint attention responses can be developed over a short period of time, and the majority of children are able to generalize the skill to other settings (Rocha, Schreibman, & Stahmer, 2007).

## Modeling

The best and clearest way to teach someone what to do is to *show* him what to do. When we are children, we learn a great deal from observing the modeling provided by our parents, siblings, peers, and teachers. Even as adults, we continue to benefit from modeling. Take the example of trying to learn a new exercise routine. Reading about it or having someone explain it will not give us a complete understanding of the actual routine. However, if someone spends a few minutes showing us exactly how that routine is performed, we benefit tremendously.

### Modeling has been shown:

- To be effective for children aged 3-18 years
- To have favorable outcomes for children with autism, Asperger's Syndrome, and PDD-NOS
- To be effective with target skills and behaviors, including:
  - ▶ Communication skills
  - ▶ Higher cognitive functioning
  - ▶ Interpersonal skills
  - ▶ Personal responsibility
  - ▶ Play skills
  - ▶ Problem behaviors
  - ▶ Sensory and emotional regulation

Modeling may be provided in several ways. Live modeling occurs when a person demonstrates the target behavior in the presence of the student with ASD. The model may be an


adult or a peer. In contrast, video modeling occurs when the individual demonstrating the target behavior has been pre-recorded.

When videos are used to model the target behavior, the student with ASD may serve as the model (i.e., self-modeling) or another person may be selected as an effective model for the targeted behavior. Self-modeling may require significant editing of the video by the educator in order to make the student appear to successfully perform the task independently.

Video allows for point-of-view modeling (i.e., seeing the target behavior from the perspective of the person performing the behavior). Point-of-view modeling often involves videotaping someone's hands performing a task.

There are some advantages in the use of video modeling over live modeling. A live model may not always be available. With a live model, you must also ensure that steps are modeled consistently (i.e., in the same manner, during every session).

Another benefit of video modeling is that it can be cost- and time-effective. For example, the same video clip can be used by multiple children and at multiple times of day. Also, teaching sessions can be as quick and simple as turning on a switch! Of course, it is not this easy with all students. Some children may need prompting to pay attention to the video. Educators may also need to stop the video and point out the salient features.



Anyone with the necessary equipment (video camera, TV, and VCR or DVD player) can use video modeling as a treatment. The first step is to create the video clip. Although making video clips is not difficult, you should be aware of several elements that make an effective clip, such as the angle of the shot, voice quality, clarity of materials, and duration of the video. Finally, be aware that technical difficulties such as equipment malfunctions can be challenging during the treatment stage.

### **Consider these examples of Modeling:**

- **Example 1:** If a speech-language pathologist needs to target conversational skills for a student, he could design a treatment using video modeling. The video might show adults having conversations (i.e., how to initiate and maintain conversation by asking and answering questions). The next step is to decide how often the student should watch the video. Typically, the video is shown to the student immediately before the student practices holding the same conversation. Keep in mind that students should be reinforced for acceptable deviations from the videotaped conversation.
- **Example 2:** In some cases, live modeling is a better option. Consider the case of Steve, a 16-year-old student for whom you have used video modeling in the past. While video modeling works well with many students, Steve seems to have a hard time performing the modeled task unless everything in the classroom setting appears exactly the way it does in the video. Therefore, you decide that the variability that may naturally occur with live modeling may be better for Steve. You train two peers to model the target behavior (in this case, how to make plans to meet a friend at lunch). Although you used the exact same teaching procedure with both peers, you notice there is some natural variation in the way they demonstrate the target behavior. It may take a bit longer for Steve to pick up how to perform the task with this variation, but he seems to respond better in the “real world” when he needs to perform this task.

## Naturalistic Teaching Strategies

When we learn to drive, we start in a parking lot. But the point of acquiring that skill is to be able to drive in our neighborhood, on city roads, and ultimately on major highways. Similarly, it is important for a child with ASD to perform skills in all environments where they naturally occur.

Children with ASD face challenges not only in acquisition of skills, but also in generalization of those skills. Generalization refers to the ability to perform any acquired skill across different stimuli and settings, and with different people. Teaching a child to tie his shoelaces in a classroom is useful only if the child can then tie his shoelaces in the playground, cafeteria, car, home, etc.


Generalization can be achieved in two ways. The first is to teach a skill in a controlled environment and then gradually vary the materials and location (in and out of classroom), and even change the instructor. The second way to achieve generalization is to embed it into teaching from the beginning, using naturalistic procedures. As the name suggests, these procedures take advantage of naturally occurring events in a student's day to teach and maintain new skills.

Many strategies for enhancing generalizations have been described in the research literature (Stokes & Baer, 1977).

### **A few of the most important principles are outlined here.**

- The first principle instructs us to use direct and natural consequences. The natural consequence that directly relates to our actions is what motivates us in everyday life. For example, the consequence for learning to drive is the freedom and independence of driving, and of being able to move from one location to another as needed. It also enables us to attain other things that may be rewarding to us: the opportunity to see a movie, purchase clothing or other desired items, visit a park, etc.

When you were 16 years old, how motivated would you be to get your driver's license if your only "reward" was to get a 5% discount at the local grocery store (instead of earning the right to drive where you wanted and when you wanted)? Not at all, we're sure! To be the most meaningful, reinforcers should be directly related to the skill that is being developed (this is known as a direct response-reinforcer



relationship). In addition, the reinforcer should be naturally available in the environment (e.g., you do not need to contrive special occasions to allow a teenager to drive—they are naturally available).

- The second principle involves the old saying, “variety is the spice of life.” In this case, we would more aptly say, “variety can lead to meaningful improvements.” Although we doubt this phrase will catch on, it is an important consideration for Naturalistic Teaching Strategies (NTS). When teaching students new skills, you should use a variety of different materials and teach skills in a variety of settings and/or situations. For example, if your goal is to teach a preschooler his colors, you might use different colored crayons, cars, mats upon which to sit, or any other appropriate materials in the classroom. Colors can also be taught on the playground, in the hallways, in the home, or in the community. When followed consistently, this principle is likely to increase generalization of the targeted skill.
- The third principle is called “programming common stimuli.” This means that the materials you use to teach new concepts or skills are likely to be available in a variety of settings (home, school, and community). For example, you might want to teach a young student to identify items that fall into the category “things you might play with” using dolls, blocks, and cars that are available at home and at school.

Generalization of skills relevant to life contexts is the foundation of NTS. There are a number of different intervention strategies that fall into this category. These strategies have several features in common. For example, Naturalistic Teaching Strategies involve following the interest of the child when structuring teaching interactions. By following the child’s interests:

- You are more likely to identify direct and natural reinforcers. This often requires careful observation and planning. You will need to set aside any preconceived notions about what might be interesting to the student and decide based on her actual contact with and response to different classroom materials.
- You will capitalize on the student’s motivation if you follow his interest. A lack of motivation is one of the great challenges most educators face when teaching students with ASD. Close observation of the student’s actual behavior is critical to making the right decisions about reinforcers.

- You will need to develop loosely structured teaching sessions that vary based on the student's interests on a given day. If your goal is to increase your student's ability to request toys, you may need to shift your plans from work on requesting different colored blocks to requesting popular action heroes based on a recent movie. If the child's interest shifts, your teaching shifts along with it—but you keep your primary goal of teaching (in this case, requesting) in mind.


Different names have been given to the treatment strategies included in the NTS category. These include focused stimulation, incidental teaching, milieu teaching, embedded teaching, and responsive education and prelinguistic milieu teaching.

### **Naturalistic Teaching Strategies:**

- Have been shown to be effective for children aged 0-9 years
- Have produced favorable outcomes for children with autism and PDD-NOS
- Have been shown to be effective with target skills and behaviors, including:
  - ▶ Communication skills
  - ▶ Interpersonal skills
  - ▶ Play skills

### **Consider the following examples of successful interventions using Naturalistic Teaching Strategies:**

- **Example 1:** A teacher wants to teach her student, Jorge, to tie his shoes. She observes Jorge's day and assesses when naturally occurring opportunities to tie his shoelaces occur (e.g., after coming back from the playground to take sand out of his shoes, after a swimming session, etc.). We know that children with ASD often need many, many teaching trials before they will fully develop a skill. There may be limited naturally occurring opportunities to practice a skill like tying shoelaces. The teacher decides to create more such opportunities for Jorge in a natural setting. She develops a daily activity of doing relaxation training for the entire class. This relaxation activity involves removing the shoes and wiggling the toes. She has just created five additional teaching opportunities per week!
- **Example 2:** A treatment called Enhanced Milieu Teaching (EMT) can be used to improve social communication skills. EMT involves arranging a child's social environment so that she is more likely to be highly engaged in classroom activities and in social interactions. The procedures used



to increase engagement include modeling appropriate social and communication skills, providing necessary prompts, following the student's lead to create teachable moments, and making sure children get access to a rich schedule of reinforcement. By structuring the learning environment in this way, your students with ASD learn important social communication skills. When these strategies have been applied in the past, skills have also been maintained over time and generalized to new situations (Hancock & Kaiser, 2002).

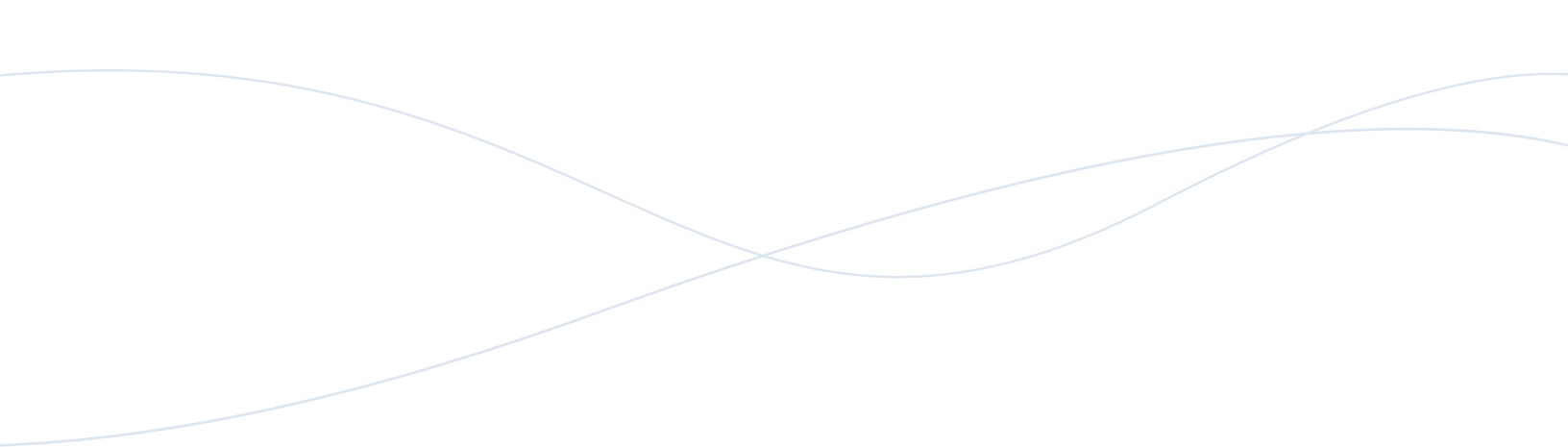
- **Example 3:** Jane is a student who often shows interest in cars. The paraprofessional working with Jane knows that the day's teaching goals focus on color identification and counting. He plans to use cars in the free play area to work on these skills. However, when class begins, Jane shows an interest in balls. The paraprofessional still works on the concept of colors and counting, but follows Jane's interest in the balls. He waits for Jane to be motivated by the material (e.g., Jane reaches for one of the balls) and then holds the ball slightly out of reach and asks Jane to identify its color. He knows Jane will need prompting. So, as soon as he finishes asking her to identify the color, he tells her the name of the color. He then gives Jane the correctly colored ball. After he hands Jane each new ball, the paraprofessional retrieves the last ball that was used. At the end of the session, he asks Jane to count each of the balls using a 1:1 correspondence.

## Peer Training Package

We interact with other people because there is a "payoff" of some kind. We like to spend time with others, enjoying similar activities and connecting with them. Are you a more social person who spends most of your time interacting with others (through phone, activities, etc.) or are you more of a homebody? There is natural variability in the degree to which we each like to socialize.

While many children on the autism spectrum tend to spend less time interacting socially than their peers do, this is not universally true. Some students on the spectrum frequently try to interact with peers, but may do so in unexpected or socially inappropriate ways. Regardless of a student's inclination toward social activities, developing social interaction skills is important to achieving long-term success in life.





As mentioned in the previous section on modeling, we all watch and learn. Sometimes the “watching” is programmed; sometimes it just happens naturally. Play groups in preschool and kindergarten offer a naturally existing modeling program to facilitate appropriate social, pre-academic, and behavioral skills. However, children with ASD demonstrate a real deficit in their “watching” and observational skills, and therefore cannot be expected to benefit from naturally occurring modeling without added structure.

In the life of a child with ASD, the role of peers and siblings is important because they are the most likely to be accessible and competent models, and because the goal of any intervention is to make the child more successful with his peers in the natural environment. Although it is completely acceptable to teach an 11-year-old to play appropriately with an adult, success for that student in his natural environment (i.e., school, classroom, family gatherings, vacations, etc.) will largely depend on his interaction with similar-age peers and/or siblings.

Some of your students with ASD may avoid their peers, so the idea of developing an intervention reliant on peers may surprise you. The behavior of peers may appear unpredictable or frightening for the child with ASD, so we can understand that the child might have a lower rate of initiating social interactions with peers than with adults. This is

why it is so essential to train peers in how to facilitate positive interactions with the student on the autism spectrum.

There are many different peer training programs, including Project LEAP, peer networks, circle of friends, buddy skills package, Integrated Play Groups, peer initiation training, and peer-mediated social interaction training.

**Peer training often begins with careful selection of peers. Ideally, these peers:**

- Are socially skilled
- Are generally compliant with instructions
- Have regular school attendance
- Are willing to participate in training
- Are able to imitate a model

Simply placing highly skilled peers near a student with ASD is not likely to produce favorable outcomes. Instead, you need thoughtful planning. It is necessary to teach peers how to get the attention of the child with ASD, facilitate sharing, provide help and affection, model appropriate play skills, be a “good buddy,” and help organize play activities.

Once the peers are trained, both groups of children should engage with each other in a structured play setting. This gives the peers opportunities to use the skills they have

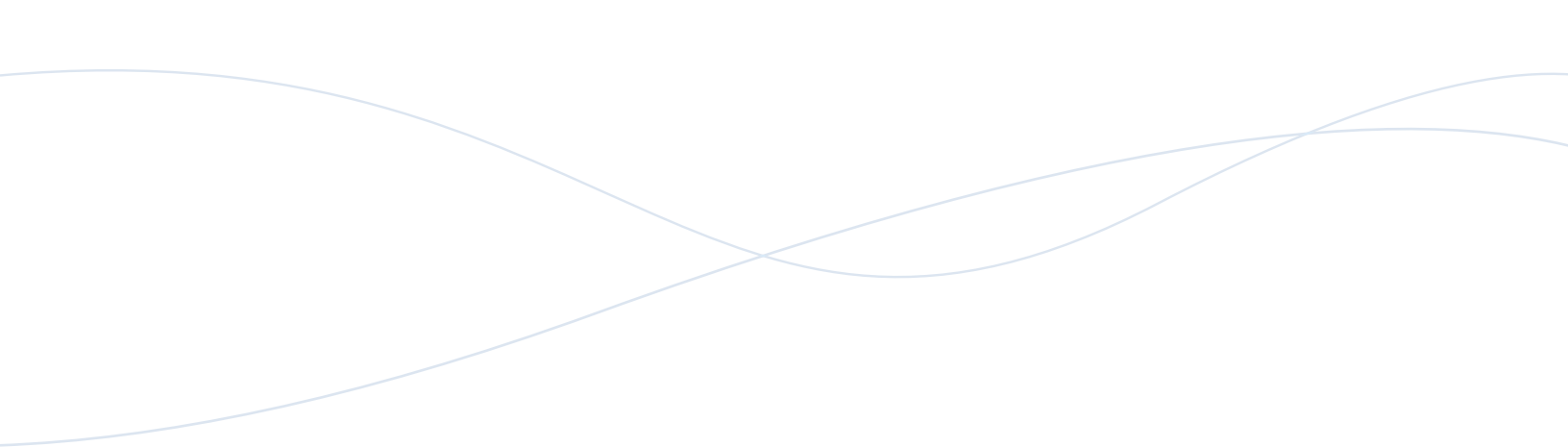
learned. At the same time, the educators can teach initiation strategies to the student with ASD. As the school professional, your role is to provide prompts and feedback to facilitate interaction between both groups.

### **Peer Training treatments:**

- Have been shown to be effective for children aged 3-14 years
- Are associated with favorable outcomes for children diagnosed with autism and PDD-NOS
- Have been shown to be effective with target skills and behaviors, including:
  - ▶ Communication skills
  - ▶ Interpersonal skills (e.g., affection, complimenting)
  - ▶ Play skills (e.g., play organizers)
  - ▶ Social interaction (bids for attention, responding to questions, etc.)
  - ▶ Sharing
  - ▶ Offering and seeking assistance
  - ▶ Being a “good buddy” (staying, playing, talking with your buddy, etc.)

### **Consider the following examples of Peer Training treatments:**

- **Example 1:** Consider the cases of Fred and John. They each were diagnosed with ASD and had older brothers who were not on the spectrum. Siblings often serve as excellent interventionists if they are taught how to interact effectively with their brother or sister with ASD. In this case, the older brothers were taught a number of behavioral strategies to help increase Fred and John’s play activities (verbal and nonverbal). The older brothers successfully used prompting (verbal and physical) and reinforcement (verbal and tangible). In addition, adults implemented a time-out component. By teaching the older brothers to interact more effectively with Fred and John, the play skills of the two boys with ASD improved and were maintained over time (Coe, Matson, Craigie, & Gossen, 1991).
- **Example 2:** Peer training can be effective not only in improving social interaction skills, but also in reducing behaviors that make the student with ASD appear very different from her peers. You probably serve students with ASD who engage in self-stimulatory behaviors (repetitive, nonfunctional motor mannerisms). By teaching



peers to “get their friends to play with them” using the strategies discussed earlier, play skills of children with ASD have been increased and self-stimulatory behaviors have been reduced (Lee, Odom, & Loftin, 2007).


- **Example 3:** As exciting as it is to see students with ASD improve their social interactions with peers following peer training, you may also notice that your student with ASD still requires additional support to develop all of the skills he needs to fully engage with his peers. Fortunately, peer training can be combined with other strategies (e.g., direct instruction and written texts cues). By teaching the peer to facilitate social interactions with the child with ASD and teaching the student with ASD specific communication skills he may need, a higher quality of social interaction may result (Theimann & Goldstein, 2004).

It is important to keep certain factors in mind while you design peer training interventions. First, the age and skill level of the students (with and without ASD) should be similar, so that it is relevant for both groups of children. In addition, the activities you include in the session should address the interests and preferences of both groups of students. This will ensure high levels of attention and engagement with the activity. You should expect challenges with both maintenance and generalization of the targeted skills, and should focus on addressing these challenges.

## Pivotal Response Treatment

Pivotal Response Treatment (PRT) holds much in common with Naturalistic Teaching Strategies (NTS). Both methods teach skills in the natural environment and create situations in which the student will be motivated to learn. The goal of PRT is to target pivotal behavioral areas that may have a watershed effect on the development of many other skills. PRT places a stronger emphasis on self-management than interventions associated with NTS. In addition, PRT is often used to target a broader range of skills (e.g., communication, social interaction, play, etc.).

PRT may be based on parental involvement in natural settings. An extension of the natural language paradigm, PRT aims to teach a student to respond to various teaching opportunities within his own environment, to increase independence from prompting/coaching, and to minimize the time spent away from his natural environment (Koegel, Koegel, & Carter, 1999).



Areas targeted by PRT include motivation to engage in social communication, self-initiation, self-management, and responding to multiple cues.

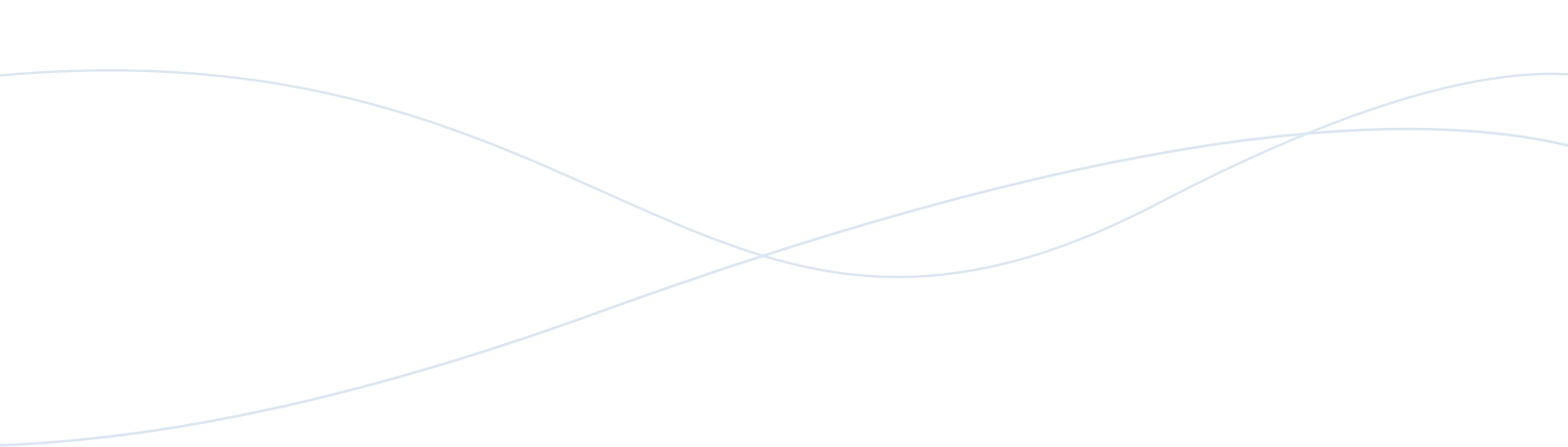
- *Motivation* is enhanced by increasing choice, building a direct response-reinforcer relationship (i.e., there is a direct relationship between the reinforcer and the activity in which you are engaged), interspersing mastered with novel tasks, and reinforcing reasonable attempts.
- *Self-initiation* involves teaching students to take action in the world. Because we want them to be independent, we do not want children to wait passively for other people to make positive situations occur.
- *Self-management* involves teaching students to regulate their own behavior by keeping track of their progress and accessing reinforcers for their successes.
- *Responding to multiple cues* involves teaching students to respond to the diverse statements of others, or to different kinds of materials (even if there is wide variability in the way things are said or the materials that are used).

### **Pivotal Response Treatment:**

- Has been shown to be effective for children aged 3-9 years
- Is associated with favorable outcomes for children diagnosed with autism
- Has been shown to be effective with target skills and behaviors, including:
  - ▶ Communication skills
  - ▶ Interpersonal skills
  - ▶ Play skills

### **Consider the following examples of Pivotal Response Treatment:**

- **Example 1:** Communication is one of the most critical skills to target for students with autism. Significant improvements in communication can result when PRT strategies are implemented. These strategies include: varying the materials used during teaching to avoid boredom; using natural reinforcers and making sure they are available for attempts at communication; and teaching in the natural environment. Using these kinds of strategies, students have learned to imitate the statements of



others (Koegel, O'Dell, & Koegel, 1987) as well as to increase their use of spontaneous utterances (Gillett & LeBlanc, 2007).

- **Example 2:** If you observe your students while they play, you will notice that there is a great deal of diversity in the toys they use, the complexity of their play behaviors, and how creative they are during their play activities. Students with ASD often have difficulty with symbolic play. For instance, students on the autism spectrum are less likely to pretend that a plastic plate is a hat, or that a play stove is hot. Instead, if they engage in appropriate play, they are more likely to use a toy exactly as it was designed to be used.

PRT has been used to target symbolic play skills for students on the autism spectrum. In this example, the adult interacting with the child used the following strategies: following the child's interest, modeling how to play with the toys (including symbolic play), reinforcing attempts, using natural and direct reinforcers, and taking turns. When improvements in symbolic play were noted, the student was expected to demonstrate more creative play (i.e., reinforcers were available when more complex play was demonstrated). By using these strategies, children between the ages of 4 and 7 were taught to engage in more symbolic play (Stahmer, 1995). These skills typically generalized to new toys, situations, and play partners. These strategies have also been used to improve sociodramatic play (an advanced form of symbolic play that includes skills like role playing, social interaction, etc.) (Thorp, Stahmer, & Schreibman, 1995).

- **Example 3:** As we have noted previously, peer involvement in interventions can lead to very beneficial outcomes. PRT strategies can be used not only by educators and parents, but also by peers to improve the social play skills of the student with ASD. Teaching PRT strategies to peers has been shown to improve social play activities (Harper, Symon, & Frea, 2008). These strategies include: gaining a peer's attention; varying the kinds of activities in which you engage; narrating play activities; reinforcing attempts to interact during play; and taking turns. In this case, the peers learned these strategies during recess over the course of seven consecutive days. This means that peers were quickly taught to use PRT strategies that led directly to more social engagement during play for the student with ASD.

## Schedules

Isn't it nice when we can predict what will happen next? When watching a movie, you might not want to know exactly what will happen. But in many situations, we like to have an idea of what to expect. Predictability in life is generally comforting to us all. Imagine a world in which someone in blue shorts just ran into the school and started tickling you; or the administrative assistant started singing tunes to the school over the intercom system. These situations seem unreasonable and unpredictable, and would leave us uncomfortable, to say the least!

Children with ASD tend to strive for predictability more than most people. This is because it is hard for them to pick up on the subtle cues which signal to the rest of us that something in the environment might be changing. Even things that appear reasonable and predictable to us do not always feel that way to students on the autism spectrum.

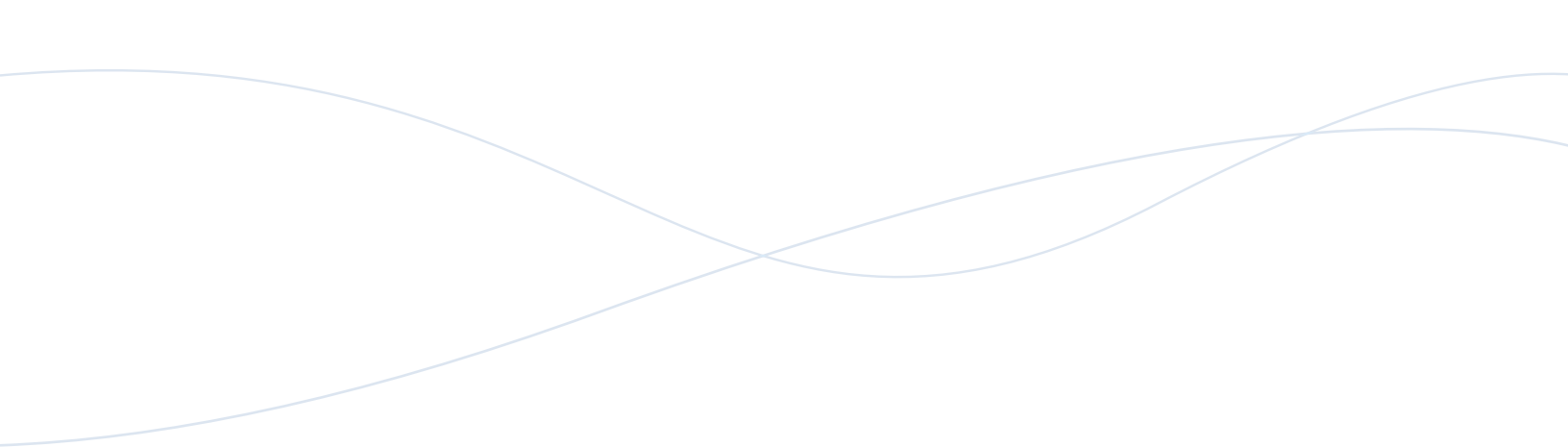
In our daily lives, we enhance our ability to predict future events by planning and scheduling. We use our planners, computers, and PDAs to schedule appointments and meetings. Similarly, the use of Schedules as an intervention aims to promote greater independence in individuals with ASD. The goal is to

target daily activities and, if possible, to include planning for events on a daily, weekly, or monthly basis.

Transitions may be better managed with the use of schedules. A student who does not enjoy academic work may benefit from an intervention in which his picture schedule is comprised of just two pictures showing the "first, then" contingencies. First he completes the academic work and then he gets access to a preferred activity. Gradually, you can add more pictures as he masters the use of the schedule and can tolerate increased demands before he gains access to preferred activities.

Schedules vary in their presentation style. Educators have used various media such as pictures (real photos or Boardmaker®), written or typed documents, or 3-D objects. These tools can be as small as a 1" icon per board to reflect a full day's schedule, to a written document that includes the full week's schedule in a grid format, to a running list of "to do" activities with no time specification.

The use of schedules may be as simple as {1} placing pictures/texts on the board at the time of the activity, {2} pointing to the activity while engaging in the activity, {3} taking the picture off the board and {4} placing it in a done/



completed/finished bin/bucket/box/pile. More advanced schedules may involve the student crossing out the activity she has completed, much as you would do with your own “to do” list. Some schedules also include photos of the staff involved in the activity, location details, and materials that are needed.

The schedules theme lends itself to great variation in setting and application. Some classrooms have a classwide schedule, and some use individualized schedules. Some students set their schedule once a day; others set their schedules in the morning and again in the afternoon. Some educators may make the schedule for the student or with the student; others allow students to make their own schedules. In all instances, individualization is the key to ensuring the student benefits completely from the schedule.

#### **Schedules have been shown:**

- To be effective for children aged 3-14 years
- To be associated with favorable outcomes for individuals with autism
- To improve self-regulation skills

#### **Consider the following examples of Schedules:**

- **Example 1:** The use of schedules can help students with ASD maintain their focus through transitions in the classroom environment. In one study, students (7-8 years old) were taught to use visual schedules to transition to and from four learning centers in a classroom (writing, reading, listening, and art center). Once teachers had the students’ attention, they instructed the students to complete four activities. To help the students transition successfully, they used pictures in a photo album in the order in which the activities were expected to occur. These visual schedules have improved on-task and on-schedule behavior for students with ASD (Bryan & Gast, 2000).
- **Example 2:** Schedules have been successfully used to address the aggressive and/or disruptive behaviors of students with ASD. For instance, picture schedules have been developed with Velcro placed on the back of each picture. The student can be taught to match the picture on the schedule to the picture on the container that includes his work material. When paired with reinforcement, this kind of schedule has been shown to increase cooperative behavior and decrease aggression for a preschooler with PDD-NOS (Dooley, Wilczenski, & Torem, 2001).

● **Example 3:** The transition from home to school (and from school to home) can be challenging to children with ASD. Teachers may partner with parents to develop and use schedules to reduce a student's level of discomfort with these transitions. Parents have successfully applied photographic activity schedules targeting leisure, social interaction, self-care, and housekeeping tasks. Schedules can be presented in a three-ring binder with one photograph per page. In one case, a student was taught to point to the page, get the materials needed, complete the activity, clean up when done, check the schedule again for next activity, and repeat the same sequence (Krantz, Macduff, & McClannahan, 1993).

## Self-management

Independence is greatly valued in our society because it increases the likelihood of success in any situation and setting. A dependent individual, on the other hand, is limited in the range of social and general life experiences he is afforded. Children with ASD may not learn to adapt and change their behavior based on naturally occurring cues in the environment. Their inability to pick up on these subtle cues and alter their behavior accordingly will impede their success in many situations.

Self-management has been widely used to promote independence in children with tasks in which adult supervision is not needed, accepted, nor expected. Most people naturally develop some degree of self-management, but it often needs to be programmed for individuals with ASD. If you have ever been on and off a diet, tried to improve your exercise habits, or endeavored to build more activities into your schedule, then you have probably tried to improve your self-regulation through the use of Self-management procedures.

### Self-management has been shown:

- To be an effective intervention for children aged 3-18 years
- To produce favorable outcomes for children with ASD
- To be effective with target skills and behaviors, including:
  - Academic skills
  - Interpersonal skills
  - Self-regulation

A student who uses self-management is responsible for selecting reinforcers, monitoring and evaluating his own performance, and independently gaining access to reinforcers when a task is accurately completed (Pierce & Schreibman, 1994). Self-management can be used to teach the student to perform steps



that his front-line interventionist would otherwise do (e.g., identify target behaviors, discriminate between correct and incorrect responses, record occurrences of target behaviors, and “deliver” reinforcers) (Koegel & Frea, 1993).

### **Benefits of Self-management include:**

- Building awareness of your behavior
- Accountability for carrying out a procedure
- Direct and immediate self-feedback when recording your own data
- Multi-tasking (i.e., managing your own behavior and recording it)
- Decreasing social stigma that occurs when an adult’s assistance with simple and personal tasks is required

Self-management begins with learning to perform each component of a task. When a student first learns a new skill, instructors may need to use one of the other active teaching strategies, such as live or video modeling.

Once the student learns each component of a task, he needs to evaluate his own efforts to determine if he has accurately completed each component of the task. In order to learn to evaluate his efforts, he needs to have:

- Clear criteria established so he knows when he has succeeded and when he has fallen short of the mark.
- A systematic method for evaluating his performance. He might keep track of his performance using checklists, wrist counters, velcroed smiley faces that move from the incomplete column to the completed column of a task list, or any number of other strategies geared toward his interest.
- A qualified person who can provide neutral feedback about the accuracy of the recording. Almost everyone who starts evaluating his performance on a task records inaccurate data (intentionally or unintentionally). Have you ever tried to record everything you have eaten for a diet? Be honest! How accurate were you? Instructors often need to give prompts (verbal and non-verbal cues) so students can learn to correctly self-record their behavior.

- This neutral, qualified person could be anyone in the school system who understands the self-management system. They first need to focus on rewarding accuracy in *recording* and not get side-tracked by inaccuracies in *performance!*
- A qualified person who can teach the child to seek and get access to reinforcers only when he has met the pre-established criteria for success. Often, the adult retains control over the reinforcers.

**Consider the following examples:**

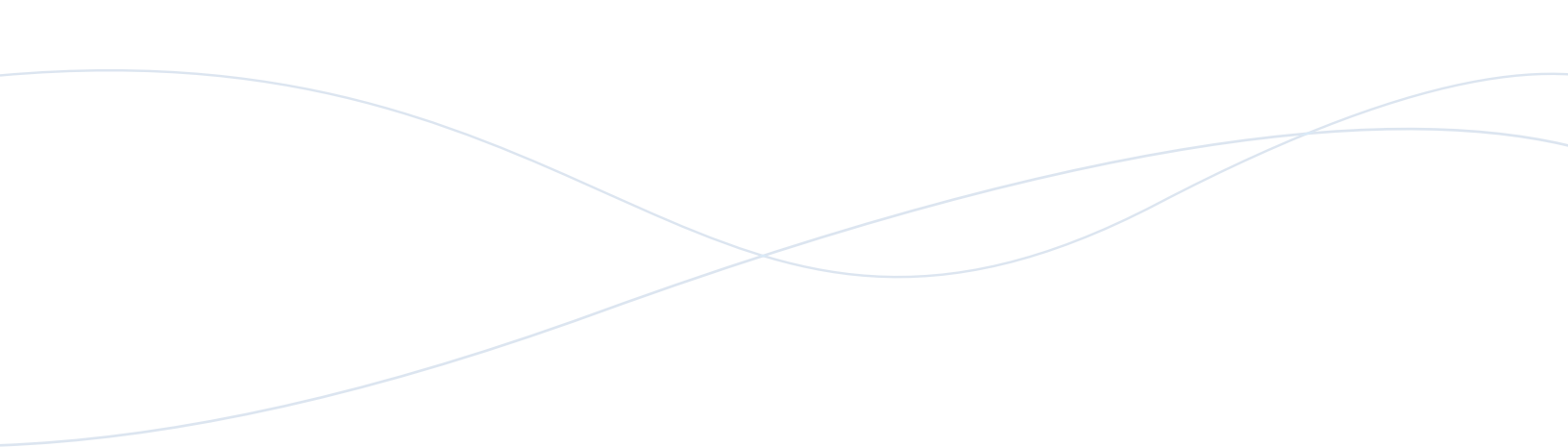
- **Example 1:** Self-management may be a natural evolution for a student who is successfully using schedules. Students with existing schedules can often be taught to increase their independence by changing a schedule into a self-management system. For instance, one of your students may already follow a schedule to transition from one activity to the next. He may not yet have developed the skill to determine when any of the activities are completed accurately, or perhaps he cannot yet arrange for access to reinforcers to maintain his efforts. By teaching the student to self-evaluate for accuracy, completion of activities, and to provide self-reinforcement, you can help successful transitioning to occur more independently.

- **Example 2:** Self-management can enhance the independent completion of tasks. To enjoy the highest level of freedom in our lives, we all need to learn to independently complete a number of daily living tasks (e.g., setting the table, getting dressed). The individual with ASD may have mastered skills, but often lacks the ability to independently perform them. Integrating access to reinforcers is essential in promoting independent use of skills.

One way to do this is to create a photo album showing each step of an activity and the materials needed for that activity. The last picture shows the reinforcer. This lets the individual with ASD know that when she is done with the task, she will gain access to the reinforcer (Pierce and Schreibman, 1994).

- **Example 3:** Regular physical activity is important for both long-term health and as a natural way for students to actively engage in leisure activities in their communities. Self-management can be used to teach students to track their physical activity. Reinforcers can be provided for completing a set amount of exercise or physical activity (e.g., snowshoeing and walking/jogging) (Todd & Reid, 2006).

Additional strategies of prompting instruction and/or intervention should be planned



(Strain et al., 1994) until the task can be completed independently. Dependency on prompts for some tasks (e.g., grocery shopping) may be acceptable as compared to tasks where an adult prompt is intrusive (e.g., getting dressed).

You should plan to systematically fade adult or external, overt cues used during self-management. In some cases, it may be necessary to continue using prompts over a relatively long period of time in order to achieve a desirable level of self-management across new behaviors.

## Story-based Intervention Package

Story-based interventions are similar to written scripts and Self-management in that they involve written materials that are designed to increase independence. The most well-known story-based intervention is Social Stories™.

### When using a story-based intervention, use written descriptions for:

- The target behavior
- The situations in which the behavior should occur
- The likely outcome of performing the behavior, which often includes a description of another person's perspective

All story-based interventions include information about the “who/what/when/where/why” of the target behavior. Most stories are written from an “I” or “some people” perspective, and they aim to increase perspective-taking skills. You can follow the stories with discussion or comprehension questions to make certain the student understands the main points. Students often receive reinforcement for reading the story and performing the behavior correctly. In addition, the stories are sometimes used to prompt the student in the natural environment. Some stories include pictures to enhance comprehension of the skills.

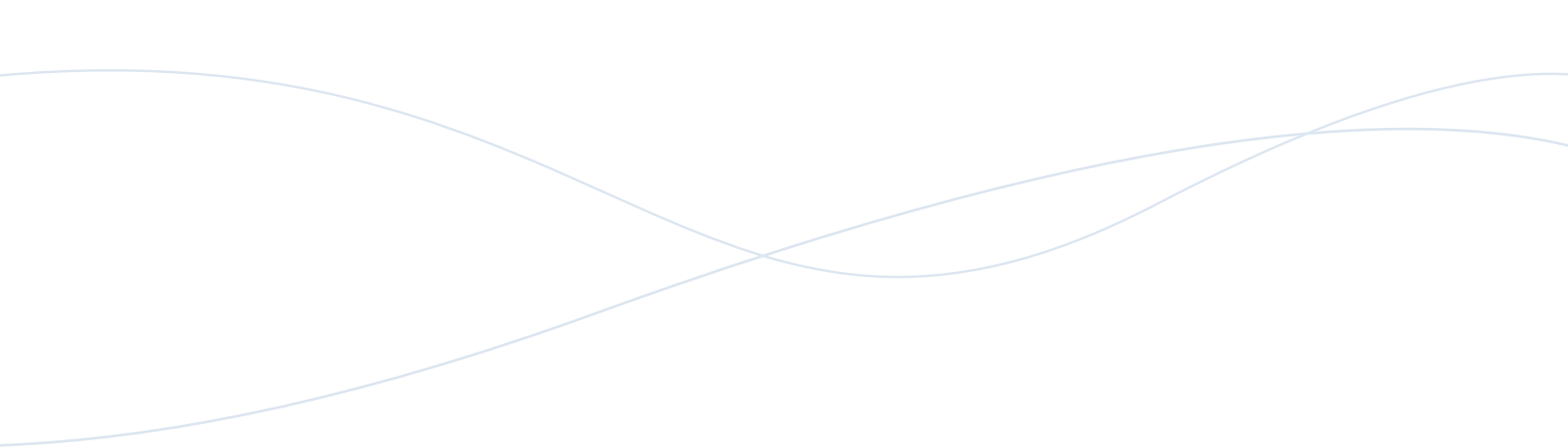
### Story-based interventions have been shown:

- To be effective for children aged 6-14 years
- To produce favorable outcomes for individuals with autism and Asperger's Syndrome

- To be effective with target skills and behaviors, including:
  - ▶ Interpersonal skills
  - ▶ Communication skills
  - ▶ Social behavior
  - ▶ Choice and play skills
  - ▶ Understanding emotions
  - ▶ Mealtime skills
  - ▶ Self-regulation
  - ▶ Problem behavior

Story-based interventions are often used with students who have acquired reading and comprehension skills. However, if a child has strong listening comprehension skills, you might read the story to her instead of having her read it independently.

- **Example 1:** Story-based interventions can be effective in modeling socially acceptable behavior. Consider the example of an adolescent who makes girls uncomfortable because he stares at them. His teacher writes a story in which the student learns to look at girls only briefly and then look away from them. His looking at girls now more closely parallels the behavior of his fellow classmates, and the girls may be more comfortable in his presence (Scattone, Wilczynski, Edwards, & Rabian, 2002).
- **Example 2:** A special education teacher successfully implemented a Social Story intervention with two children with severe autism to teach them choice-making and appropriate engagement with play materials (Barry & Burlew, 2004). The Social Story was paired with prompting and reinforcement in the form of praise. The students each improved their ability to make choices without a great deal of teacher prompting. They also went from spending no time playing appropriately during center activities to spending a minimum of 5-15 minutes playing appropriately.
- **Example 3:** Some students with ASD engage in very disruptive behavior (e.g., yelling, humming, loud noises, etc.). These behaviors can interfere with the smooth running of a classroom and may even result in the placement a student with ASD in a more restrictive environment. In one case, university researchers collaborated with educators to develop and implement Social Stories™ paired with a reinforcement in the classroom. The study demonstrated the benefits of university-school



collaboration to reduce yelling and increase appropriate sitting for a young child with ASD (Agosta, Graetz, Mastropieri, & Scruggs, 2004).

Each of the above examples followed the same general strategy. A story was written from the student's perspective, and addressed the following questions:

- What was the student supposed to do?
- When was he supposed to demonstrate this behavior?
- What would likely happen if he correctly performed the behavior (e.g., others would like it)?

## Final Considerations

**As you provide services to students with ASD, there are many interventions from which you can choose.**

Although a great deal more research is necessary to determine whether numerous interventions can lead to favorable outcomes, scientists have already conducted enough research to show that many interventions are effective.

The great news is that there are now 11 Established Treatments that have sufficient research support to demonstrate they are effective. The overwhelming majority of these interventions were developed in the behavioral literature. Importantly, several interventions were also influenced by fields such as special education and developmental psychology.

Selecting among these 11 Established Treatments may still pose challenges. This is one of the reasons professional judgment (Chapter 3) and family input (Chapter 4) are essential. We hope the upcoming chapters clarify the roles of professional judgment and family input in the delivery of evidence-based practice in the schools. It is not possible to develop systematic capacity to deliver research-supported treatments without first understanding the information contained in the present chapter. We hope you are on your way to providing evidence-based practice to students with ASD in your schools!

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# 3

## Professional Judgment & Data-based Clinical Decision Making

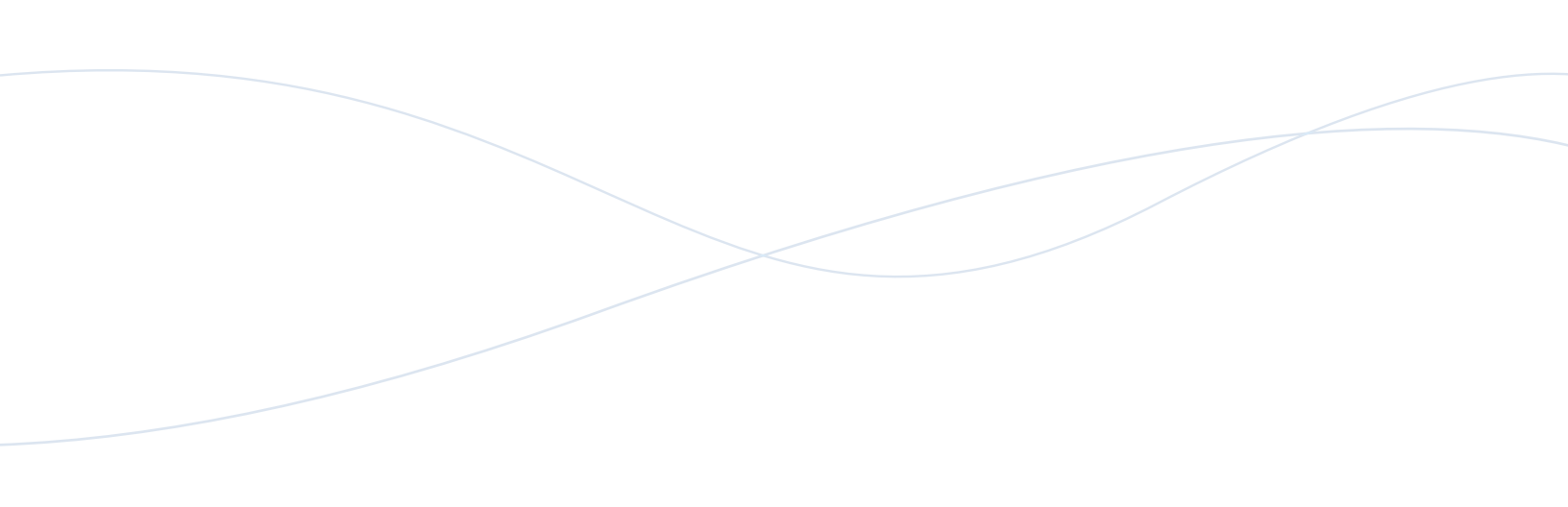
As we go through our day-to-day lives, we sometimes base our decisions on personal perspectives, or “gut feelings.” However, when it comes to making treatment decisions for students with Autism Spectrum Disorders (ASD), we must be much more systematic in our approach.

In previous chapters, we discussed the importance of making treatment decisions, in part, on the strength of scientific evidence supporting the intervention. You have learned that there are a number of treatments that are known to be effective. You might ask, then, “Can’t I just go to the list of Established Treatments, close my eyes, and pick one?” We never recommend this kind of “cookbook method” to selecting treatments. We believe your professional judgment is a critically important part of the decision-making process. You must play an appropriately significant role in the selection, implementation, and assessment of treatments for your students with ASD.

So why is professional judgment so important?

It’s important because selecting and implementing treatments is a complex process! There are an unbelievable number of intervention options available to school personnel when they select treatments for students with ASD. Even if you restrict your choices exclusively to treatments that have produced favorable outcomes in research, you will need to select among the field of 11 identified by the National Standards Project (NSP). This means your professional judgment will play a central role.

Your experience working with a specific child with ASD, your understanding of interventions that have been effective or ineffective in the past, and your awareness of the environment in which the treatment would be implemented will help you identify which treatment might be most useful.




Since research is ongoing and best practices evolve, your professional judgment also extends to your awareness of additional research support beyond those reported in the *Findings and Conclusions* report (see Appendix).

In summary, professional judgment is certainly more than just relying on your “gut” to tell you what to do. It involves {1} integrating information about a student’s unique history, {2} an awareness of research findings that go beyond the *Findings and Conclusions* report, and {3} the need to make data-based treatment decisions. In the following pages, we explore these three critical components in more depth. Understanding the importance of professional judgment will help you make your voice heard when treatment decisions are made. Without your input, the best treatment selection decisions may not be made.

## Integrating Information About the Student

Your professional judgment comes into play when you have specific information that sheds light on the appropriateness of a treatment for a given student.

Consider the case of Chun, a third grade boy diagnosed with ASD who has a history of becoming obsessed with written materials (e.g., magazines, books). He engages in high rates of self-stimulatory behavior and avoids school tasks when he has access to written materials. In addition, whenever books or magazines are taken away from him, he throws objects and hits anyone who is nearby.



Armed with this knowledge, you recommend against using a story-based intervention package. Despite its inclusion as an Established Treatment in the *Findings and Conclusions* report, your professional judgment is that interventions requiring written materials (like a Social Story™) are not a good choice for Chun at this time.

This is not to say that a story-based intervention package will never be appropriate. In this case, you would need to develop an intervention to reduce Chun's response when written materials are taken from him. At that point, a story-based intervention package may be beneficial for other goals you have set for Chun. Throughout this process, your professional judgment (which is informed by both data and experience) should influence treatment selection.

## Awareness of Additional and New Research Findings

The *Findings and Conclusions* report provides a strong foundation upon which to base treatment decisions. Even so, there will be times to look beyond the results of the report.

For example, the NSP included articles published before the fall of 2007. We are happy to report that additional research has been conducted and published since this date! If you are aware of additional well-controlled studies published after the fall of 2007 that show beneficial outcomes for a treatment, you might give serious consideration to the treatment.

Your awareness of additional research on any of the treatments for ASD will inform your judgment about which interventions will be most appropriate for a student. Articles that were excluded from the NSP may be one source of additional research that you might consider. Similar to other evidence-based practice guidelines, the NSP set clear parameters for its review and report.


**For example, the following studies were excluded from the NSP review:**

- ASD articles across the entire lifespan. For example, the NSP did not include articles on older adults. The focus of the review was on children or young adults who could be served by early intervention and school programs or health and community-based settings targeting this age group.
- Articles in which individuals with ASD also had various co-occurring conditions (see Differential Diagnosis and Co-morbid Conditions section of Chapter 1). If {a} an individual has unusual disabilities and/or disorders in conjunction with ASD and {b} a study shows the intervention is not effective, it is impossible to know whether the treatment was ineffective for individuals on the autism spectrum or people with both ASD and additional conditions.
- Articles that focused on the “change agents” (e.g., educators, therapists, or parents). The goal was to focus on treatment as it relates to the individual with ASD.

By excluding all of the articles looking at older adults, individuals with co-occurring conditions, and the change agent, the number of studies reviewed for a given treatment were at times reduced, and in some cases significantly reduced. For example, this meant excluding almost all of the articles on Facilitated Communication. You will find Facilitated Communication is classified as an Unestablished Treatment in the *Findings and Conclusions* report.

As a professional, you are likely aware that many professional organizations advise against the use of this treatment due to concerns regarding “immediate threats to the individual civil and human rights of the person with autism...” (American Psychological Association, 1994). These advisements were written based on all of the research that had been published to date on Facilitated Communication. In this case, your professional judgment should also play a role in treatment selection.

You may also be aware of additional studies beyond the ASD literature that should influence your decision-making process. Whenever possible, you should make decisions about the effectiveness of a treatment based on research involving the specific



population you are serving. That is, if you serve a child on the autism spectrum, you should make treatment decisions based, in part, on the scientific evidence supporting a given treatment specifically as it pertains to that population.

There may also be occasions when information from the NSP or similar projects must be supplemented by research in other areas. You may have information about treatments for symptoms that can co-occur with ASD and are the source of concern for the student. For example, some adolescents with Asperger's Syndrome may experience anxiety or depression. There are research-supported treatments for anxiety and depression for individuals who are not diagnosed with an ASD. Your awareness of this important literature should assist in treatment selection.

We hope we have made it clear that your professional judgment can and should play an important role in treatment selection. Further, professional judgment should always be informed by data. For this reason, we spend the rest of this chapter discussing data collection procedures, strategies for analyzing data, and decision-making guidelines for modifying treatments based on data. After all, treatment selection is only the first step in a dynamic process. We should all be prepared to consider alternate treatment choices if the data show that an intervention does not result in timely progress for students' targets.

## Data Collection

Data collection is essential in your work with students with ASD. It is relevant whenever you develop an intervention designed to increase skills or to decrease behaviors that interfere with life functioning. Why is data collection so critical? Collecting data before and after you put an intervention into practice helps you assess whether your student is making progress.

We all tend to rely on anecdotal evidence (e.g., what we happen to notice, what our “gut” tells us, etc.). Although it seems helpful, it is often unreliable. Therefore, we should only use anecdotal evidence alongside empirical evidence. Consider a behavioral package treatment (token systems) as an example. Token systems are commonly used in school and home settings. When educators and parents meet to discuss a student’s behavior, they might also discuss the use of token systems in the classroom.

In this example, John’s parents ask if the token system is effective with their son. If John’s teacher doesn’t collect data regularly, her response might be influenced by a number of factors. If John has had a good week, she might say, “John seems to be talking out of turn much less frequently in the classroom since I started using the token system.” On the other hand, if John had a particularly bad day, she might respond more negatively: “It doesn’t seem like the token system has affected John’s talking out much at all.” We have all made comments like these from time to time. But consider the downside of this type of anecdotal evidence:

- We are more likely to remember what has happened in the last day or two than how John has responded since the token system was introduced.
- Human beings tend to look for confirmatory evidence. If we believe the token system will be effective, we are more likely to pay attention when John is doing better.

If we believe John is not likely to respond to the token system, we are likely to pay attention when John is breaking the rules.

- Educators spend much of the day multi-tasking (i.e., providing discipline, teaching lessons, grading papers). When you are this busy, you are more likely to notice when things go wrong than when things go right.

Can you really be expected to accurately recall the effectiveness of an intervention over the course of several weeks or months? No. Data collection is important because it provides you with a firm basis on which to draw conclusions and make decisions about intervention effectiveness. Before you can do so, you need a foundation in data collection procedures.

The idea of collecting data can seem overwhelming. Here are a few recommendations for building data collection into your daily activities:

- Use efficient data collection techniques. You do not typically need to collect data throughout the entire day.
- When possible, select data collection procedures that can be used while you perform your other essential duties (see Procedures for Collecting Data section).
- Get help while you perform essential duties. The school psychologist, behavior analyst, principal, or other professionals can often assist with data collection.



# Setting Goals and Defining Target Behaviors

## Setting Goals

School professionals typically have two goals when targeting behavior change. First, they may try to decrease maladaptive or problem behavior. Behavioral reduction interventions are put in place when students show excessive behaviors (e.g., self-stimulatory behavior, aggression, self-injury, disruptive behavior, etc.). Behavioral acceleration interventions are put in place when students show a deficient level of responding (e.g., adaptive, communication, social functioning, etc.). Before data collection begins, you must develop a clear goal for the intervention, irrespective of whether you plan to put a behavioral reduction or behavioral acceleration intervention into place. There are two rules that can help you identify an appropriate goal.

The first rule is the “dead man’s test.” Whenever possible, it is best to write a target behavior so that it clearly identifies what the student should do (instead of what she should *not* do). As you develop your goal, make sure it passes this test.

The “dead man’s test” simply requires that your goal does not reflect an activity a dead man might demonstrate. For example, let’s say your student, Mario, obsessively sharpens his pencil. The constant pencil sharpening interferes with the time he spends on his assigned tasks and disrupts the students around him. You set a goal of “Mario will not sharpen his pencil in class.” Unfortunately, your goal does not pass the test, since a dead man is perfectly capable of not sharpening his pencil! Instead, consider setting a goal of “Mario will sharpen his pencil only once per class.” Can a dead man sharpen his pencil once per class? Not unless he is a zombie—which is a topic well beyond the scope of this manual!

The second rule is related to relevance. Before we begin the process of data collection, we need to make certain a behavior should actually be targeted for change. You can determine this by identifying whether a change in the behavior would actually produce meaningful improvements. Learning to communicate, play with peers, or

study often leads to meaningful improvements in a student's life. Similarly, "reducing disruptive behavior" may lead to improvements in a student's social interaction with peers and increase the amount of time spent on task.

**There are two issues to consider before you make a final determination about a goal:**

- 1.** Goals should be developmentally appropriate. A student who can label 200 pictures of objects but cannot request one of those items without being asked "What do you want?" should not begin working on the next 200 labels until basic requesting skills have been targeted for improvement.
- 2.** Some behaviors are only irritating to adults who share the life of an individual with ASD. A child who yawns excessively might distract the teacher at the front of the class. But if the student gets his work done and his classmates do not seem to notice, this "disruptive behavior" should not necessarily be targeted for change.

You will need to use your professional judgment to identify an achievable goal for the student. For example, you may attempt to decrease the number of times a student "talks out of turn." A baseline frequency count reveals that the student talks out of turn 100 times during an average school day. You must decide what a reasonable and achievable goal may be for the student and whether your goals should shift over time.

Your professional judgment tells you the final goal should be that the student does not talk out of turn more than the other students in the class. You collect data on the frequency of "talking out of turn" for students in your class and decide it is acceptable to talk out of turn eight times during each school day. You decide that going from 100 to eight times a day is not going to happen overnight, so your first goal is to reduce his talking out to 75 times a day. You know that this number is still excessively high, but you want him to be successful. You are now ready to proceed to intervention, with ongoing data collection to assess its effectiveness. You will need to set a number of intermediary goals (e.g., 50, 25, 10) before you expect him to talk out eight or fewer times per day.

## Defining Target Behaviors

As you have established your goal, you will need to clearly define the target behavior. The definition should be written with enough clarity that a stranger would be able to identify the presence or absence of the target behavior. Let's take the example of the following target behavior: "Given the choice of three pictures, the student will point to a picture of the correct animal in receptive labeling tasks." A stranger (who happens to be familiar with a speech-language pathologist's jargon) should be able to identify the presence of the target behavior (e.g., the student correctly pointed to the picture of the dog when the teacher said "Point to the dog.") or the absence of the target behavior (e.g., the student incorrectly points to the picture of a goat when the teacher said "Point to the dog.").

You will note that the target behavior identified here is very specific, it is observable, and it can be easily measured. There are many behaviors that are written in a vague way. To state the same goal as "The student will recognize the correct picture when completing receptive labeling tasks" is not very measurable. How do you know if the student *recognizes* it or not? Can you actually observe someone "recognizing" the correct picture? No. It also does not include what the parameters of the observation may involve. For example, are you supposed to show the child one picture, two pictures, three pictures, or more when completing this receptive labeling task?

**You should be able to answer each of the following questions when evaluating your definition:**

- Is the definition specific?
- Is the target behavior observable?
- Is the target behavior measurable?

## Procedures for Collecting Data

There are many data collection options (Alberto & Troutman, 2003; Webber & Scheuermann, 2008). Some data collection procedures that are used most often include frequency, time sampling, duration data, and latency data.

- **Frequency.** Frequency data involve counting the number of times a behavior has occurred within a given time period.
- **Time sampling.** Time sampling data involve determining whether or not behaviors occur within a specific interval of time.
- **Duration.** Duration data involve determining the length of time over which a behavior occurs.
- **Latency.** Latency data involve the length of time that passes between when an instruction is delivered and a behavior is initiated.

The type of behavior you attempt to increase or decrease will determine the type of data collection technique you should use. The following discussion of these techniques may help you decide which option is most appropriate.

### Frequency Data

When you want to record the frequency of a behavior, you make a tally mark each time the targeted behavior occurs. At the end of the observation period, you count the number of tally marks you have made and this represents your frequency count.

Before beginning frequency data collection, you need to determine the length of the observation period. Should frequency data be collected during the first or last 10 minutes of class? Should they be collected during the entire class period? Should they be collected whenever the child is in the classroom? Or, should the data be collected all day long—across every setting in which the child spends time?

Frequency data collection is typically used when a behavior has a distinct beginning and end. For example, you can use a frequency count to record number of words read aloud, math problems completed independently, or hand slaps on a desk. Figure 1 provides an example of a frequency count data sheet.

**Figure 1}** Frequency Recording Data Sheet

<b>Student:</b> <u>Jose</u>		<b>Date:</b> <u>10/2</u>	
Record a tally mark (/) for each occurrence of the target behaviors during the specified time period. Record a 0 if no target behavior occurred during the specified time period.			
<ul style="list-style-type: none"> <li>• <b>Aggression</b> is defined as any occurrence of kicking, hitting, pinching, or throwing objects at another person. Attempts to kick, hit, pinch, or throw an item are also recorded.</li> <li>• <b>Talking Out</b> is defined as any occurrence of Jose speaking without permission during group activities in the classroom.</li> </ul>			
	<b>Aggression</b>	<b>Talking Out</b>	<b>Staff Initials</b>
9-9:15 a.m.	////	//	SF
9:15-9:30 a.m.	0	0	SV
9:30-9:45 a.m.	///	0	LB
9:45-10:00 a.m.	0	////	LB
10:00-10:15 a.m.	0	///	SF
10:15-10:30 a.m.	0	/	SF
<b>Total</b>	<b>7</b>	<b>10</b>	

There are advantages and disadvantages to collecting frequency data. Recording frequency data is relatively easy. Unfortunately, it may not always best represent the student’s problem behavior. For example, you only make one tally mark if a student throws a tantrum for 60 minutes, 30 minutes, or five minutes. If you use frequency data collection procedures for a problem like tantruming and you put an intervention in place, it is harder to see improvement when the tantrum decreases in length from 60 minutes to five minutes, since a tally mark records the *occurrence* of a behavior, but not its duration.

## Time Sampling

Time sampling methods vary but essentially require breaking down an observation period into smaller intervals and then recording whether the behavior occurred during the interval (Sulzer-Azaroff, 2008, p. 208). For example, a five-minute observation period can be divided into 10-second intervals. There would be 30 opportunities to mark the presence or absence of the target behavior.

This data collection method is used most often when a behavior occurs at relatively high rates or does not have a distinct beginning and end.

Time sampling methods require the use of a timer to mark the beginning of each interval. Often, professionals using interval recording procedures use a watch with an interval setting, or they listen to a prerecorded CD of someone marking every interval.


Consider the time sampling data sheet in Figure 2. Let's say you have made the decision to collect data at three different five-minute observation periods during the school day. The first five-minute observation will occur at the beginning of English class, between 9:40 a.m. and 9:45 a.m. You have clearly defined Stacey's self-stimulatory

behavior and stated it at the top of the data sheet. You have a prerecorded CD that clearly states the beginning of the observation period (e.g., it says "Observation begins now."). At the end of the first 10-second interval, the recording states "1-1" to indicate the end of the first interval of the first minute. You now record the presence or absence of the self-stimulatory behavior. Since Stacey engaged in self-stimulatory behavior during observation interval 1-1, you use a plus sign "+" to record the presence of the self-stimulatory behavior. The self-stimulatory behavior occurs during the first three observation intervals.

During observation interval 1-4, Stacy stops engaging in self-stimulatory behavior. You record the absence of her self-stimulatory behavior by marking a minus sign "-" in interval 1-4. At the end of the five-minute observation period, you count the *number* of intervals in which the behavior occurred so you can calculate the *percentage* of intervals in which that behavior occurred. In this case, self-stimulatory behavior was recorded in 13 of the intervals. By dividing 13 by the total possible of 30 intervals, and then multiplying by 100, you determine that Stacey engaged in self-stimulatory behavior during 43% of intervals.

**Figure 2}** Interval Recording Data Sheet

<b>Student:</b> <u>Stacey</u>												<b>Date:</b> <u>4/9</u>					
<p><b>Self-stimulatory Behavior</b> is defined as any occurrence of Stacey rocking her upper body in a back and forth motion while seated in her chair.</p> <p>Record self-stimulatory behavior during three 5-minute observations each school day.</p> <p>The 5-minute period is divided into 10-second intervals. Self-stimulatory behavior is recorded during a partial interval. Record a "+" if the behavior occurs during the interval and record a "-" if the behavior does not occur during the interval.</p>																	
<b>Time Start:</b> <u>9:40 a.m.</u>						<b>Time Start:</b> _____						<b>Time Start:</b> _____					
<b>Time End:</b> <u>9:45 a.m.</u>						<b>Time End:</b> _____						<b>Time End:</b> _____					
1-1	1-2	1-3	1-4	1-5	1-6	1-1	1-2	1-3	1-4	1-5	1-6	1-1	1-2	1-3	1-4	1-5	1-6
+	+	+	-	-	+												
2-1	2-2	2-3	2-4	2-5	2-6	2-1	2-2	2-3	2-4	2-5	2-6	2-1	2-2	2-3	2-4	2-5	2-6
+	-	+	-	+	+												
3-1	3-2	3-3	3-4	3-5	3-6	3-1	3-2	3-3	3-4	3-5	3-6	3-1	3-2	3-3	3-4	3-5	3-6
-	-	-	+	+	+												
4-1	4-2	4-3	4-4	4-5	4-6	4-1	4-2	4-3	4-4	4-5	4-6	4-1	4-2	4-3	4-4	4-5	4-6
+	+	-	-	-	-												
5-1	5-2	5-3	5-4	5-5	5-6	5-1	5-2	5-3	5-4	5-5	5-6	5-1	5-2	5-3	5-4	5-5	5-6
-	-	-	-	-	-												
Number of intervals with + <u>13</u>						Number of intervals with + _____						Number of intervals with + _____					
Number of intervals with - <u>17</u>						Number of intervals with - _____						Number of intervals with - _____					
% of intervals target behavior occurred: <u>43</u>						% of intervals target behavior occurred: _____						% of intervals target behavior occurred: _____					



There are several different types of time sampling procedures. These procedures differ based on how you decide to record the occurrence of the target behavior.

**The most common forms of time sampling procedures include:**

- **Partial interval.** The observer records the presence of the target behavior (with a “+”) if the behavior occurs at *any* point during the interval. The observer records the absence of the target behavior (with a “-”) if the behavior does not occur during the interval.
- **Whole interval.** The observer records the presence of the target behavior if the behavior occurs during the *entire* interval. The observer records the absence of the target behavior if the behavior does not occur throughout the entire interval.
- **Momentary time sampling.** The observer records the presence of the target behavior if the behavior occurs at the *end* of a specified interval. This means the target behavior is recorded only if it is present at the exact moment the interval ends (e.g., when the recording states “1-4”). Even if the behavior occurs at other times during the interval, if it does not occur at the exact moment when the interval ends, the observer records that the behavior was absent.

There are advantages and disadvantages with each of these time sampling procedures. For example, momentary time sampling is much easier, but it may not accurately represent a target behavior. A student could spend much of her time engaged in inappropriate behaviors, yet no instances of problem behavior would be recorded because of the timing of her actions. On the other hand, partial interval recording may easily result in recordings of inappropriate behavior, but it might not be very sensitive to improvements because behaviors are recorded even if they are fleeting.

There is no perfect data collection system! You simply need to consider these points to minimize your greatest concerns about the accuracy of the data.



## Duration

A measure of duration simply means that you record the “start” and “stop” of a behavior (e.g., the length of a tantrum). This generally requires the use of a stopwatch. An advantage of duration recording is that you manage to capture *all* of the problem behavior. That is, you record every moment of the problem behavior. On the other hand, it also has its limitations. For example, completing other activities while you collect data can be challenging. Also, for some behavior, it is hard to know when the beginning and the end of a target behavior occurs. You can clarify exactly what should be considered an instance of a target behavior by writing a very careful definition. Let’s use our tantrum example to consider the question, “What is a continuous tantrum?” That will require you to answer various questions to arrive at a specific definition.

- Do you stop recording when the child has to take a breath to inhale? He did stop screaming at that point.
- Do you stop recording if the child stops flailing for two seconds but then starts up again?
- Do you stop recording when the child’s volume reaches a low level even though she is still “whining” and arching her back?

## Latency

Like duration data, latency data are directly related to the concept of time. While duration recording focuses on the length of time a behavior actually occurs, latency recording focuses on the length of time that passes between when the instruction is delivered and a target behavior occurs. Similar to duration data, a stopwatch is usually required for latency data.

Why would we want to focus on the length of time before a target behavior occurs? In order for most people to be successful, they need to be able to quickly respond to demands in their environment. Many students (including those on the autism spectrum) do not jump to complete an activity the moment they receive an instruction. Some students spend a lot of time looking at materials instead of getting started with a project, or delay turning to the right page until a minute or two after the other students do. These students are more likely to miss out on instructional time and be unable to keep up when they do initiate the task. Latency recording is a perfect tool in these situations.

## Additional Data Collection Considerations

The data collection procedures we have addressed to this point are extremely versatile. You can use the same data collection methods (i.e., frequency, time sampling, duration, and latency) for behavioral reduction or behavioral acceleration.

An often overlooked way of collecting data is to monitor permanent products such as completed worksheets or homework assignments. Permanent products are ideal for the classroom setting because a good deal of academic work lends itself to these measures. Like the other data collection procedures we have described, these permanent products can be used both as baseline and intervention data. Permanent products are used for behavioral acceleration interventions (i.e., to increase academic success).

Self-monitoring is another data collection method that is not used frequently enough. Self-monitoring systems require the student to record the occurrence of his own target behaviors. This data collection method can be applied with behavioral reduction and behavioral acceleration interventions. There are many studies suggesting that self-monitoring systems can be effectively implemented in the classroom setting (e.g., Cole & Bambara, 1992; Mithaug & Mithaug, 2003).

There are several advantages to self-monitoring. For example, self-monitoring is efficient for the smooth running of the classroom. If the teacher, paraprofessional, or school psychologist does not need to consistently spend time collecting data on a student's progress, their professional skills can be used in other essential ways. Further, learning to monitor their own activities is an important skill for all students. To best support students with ASD, we need to take advantage of any strategies that lead to greater independence.

Please see the Self-management section in Chapter 2 for a more detailed description of self-monitoring procedures and the process of teaching students self-management skills. You will also learn why self-monitoring data are not the ideal baseline data. Hint: You might need to collect your own baseline data because students are not very accurate when they first learn to record their own behavior!



## Using Data to Establish Baselines

We recommend that data be collected before you implement an intervention.

The data you collect before beginning treatment are called “baseline” data.

Without collecting baseline data, it will be impossible to clearly show that the intervention you put in place have led to student improvement. Baseline data collection need not be tedious or time-consuming once you have a system in place.

**We recommend the following steps:**

- 1.** First, decide on the type of data you will collect (e.g., frequency, duration, etc.).
- 2.** Second, decide the time of day or the type of activity for which you will collect data. Also determine the minimum number of days you will collect baseline data. At least three data points are required to identify a trend (see data analysis section for details).
- 3.** Third, gather the tools you will need to collect the data (e.g., data sheet, timer, pencil). Educators can access a number of examples of data collection sheets online or in various textbooks and manuals (e.g., Alberto & Troutman, 2003; Webber & Scheuermann, 2008).



## Intervention Data

Once you have identified your goal, it's time to implement the intervention. You will have selected the intervention based on research findings (see Chapter 2), the professional judgment of staff involved (this chapter), family input (see Chapter 4), and the capacity to correctly implement the intervention at this time (see Chapter 5). You will need to collect data during the intervention phase so you can determine whether the treatment you are implementing is working.

There is no doubt that it takes time and energy to accurately implement an intervention. This can take time away from some of your usual activities, but you know it's worth it if the student makes progress. If you do not collect data during the intervention phase, it might be hard to know if the treatment is working. Your time and energy are too valuable to waste. More importantly, you do not want to continue using an ineffective intervention for the students in your care. For the student who talks out an average of 100 times per day, what are the odds you will notice if it drops to 90 or increases to 112 unless you collect data?

You must analyze and compare data between baseline and intervention conditions to determine what to do next. You may decide to continue with the intervention if you see improvements based on the comparison of baseline and intervention data. Or you may decide to revise the current intervention or implement an entirely new intervention if it becomes clear things are not improving or are getting worse!

Ongoing data collection helps you to determine how changes in the intervention affect the targeted behavior. It is important to use the same data collection procedure during both baseline and intervention phases.

## Graphing Data

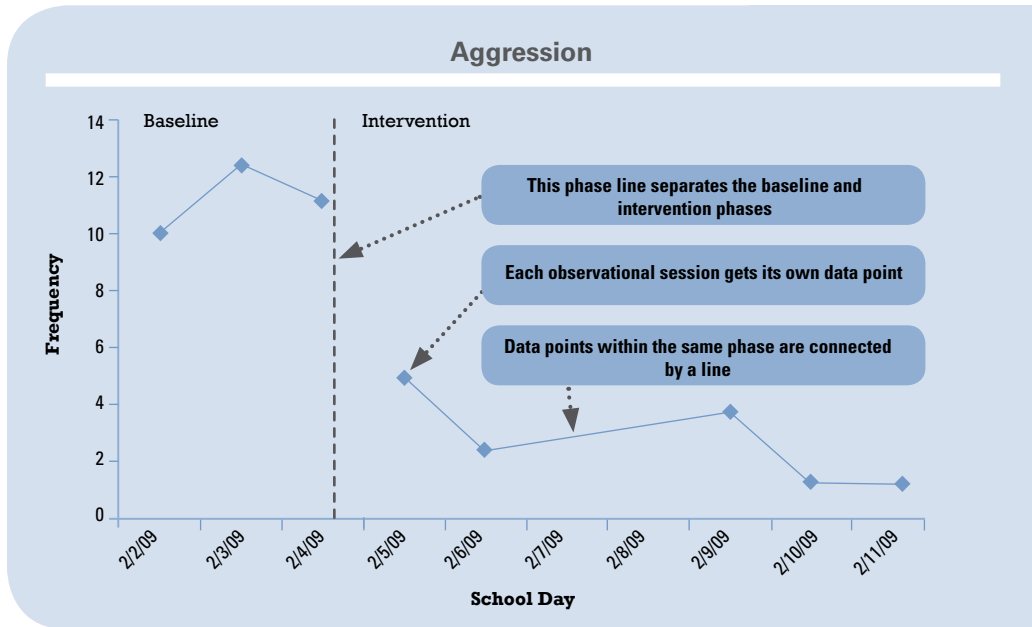
Once you have collected baseline and intervention data, what do you do with them? Is there an easy way to see if the intervention worked? There is. Graphing is a useful tool that can help you make decisions and use your professional judgment (Alberto & Troutman, 2003; Cooper, Heron, & Heward, 2007).

Looking at tally marks on a data sheet can be informative. But what happens when you need to look across 5, 10, or 20 data sheets? Putting the data into a graph allows for easy interpretation. Line graphs are commonly used to track changes in behavior over time (e.g., Carr & Burkholder, 1998). Basic computer software such as Microsoft Excel™ can be used to generate a simple but effective graph.

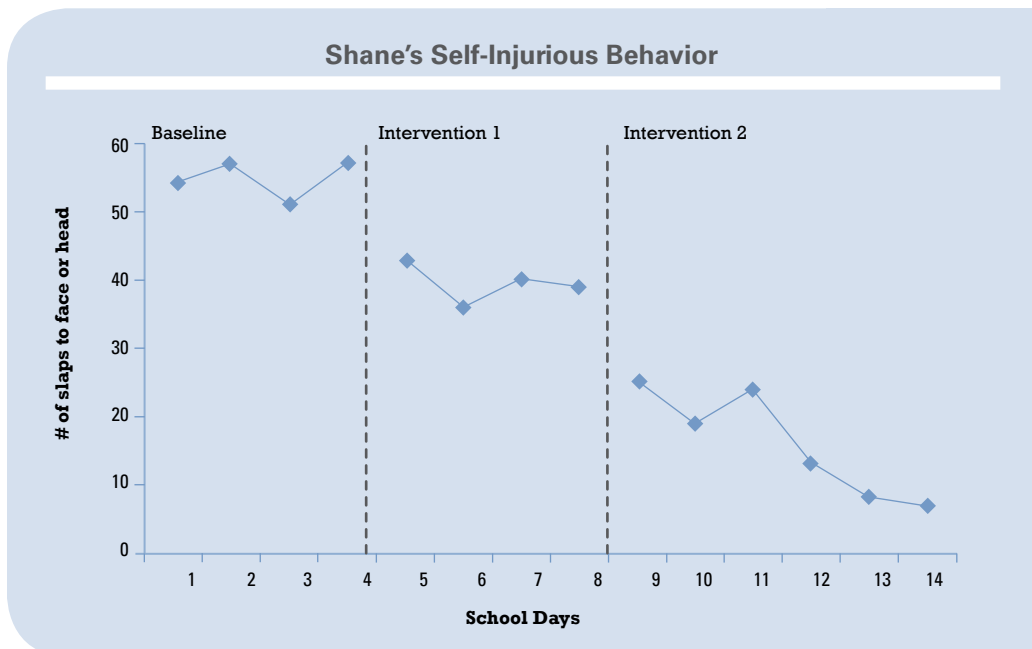
On a line graph, each data point represents one data collection session (e.g., one school day, one class period, etc.). A vertical line (i.e., phase line) can be drawn between the baseline and intervention phases to indicate the introduction of the intervention. All data points in the same phase are connected by a line, but data points are not connected across phases (see Figure 3).

Phase lines can also be drawn at various points to indicate where a change in the intervention occurred. For example, if you learned that a student started on a new medication while you were implementing a new intervention, you would draw another phase change to show the new intervention phase (intervention 2: school intervention + medication). This would reflect the multi-component aspects of treatment that may be influencing the student's behavior (see Figure 4).

**Figure 3}** Graphical Representation of Data



**Figure 4}** Showing Changes in Phases When Modifications to Treatments are Made



## Visual Analysis of Data

Once you've graphed your data, you can begin to visually analyze your results. You will want to inspect the line graph to determine whether the behavior is changing and, if so, whether the change occurred in the desired direction. Ideally, the change from baseline to intervention is so fast and dramatic that the improvement will just jump out at you.

Unfortunately, that may not always be the case. Interpreting the graphed data is easier if you account for stability and trends in the data. Also, the percentage of overlapping data points aids in the interpretation of data (e.g., Alberto & Troutman, 2003). We will discuss each of these concepts in more detail.

Stability simply refers to how consistent the behavior is over time. Let's apply the concept of stability to James, a fifth grade student with ASD. James is capable of doing his work when you can get him on task. Unfortunately, you believe he "stares off" (e.g., looks out the window, gazes at the ceiling, etc.) too much during his social studies class. You decide you need baseline data on James' off-task behavior and you select a partial interval recording system. The school principal completes five-minute observations during social studies for a week because she does not want data collection to interfere with your teaching.

### **You determine that James was off-task during:**

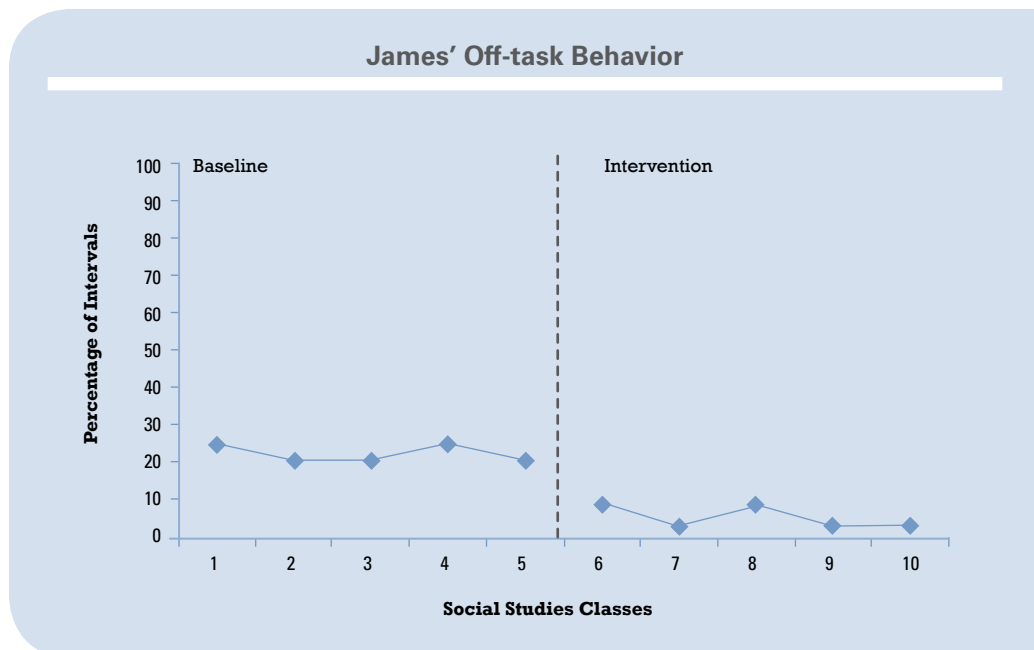
- 23% (7 out of 30) of the intervals on Monday
- 20% (6 out of 30) of the intervals on Tuesday
- 20% of the intervals on Wednesday
- 23% of the intervals on Thursday
- 20% of the intervals on Friday

When you implement your intervention, the principal collects the following data and you determine James was off-task during:

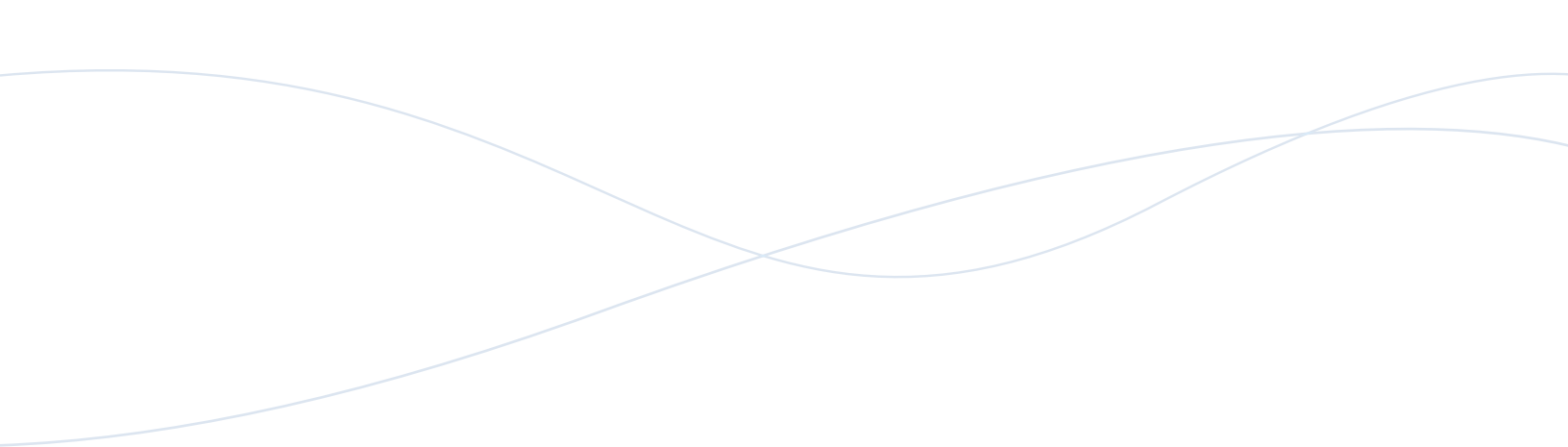
- 7% (2 out of 30) of the intervals on Monday
- 3% (1 out of 30) of the intervals on Tuesday
- 7% of the intervals on Wednesday
- 3% of the intervals on Thursday
- 3% of the intervals on Friday

You graph your data (see Figure 5) and see that there is great stability in James' off-task behavior in both baseline and intervention phases. It is easy to see that the intervention was effective because James' behavior has been so consistent in both baseline and intervention phases. The good news is that he is clearly improving.

**Figure 5}** Graphical Representation of James' Off-task Behavior







You then contrast James' performance with another student in the class. Kelly is a student with Asperger's Disorder who also experiences problems with concentration. While collecting data on James, the principal also collected data on Kelly's off-task behavior. Her data are graphed in Figure 6. You see that there is little stability in the time she spends off-task.

High variability may indicate an unidentified environmental variable that affects the target behavior on some days but not others. You see that Kelly was highly on-task on Tuesday and Friday during the baseline condition. You remember that she asked to use the restroom before class began on each of these days.

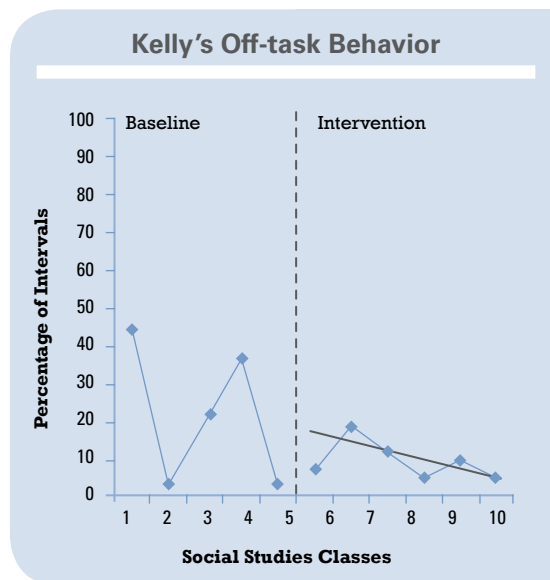
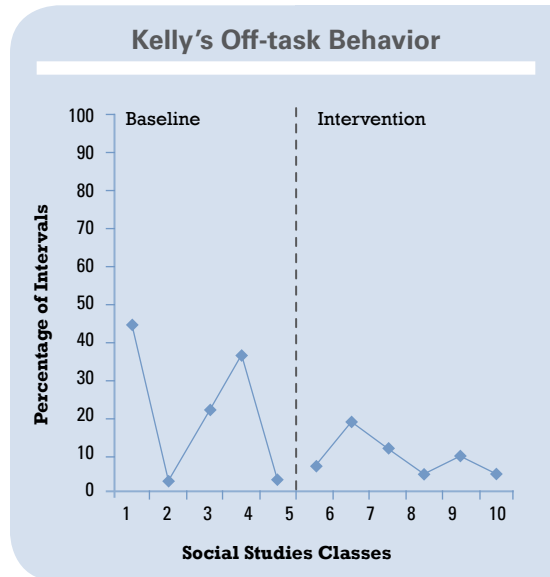
Armed with that information, you develop an intervention in which you give Kelly the opportunity to use the restroom each day before social studies. The lack of stability in Kelly's baseline data makes it a little more challenging to interpret the outcomes. If you based your decision exclusively on stability, you might interpret the data to mean that the intervention was not effective (because there is still not a perfectly stable pattern of responding). But you realize there are

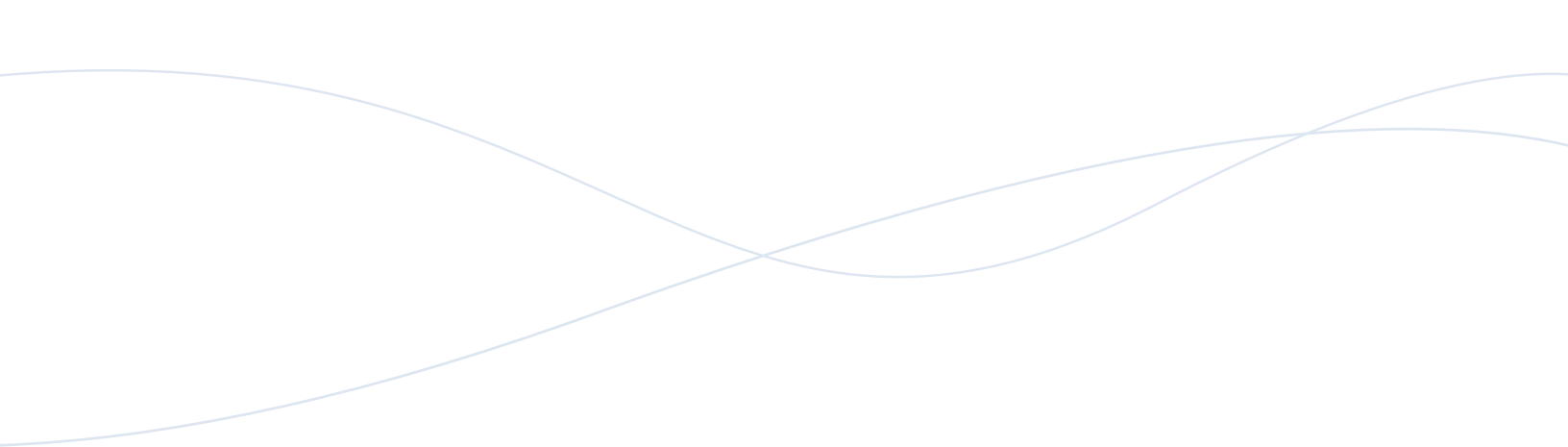
more indicators that aid in interpretation of visually presented data. You also see that she spends more time on-task at the end of the first week of intervention. You decide to consider one of the other key indicators of intervention effectiveness—trends—before interpreting these data.

Trend refers to the direction of change across data points within a phase (e.g., during baseline or the period of time in which a treatment is being implemented). There are several ways to show a trend. The easiest way is to visually determine what line best "describes" all of the data. You can "draw" this trend line using a program like Excel. If you would rather use a mathematical approach to calculating the trend line, we recommend the chapter on single-subject designs in *Applied Behavior Analysis for Teachers* (Alberto & Troutman, 2003).

Analyzing trends in the data will help determine if behavior change is moving in the desired direction. Ideally, when implementing a behavior reduction intervention, the desired effect would be a decreasing (or descending) trend relative to baseline. In contrast, when implementing an intervention to increase behaviors or skills, the desired effect

**Figures 6a and 6b}** Graphical Representation of Kelly’s Off-task Behavior (without and with trend line, respectively)





would be an increasing (or ascending) trend relative to baseline. As mentioned earlier, you will need to collect at least three data points per condition. Identification of a trend requires at least three data points and often may require five or more. It can be difficult to identify a trend when the increase or decrease in behavior is gradual over time.

Let's look back at Kelly's off-task behavior (see Figures 6a and 6b). If you were to draw a line that best represents all of the data in the intervention phase, you would see a descending trend. Because our goal is to decrease off-task behavior, the descending trend tells us our intervention is leading to favorable outcomes.

Percentage of Overlapping Data Points (POD) refers to the percentage of data points in one condition (e.g., baseline) that falls within the range of a second condition (e.g., intervention phase). POD is one indicator of treatment effectiveness.

More effective intervention data will generally produce lower percentages of overlapping data points (e.g., less than 20%); less effective interventions will produce higher percentages of overlapping data points (greater than 30%). Lower percentages of overlapping data points indicate that the difference between baseline and intervention phases are so robust that there is an easily noticeable difference between baseline and intervention. That is, the difference is large enough that almost none of the data points overlap.

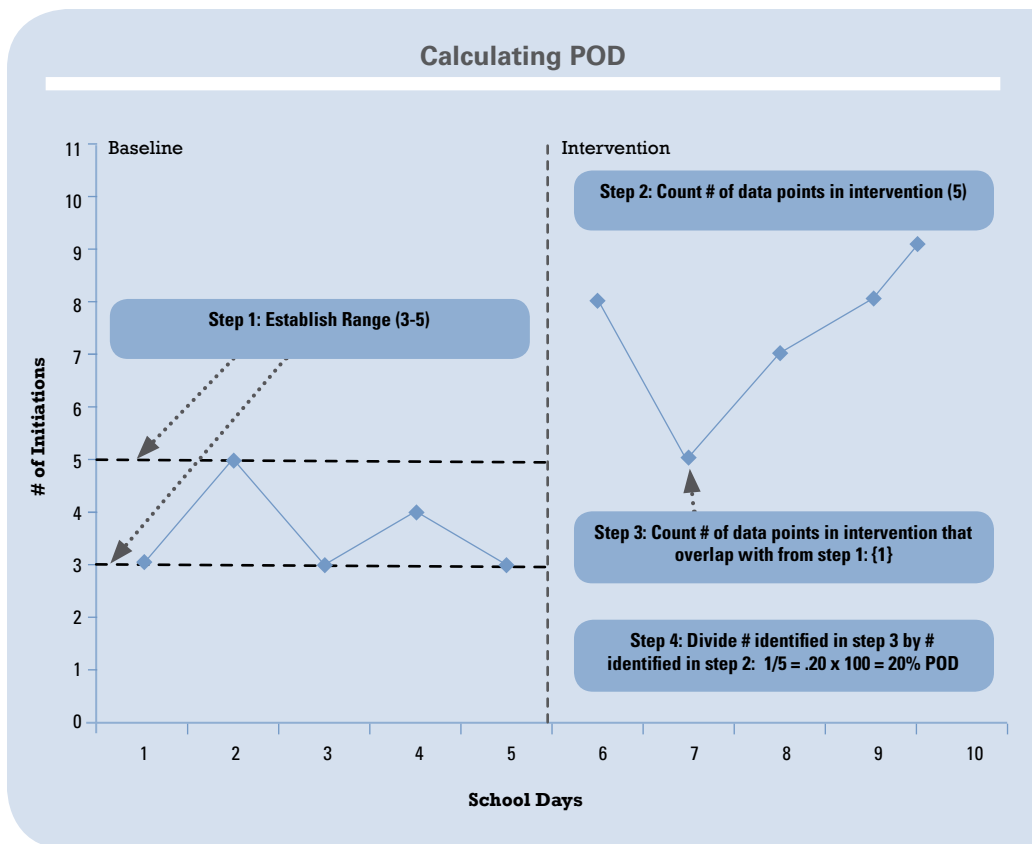
## Calculating the Percentage of Overlapping Data Points

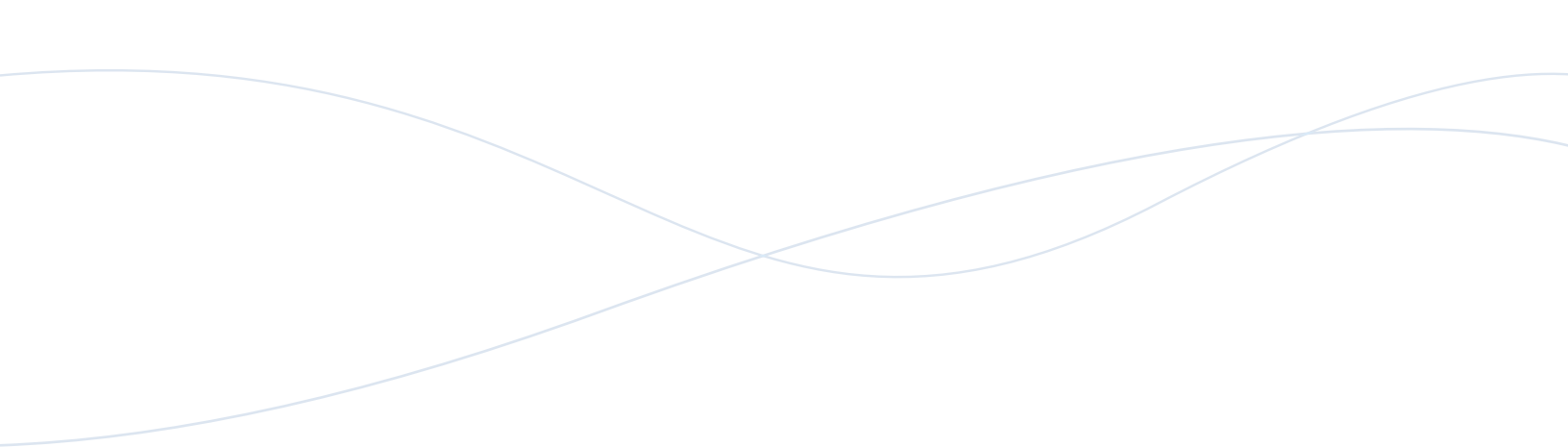
There are several steps to calculating POD. The process of calculating POD is easy once you have done it—but the language used to describe the process is cumbersome! Try not to be overwhelmed when you review the steps. In the end, you are only trying to figure out what percentage of the data points in baseline overlaps with the data points in your intervention condition.

**See Figure 7 to help illustrate the following narrative description:**

- **Step 1:** Identify the range of data points for condition 1 (e.g., baseline). You determine the range by identifying the lowest and highest numbers in the condition. For example, if your goal is to increase the number of social initiations your student

**Figure 7}** Graphical Representation of Calculating Percentage of Overlapping Data Points





makes toward his peers, you might measure the frequency of social interactions during recess. The fewest number of times Jacob initiates with peers in baseline is three; the greatest number of times Jacob initiates with peers is five. The range you calculate is: 3 – 5.

- **Step 2:** Count the number of data points in condition 2 (e.g., intervention).

In Jacob's case, you collected data while implementing your intervention during five recess periods. The number of data points you calculate is 5.

- **Step 3:** Identify the number of data points in condition 2 that fall within the range of condition 1. (In this case, the number of data points in the intervention phase that fall within the range in the baseline phase. Note the range was calculated in step 1.)

You then examine Jacob's frequency of initiations with peers for each day of intervention. You compare each data point to the range of social initiations Jacob demonstrated during baseline. That is, you compare each data point in intervention to the range you calculated in step 1. If a data point falls within the range for baseline (which you calculated to be 3-5), you count that as an overlapping data point. If a data point falls outside the range for baseline, you do not count that data point. In Jacob's case, there is one data point that falls within the range for baseline.

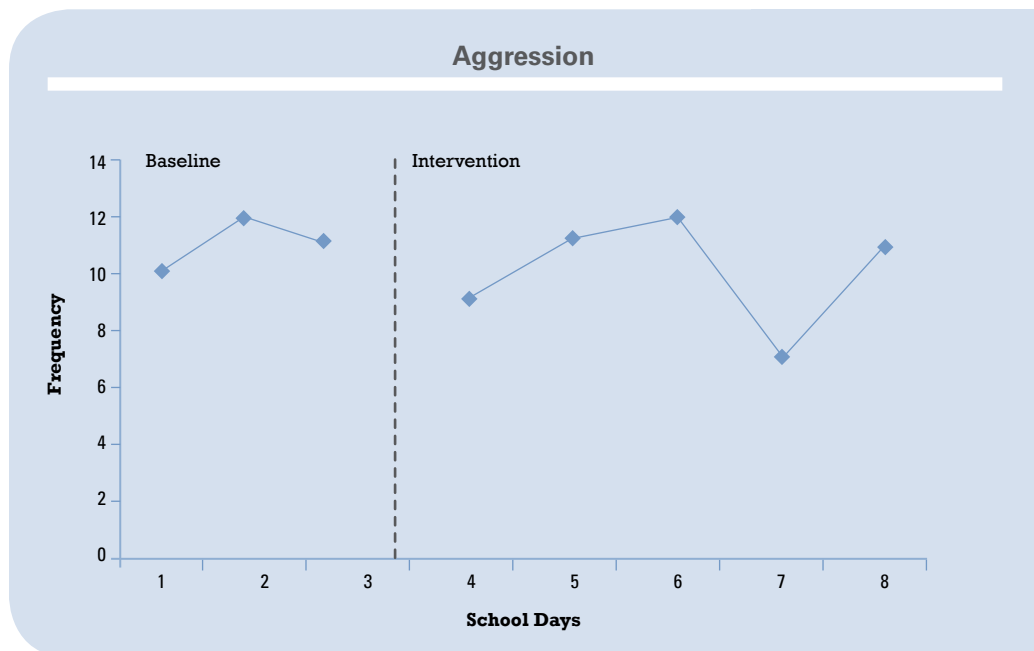
- **Step 4:** Divide the number of data points identified in step 3 by the number of data points established in step 2. Multiply by 100 to calculate the POD.

Your last step is to calculate the percentage of data points in Jacob's intervention condition that overlap with the data points in the baseline condition. You determined that there was only one data point in intervention that overlapped with the range you calculated in baseline. To calculate the POD, you divide the one data point that overlaps in the intervention condition by the total number of data points in the intervention condition. You already calculated the total number of data points in intervention to be 5 (see step 2). You apply the formula described above to derive the following POD:  $1/5 = .20 \times 100 = 20\%$ . Your POD is 20%.

Let's look back at James' data to compare the baseline and intervention phases (Figure 5). The intervention was so effective that there are no overlapping data points.

Unfortunately, not all of our interventions produce such dramatic improvements. Figure 8 provides an example of a behavior reduction procedure that resulted in a relatively high POD (i.e., most of the data points across baseline and intervention phases overlap). The intervention depicted in Figure 8 is not considered effective, in part, because of the high percentage of overlapping data points.

**Figure 8}** Example of Ineffective Intervention: High Percentage of Overlapping Data Points Between Baseline and Intervention



## Challenges in Visual Analysis

As we have stated previously, stability, trend, and overlapping data points are indicators of intervention effectiveness. However, visual analysis often requires that you give lesser importance to one or more of these indicators.

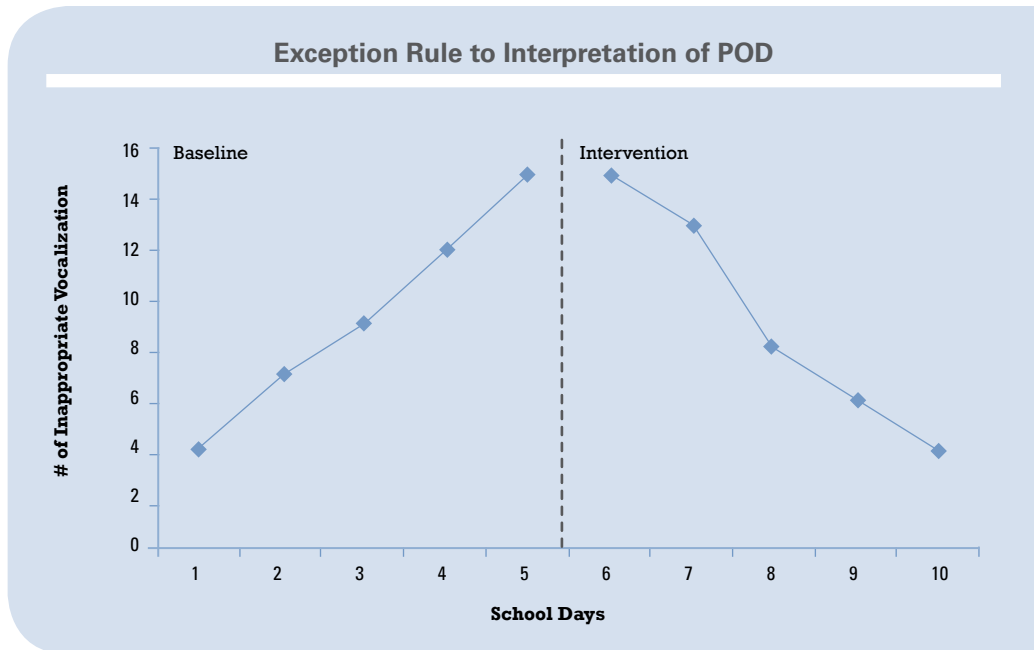
For example, Figure 5 shows James' off-task behavior during baseline and intervention phases. It's clear that there is a great deal of stability in the data that makes it easy to see the intervention was effective. You can calculate the POD and see that none of the data points in the baseline phase overlap with the data points in the intervention phase. But what about trend? We do not need to see a descending trend in this case because the combination of stability in conditions and POD clearly demonstrate improvements in James' off-task behavior.

Interpreting Kelly's data is more challenging (see Figures 6a and 6b). The baseline condition is not stable and there is a high POD across baseline and intervention phases. But when you examine the data in the intervention phase, it is clear there is a descending trend. Kelly's off-task behavior is very low by the end of the intervention phase, which suggests she is improving. When all of these indicators are taken into consideration, you decide that you may need to collect additional data so that you can be certain about the effectiveness of the intervention (see next section on details).

Ironically, an excellent intervention can produce a high POD (although this rarely happens). This exception is as follows: if you have nearly perfect trends in one direction for baseline phases (e.g., ascending trends) and nearly perfect trends in the opposite direction for intervention phases (e.g., descending trends), you will have a high POD. However, the nearly perfect trends suggest that the intervention is very effective.

Consider the following example. Shaliqua is a fourth-grade student with ASD. She has recently started making inappropriate vocalizations that interrupt the students around her. You begin collecting baseline data and find that the frequency of these inappropriate vocalizations seems to be increasing (see baseline phase of Figure 9).

**Figure 9}** Example of Exception to the POD Rules



You decide to put a Self-management intervention in place. Shaliqa learns to correctly record the frequency of her vocalizations and to get access to reinforcers if she remains quiet. The frequency of inappropriate vocalizations quickly begins decreasing (see intervention phase of Figure 9). Despite the fact that there are 100% overlapping data points, you are thrilled with the results. You can see by examining the trend lines that impressive differences exist between baseline and intervention phases. That is, inappropriate vocalizations just kept becoming a bigger problem in baseline and they consistently became less problematic in intervention.

A final challenge to visual data analysis relates to the length of time it takes for an intervention to produce a desirable outcome. You will serve some students with ASD who quickly respond to the intervention you select and others who will take time to learn to change their behavior or develop their skills. The examples we have provided thus far reflect typical data for students who respond quickly to an intervention.

Let's consider the example of Sami, a sixth-grade student with Asperger's Disorder. She did not master multiplication and division of fractions during her fifth grade year so her sixth-grade teacher decides to begin with these skills at the beginning of the school

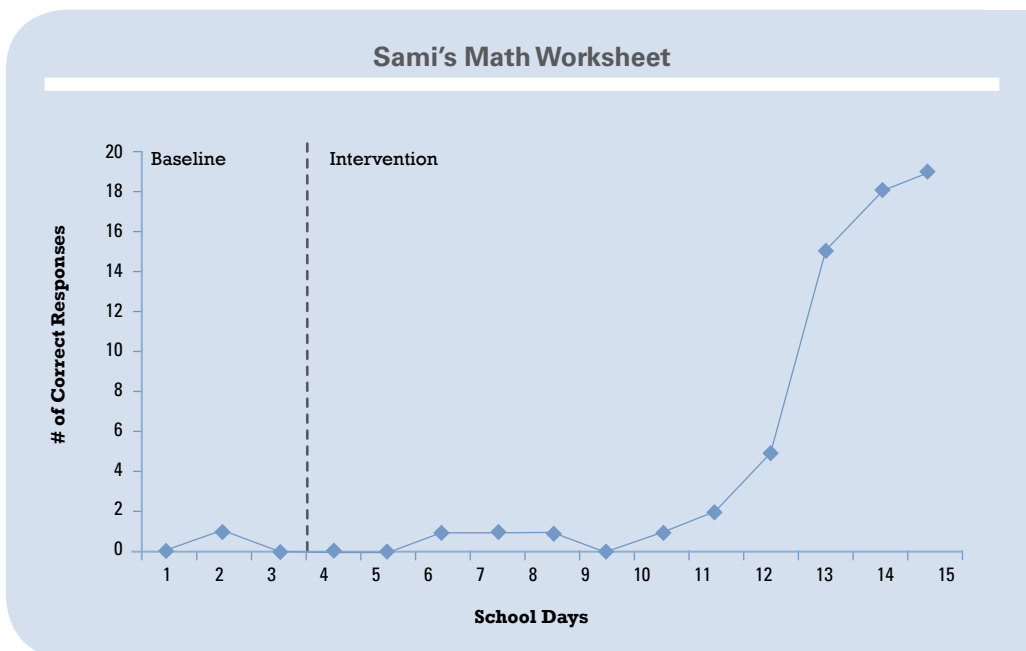


year. Not surprisingly, Sami had not learned how to multiply or divide fractions over the summer!

After collecting baseline data, Sami's teacher puts a reinforcement system into place and begins teaching her essential concepts related to multiplication and division of fractions (see Figure 10). Over time, Sami begins developing these skills. Eventually, there comes a point at which she really begins mastering these skills. Note that this did not happen the moment her teacher put the intervention into place. The teacher understood that Sami needed time to develop sufficient skills to show significant improvements.

Because visual analysis can be very challenging, we recommend all school staff should consult with a professional (e.g., behavioral analyst, psychologist, special education teacher, etc.) with expertise in single-subject research design. We explore this research design in the following pages.

**Figure 10}** Example of an Intervention that Requires Time Before Change is Produced



## Is the Intervention Effective?

In order to really know if a treatment is effective, you need to compare two or more baseline conditions with two or more intervention conditions. A single-subject research design allows comparison of an individual's response to an intervention over time.

This research design is used by scientists, but it is often used by practitioners as well. Practitioners like single-subject research design because it can be applied to one individual. It can also be applied to a small group of students or an entire classroom (although we do not cover these examples here).

One of the most commonly used single-subject designs is the reversal design. It is also known as an ABAB design. Don't be intimidated by terms like "research design." These kinds of designs even occur naturally in our daily lives. We encourage you to harness the strength of this research design to answer the questions you have about your students.

Reversal (ABAB) designs most often involve a baseline phase followed by an intervention phase—and then another baseline phase followed by an intervention phase. This type of design demonstrates the relationship between the intervention and the target behavior. Here is an example of ABAB research design from everyday life.

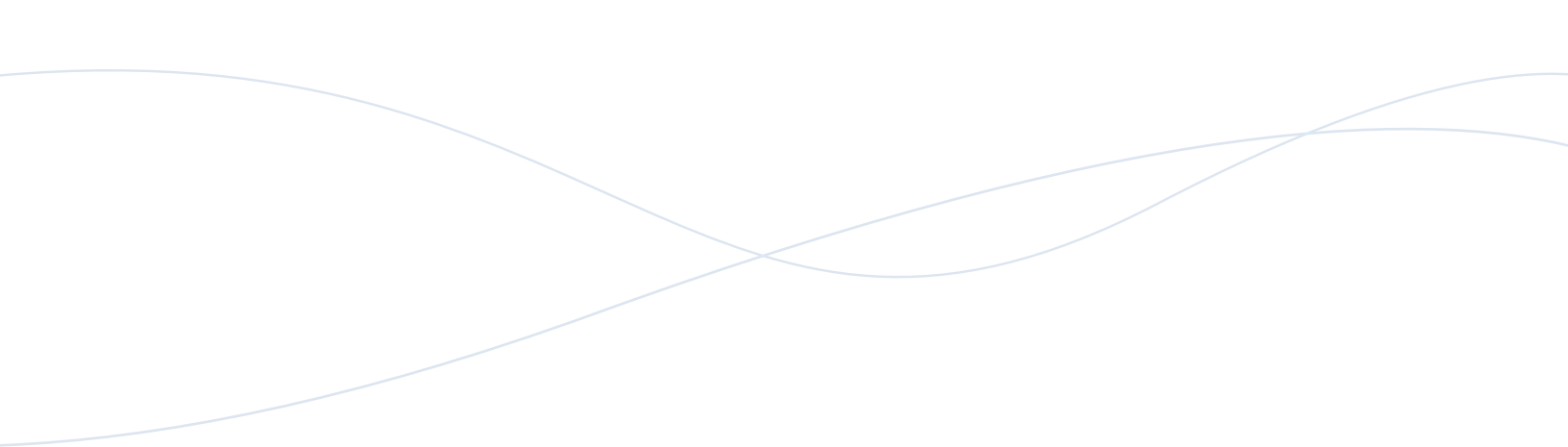
**Have you ever dieted before? If so, it might have gone something like this:**

**A (Baseline):** You decide you need to lose a few pounds.

**B (Intervention):** You go on a diet and drop a few pounds.

**A (Baseline):** You go off the diet—only to find a few months later that you have gained a few pounds.

**B (Intervention):** You go on a diet and drop a few pounds!



Now let's apply this research design to Caleb, a four-year-old with ASD who is learning to play. You have decided to use video modeling to teach Caleb new play skills. You collect data in one baseline and one intervention phase. You look at the stability, trend, and overlapping data points and conclude the intervention is effective. Some people would rather skip the second baseline and intervention phases and might wonder why they would need to repeat them.

There is a very good reason. Often, a number of environmental variables change in the classroom at the same time. Let's say a new student is introduced into the classroom and befriends Caleb at the same time you begin the video modeling intervention. If both of those events occur at the same time, how can you determine whether the video modeling intervention is responsible for the behavior change? By using an ABAB design, you can see a clear relationship between the treatment and the behavior.

With Caleb, you saw an improvement in play skills during the video modeling intervention phase. Although you would like to see those play skills continue to improve, you decide that you can take a few days to re-introduce a baseline

phase. This will help you determine whether the intervention is really effective. After graphing your data (see Figure 11), it becomes apparent that removing the intervention has resulted in a substantial decrease in Caleb's play skills. You quickly re-introduce the intervention and his play skills just as quickly begin improving again.

You are now confident that you should continue using the video modeling intervention.

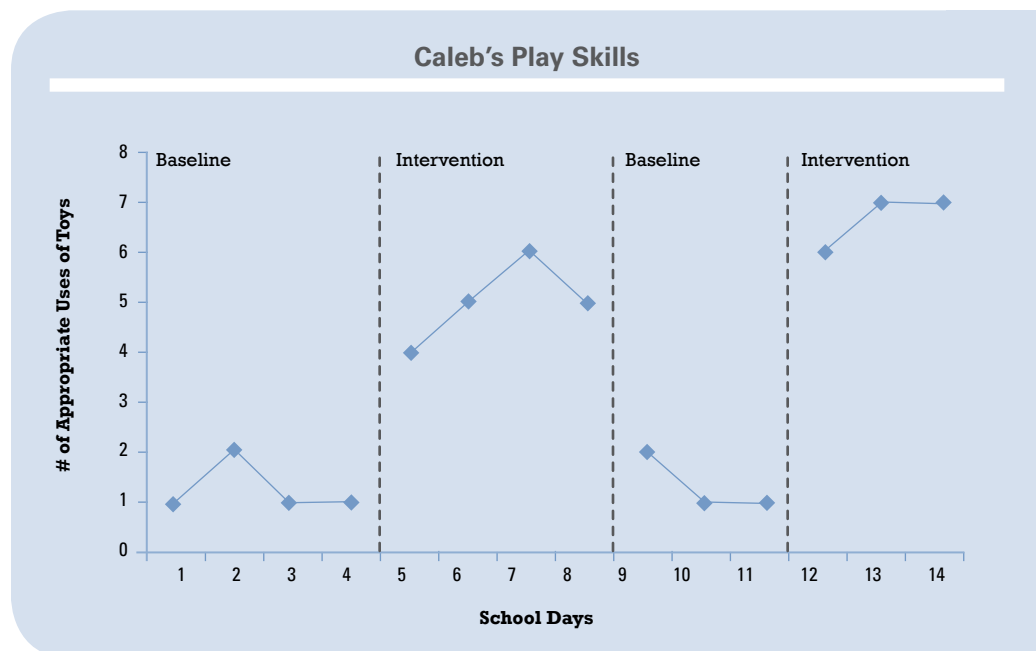
You may think, "But I already thought the intervention was effective. Was it really necessary to remove the intervention?" We would argue that, in this case, it *was* necessary. The data could have just as easily shown that the intervention was not the reason Caleb's play skills improved. Perhaps his new classmate was showing Caleb how to play and his skills were improving due to live modeling. If this was the case, spending all of the time it takes to make videos is not the best use of your time!

Although the reversal (or ABAB) design is the most commonly used single-subject research design, there are actually many others that might work better for your needs. Sometimes you need to implement an intervention

with more than one student and you can use a “multiple baseline across students” design. In this case, the intervention is staggered (i.e., introduced one at a time) across students. If you need to implement an intervention for one student across numerous settings, you can use a “multiple baseline across settings” design. In this case, the intervention is staggered across different situations (e.g., classroom, then cafeteria, then playground).

Identifying and providing sufficient descriptions of all research designs that might be useful to you is beyond the scope of this manual. One book we have found that clearly describes research designs as they apply to school settings is *Applied Behavior Analysis for Teachers* (Alberto & Troutman, 2003). This book can be an excellent resource to you in other ways as well (e.g., knowing how to develop the best operational definitions before starting to collect data, etc.).

**Figure 11}** Graphical Representation of Caleb’s Play Skills Based on Reversal Design



## Final Considerations


Although single-subject designs and the various data collection methodologies are well-defined in the literature, use of these strategies requires professional judgment during each phase.

For example, you must decide the following:

- How long to continue baseline and treatment phases
- The point at which your team has the capacity to implement the intervention accurately (see Chapter 5 on capacity building)
- If environmental variables are influencing the stability of your data
- Whether the intervention is effective (based on your visual analysis)

In a perfect world, student behavior would respond to all interventions in the desired direction. In reality, professional judgment is essential when things don't go as planned. So, what do you do when an intervention fails to produce the desired behavior change? While this can be frustrating and discouraging, there are problem-solving steps that will help you assess the situation:

- 1. Be clear about definitions.** Review the definition of the target behavior. It is not uncommon to have an operational definition that does not reflect the actual targeted behavior. This can result in inaccurate or misleading recording of data—especially if you have multiple data collectors (e.g., teacher, speech-language pathologist, paraprofessional, etc.).
- 2. Identify relevant variables.** Determine if there are environmental variables that could influence the daily recordings. If so, you may be able to “gain control” over them, or at least predict when they will occur. It may be that you have to add another research-supported treatment to your intervention on days when the environmental variable (e.g., lack of sleep) occurs.

- 
- 3. Use available expertise.** Be sure to draw on the expertise of all school professionals. Perhaps the speech-language pathologist determines that your target behavior is not appropriate given the student's communication delays. Similarly, the psychologist or behavior specialist might help you identify the function or purpose of challenging behavior. (A challenging behavior may function to gain attention, to escape or avoid a person or activity, or to gain access to a preferred item or activity; or the behavior may be automatically reinforced [e.g., self-stimulatory behaviors].) The psychologist or behavior specialist could help identify the function(s) of the behavior to develop more effective interventions.
  - 4. Implement treatment accurately.** You should ensure the intervention is implemented accurately. We all deviate from the way a treatment is supposed to be implemented from time to time, and often we are unaware of the changes we have put in place (see Chapter 5 on treatment fidelity).

Problem-solving strategies rely heavily on professional judgment. As mentioned earlier, it is important to avoid using a “cookbook” method in treatment selection. Problem solving through a difficult case is not just dropping the current intervention for another intervention. It is case conceptualization with a critical eye. This requires your training, your experience, and your professional judgment.

## Recommended Readings}

- Cooper, J. O., Heron, T. E., & Heward, W. L. (2007). *Applied behavior analysis* (2nd Ed.). Upper Saddle River, NJ: Pearson Education, Inc.
- Gulick, R. F., & Kitchen, T. P. (2007). *Effective instruction for children with autism*. Erie, PA: Dr. Gertrude A. Barber Educational Institute, Inc.

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- Cole, C. L. & Bambara, L. M. (1992). Issues surrounding the use of self-management interventions in the schools. *School Psychology Review*, 21, 193-201.
- Cooper, J. O., Heron, T. E., & Heward, W. L. (2007). *Applied behavior analysis* (2nd Ed.). Upper Saddle River, NJ: Pearson Education, Inc.
- Mithaug, D. K., & Mithaug, D. E. (2003). Effects of teacher-directed versus student directed instruction on self-management of young children with disabilities. *Journal of Applied Behavior Analysis*, 36(1), 133-136.
- Sulzer-Azaroff, B. (2008). *Applying behavior analysis across the autism spectrum: A field guide for practitioners*. Cambridge, MA: Sloan Publishing.
- Webber, J., & Scheuermann, B. (2008). *Educating students with autism: A quick start manual*. Austin, TX: Pro-Ed, Inc.

# 4

## Incorporating Family Preferences & Values Into the Educational Process

As we noted in the introduction, federal legislation requires that schools use research-supported interventions for students. Educational legislation also supports the involvement of family members in the educational process.

Parents are experts on the strengths and needs of their children with Autism Spectrum Disorders (ASD) (Danya International & Organization for Autism Research, 2004, p. 10). As such, parents should actively participate in decisions about their children's education. Parents should be involved both in their child's assessment and in decisions that are made regarding service needs. In addition, parents and teachers should collaborate when identifying skills to target for development (IDEIA, 2004).

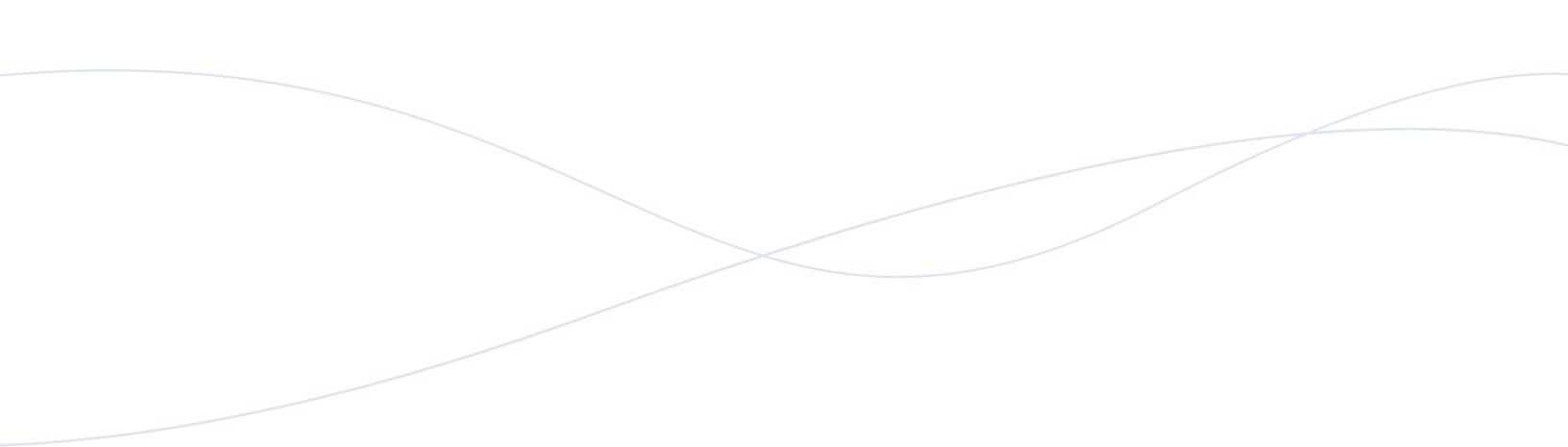
Family choice is one of the most important components of a family-centered approach. It recognizes the partnership of parents with school personnel and other professionals in decision making (Murray et al., 2007). The family-centered model of service delivery acknowledges that interventions and supports for children with disabilities are most successful when the family's concerns, priorities, and strengths are considered (Peterson & Speer, 2000). Ask yourself, "How often do I fully engage the family in a discussion about the educational and treatment services I provide?" and "How intently do I try to include the student's perspective when developing treatment targets or selecting interventions?" Many of us can improve in these areas.

If we want to renew our efforts to apply a family-centered service delivery model for students with ASD, we need to begin by understanding the unique challenges faced by the families of children with ASD.

### Here are a few points to consider:

- Parenting stresses and social restrictions are common difficulties for families with a child with ASD. Parents of children with disabilities say they experience challenges in activities such as: enjoying family outings; going to other people's homes; leaving their child with a babysitter; and shopping with the child (Cassidy, McConkey, Truesdale-Kennedy, & Slevin, 2007).



- 
- Children with ASD are often involved with several different therapy activities that take up a tremendous amount of the family's time. Maintaining this level of support for the child requires a great deal of time from parents, and often has financial implications for a family as well (Kohler, 1999).
  - Many students with ASD take prescription medication or are on special diets, which require additional resources from parents.
  - Parents may experience stress as they decide how to allocate their attention and energy across family members. Parents may feel the strength of their marriage is challenged or they may feel guilt about the limited time they spend with their other children when so much of their attention is focused on the child with ASD.
  - Parents worry they lack sufficient information. They grapple with their child's disability, uncertainty about their child's future, and the physical and mental difficulties associated with raising a child with a disability.

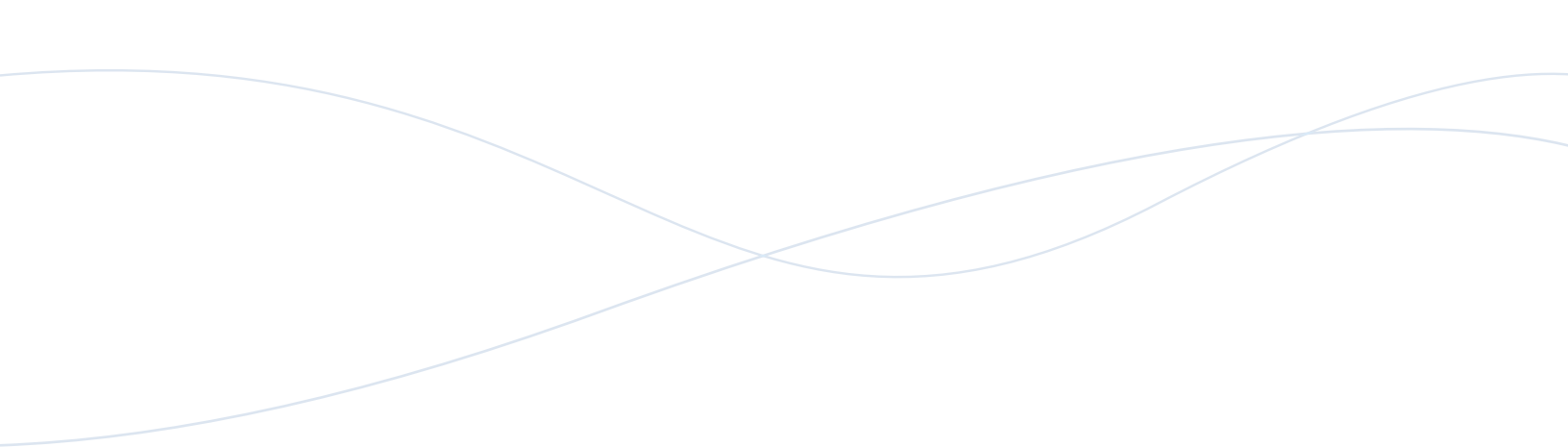
Considering these challenges, it seems clear that supporting a family member with ASD can place heavy demands on the family and tax its physical, financial, and emotional resources.

The good news is that appropriate family supports can reduce these kinds of stressors. Appropriate supports enhance the well-being of both parents and children. When schools use a family-centered approach and work to increase parental involvement, not only do the parents and children benefit, but so do school personnel. For instance, parents can provide information to help staff better understand their students. Improved communication can also promote opportunities for generalization of skills in settings outside of school (Davis-McFarland, 2008). Given the fact that generalization represents one of the greatest challenges to individuals on the autism spectrum, the advantages of family-centered care are quite strong. In addition, students who participate in the educational process are better prepared to participate in treatment decisions in adulthood.

## Supporting Family Involvement in Evidence-based Practice

Encouraging parental involvement can include activities in the school, home, and community. Examples of parental participation and student involvement include activities such as:

- **Serving as a classroom volunteer.** Parents can be involved in everything from supervising during a field trip to collecting data in the classroom (see Chapter 3).
- **Maintaining frequent communication with teachers.** School-home notes that help everyone focus on the student's increasing school successes can be useful.
- **Attending school-sponsored events.** These can include things like support groups or educational seminars. For instance, if a school autism program implements discrete trial instruction (DTI) as part of its educational model, parents often receive education and training on DTI from school personnel. Training may be followed by parents observing DTI with their child in the classroom, as well as frequent communication regarding the child's progress based on data collected during DTI.
- **Incorporating learning activities into a student's daily routines.** This can include tasks such as working on greeting skills at the grocery store or prior to religious activities, identifying shapes and colors while driving, and encouraging independence during the bedtime routine. Working collaboratively across settings provides better supports to everyone and benefits the student the most.
- **Securing student input.** Whenever possible, it is important to secure input from students regarding their target behaviors and intervention options. Not all students on the autism spectrum are capable of actively participating in the educational process. But there is a danger in assuming all students are unable to help identify educational and behavioral targets for improvement. Further, many students may hold opinions about which interventions they prefer. If we can work collaboratively with students in target identification and intervention selection, they are more likely to actively participate in their own development throughout their lifetime. Leaving



students out of these processes is a lost opportunity for schools striving to help all students reach higher levels of independence prior to graduation.

There are several factors a school must consider in order to effectively implement a family-centered care approach. These include cultural variables, socioeconomic status, family composition and availability, severity of symptoms, and school factors. Each of these considerations can directly influence the level of parental involvement.

## Cultural Variables

We can serve all students better when we improve our awareness of cultural variables. Certainly, having successful family-school collaboration requires an appreciation of the views held by both groups. These views can be heavily influenced by the cultural experiences of the parties involved.

Research suggests that cultural values often influence a person's views on disabilities. In order to best serve families from diverse cultural backgrounds then, educators must be willing to learn about a family's customs, belief systems, communication styles, and other factors that may impact parental involvement and their level of acceptance of various treatment options.

You can take several steps to increase the likelihood that research-supported treatments will be successful for learners from diverse backgrounds:

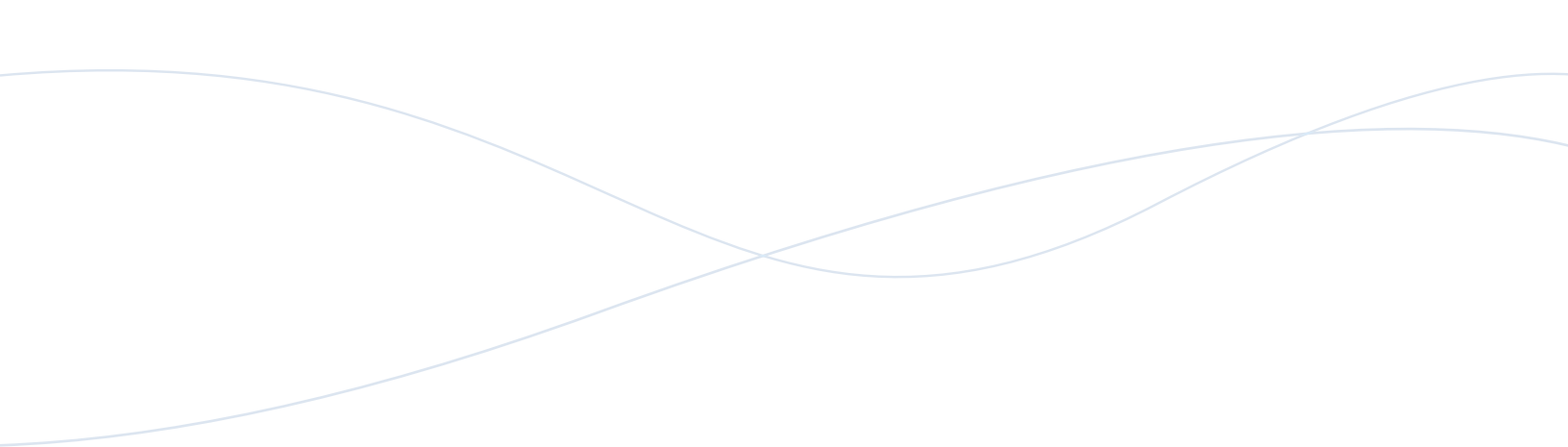
- Take cultural values into consideration when the school team and the family select treatment targets. For instance, many young students with ASD do not make eye contact with the frequency of their peers or, when they do, the eye contact is fleeting. We often target eye contact in the course of educational services because {a} it is a socially important skill for most individuals in our culture to develop, and {b} it is often one of the first skills taught within the context of some research-supported treatments (e.g., Comprehensive Behavioral Treatment for Young Children) in order to improve responding. However, in some Native American and Asian American cultures, avoidance of eye contact with adults is considered a sign of respect (Lian, 1996; Wilder et al., 2004).

Similarly, many of us would consider reduction of self-stimulation to be a critical educational goal to target. Yet these behaviors are largely ignored by Navajo parents of children with disabilities, who tend to focus more on the strengths of their children rather than behavioral excesses or deficits (Connors & Donnellan, 1998).

Consideration should be given to both cultural variables and educational implications when developing treatment targets for students with ASD.

It is important to understand cultural variables, identify behaviors that actually need to be targeted, and then work to develop an open and ongoing dialogue when differences in perspective emerge. For example, is the family comfortable with the student having eye contact in a limited number of settings (e.g., when seated at a table across from an educator in the school)? Can the school ignore self-stimulatory behavior unless it interferes with teaching (e.g., when the child cannot divert his attention away from self-stimulatory behavior to complete his work)?

- Educators and service providers may need to be willing to modify teaching and intervention strategies as appropriate to meet the needs of students with cultural values and experiences different from the dominant culture. Consider the following examples:
  - ▶ Let's say the teacher and paraprofessional use DTI as a means of teaching a broad array of skills to a student with ASD. They may find it helpful to supplement DTI with strategies such as {a} English as a Second Language (ESL) instruction from the child's school district (Winzer & Mazurek, 1998), {b} alternative communication systems such as pictures (Snell & Brown, 2000), or {c} teaching materials in the most relevant language for the student (Baca & Cervantes, 1998).
  - ▶ Imagine that support staff have recommended the use of another research-supported treatment, such as Schedules. Steps should be taken to ensure that symbols and pictures are culturally meaningful for the child, as well as for persons with whom the child interacts in the home and school settings (Trembath, Balandin, & Rossi, 2005).
  - ▶ Social development should be targeted for all individuals on the autism spectrum. The school may have developed a Peer Training Package (another research-supported treatment) to facilitate social skill development. When selecting peer models, efforts should be made to identify peers from similar cultural backgrounds to that of the child with ASD (Wilder et al., 2004).
- Like professionals in all other settings, school staff may have biases that can inadvertently enter the educational process. As with any treatment approach, educators must examine their personal biases and expectations in relation to service delivery



for their students who come from a different cultural background than the dominant culture (Wilder et al., 2004).

Biases may enter our interactions in the most unexpected ways. For example, we may *over-generalize* information we learned in a course on multiculturalism! Consider the issue of collectivism. Collectivism describes a particular outlook that stresses the group over the individual, and interdependence of group members. Some (but not all) cultures adhere to a collectivist perspective.

Several studies have indicated that people from the dominant culture assume that collectivist aspects of certain cultures can lead to strong family support (Bailey et al., 1999; Gatford, 2004). This may be true for some families, but it is certainly not true for all.

In some cultural minority populations, having a child with a disability can be a source of shame for a family. Also, cultural norms may discriminate against individuals with disabilities, or can undermine the likelihood that parents will seek information about disability issues. So, while knowledge of common cultural norms is helpful, school professionals must keep in mind the individual needs of each family.

## **Socioeconomic Status**

A family's socioeconomic status has been shown to have a significant impact on parental involvement in education. Many low-income families report that they have limited access to information and professional supports for their child's disability (Baxter & Kahn, 1999; Diamond & Kontos, 2004). This means the quality of total care may be compromised and a child's progress may depend almost exclusively on supports he receives through the school system.

Even when you try to establish a collaborative relationship with the family, financial issues may present a problem. For example, families are often asked to make certain their children practice skills at home. But some families do not have the necessary financial resources to obtain the materials required for the learning activity.

Financial resources can also impact issues such as transportation. Schools should consider a family's transportation needs when scheduling team meetings or other school-based activities.

## Employment and Family Issues

Employment can impact financial resources and the amount of time parents have available for participating in the educational process (Brotherman & Goldstein, 1992).

For two-parent households, one parent may stay home to coordinate the various services that are required for the child with ASD. A mother or father may also make the decision to stay home because no childcare is available for their child, or may become one of the primary out-of-school “therapists” for the child.

Complicating matters still further, it is not unusual for parents to have more than one child with some type of disability or educational need. In this case, the stressors are increased as parents try to make certain each of their children receives sufficient support.

The choice for one parent to stay home can be a double-edged sword. Although it resolves some issues, it may create others (e.g., limited financial resources). Parents who make the decision to stay home to address service delivery concerns for their child with ASD may bring unique expertise to the table when you engage in evidence-based practice.

Military activity may temporarily affect family composition. Military families who are served in your school system may face

unique challenges. When military personnel are sent overseas or are on duty at an undisclosed location, the entire family is missing one parent. The child with ASD, his siblings, and the remaining parent are all left with more limited support under stressful conditions. In addition, because military families are often required to move frequently, the parent who remains behind may lack a well-established network of friends or extended family. Under these conditions, it is even more necessary to create an open line of communication and a collaborative relationship between school and home.

While involvement by extended family members, such as grandparents, can be a source of emotional and practical support, it can also present significant challenges. Parents may be pressured by relatives to modify the intervention strategies used to help the child with ASD. Some extended family members may deny the fact that the child is on the autism spectrum, whereas others impose their views about child rearing when the family is already under severe stress.

These factors reinforce the need for and usefulness of building a collaborative relationship between family and school. By working together, the stressed family member may be better prepared to address skills you have taught in the school setting and generalize them to the home and community.

## Severity of Symptom Presentation

Has a student on the autism spectrum ever worn you down by the end of the day? Imagine how challenging it is to care for this child for all non-school hours of the day, year-round. No matter how much parents love their children, they, like all of us, have limited energy.

Parental participation in the educational process may be affected by a child's problem behaviors, and the severity of those behaviors. Research has shown that maternal involvement in educational activities in both home and school settings is related to the severity of the child's behavior problems (Benson et al., 2008). In other words, a mother whose child with ASD exhibits severe behavior problems is more likely to identify lack of time and limited energy as barriers to participating in educational activities.

Severity of symptoms may also affect how welcome parents feel in the school. It is always difficult for parents to learn their child is not successful in school. It is still more challenging when parents find out their child is disruptive or creates an unsafe environment for himself, other students, or school staff. Imagine how difficult it is to face this news over and over again. Unless we work hard to understand how tough this is for families, it will be difficult to create an environment in which they feel welcome to openly discuss the need for specific intervention procedures.

Finally, the severity of a student's symptoms has a significant effect on his ability to participate in the educational process. Parents of students who can participate in the selection of appropriate treatment targets and interventions may be more hopeful about their child's ability to manage his own affairs in adulthood.

## School Factors

It is important to note that school factors can also influence family participation in the educational process for children with ASD.

### Consider the following:

- School personnel often feel they are unable to provide emotional support for parents because of large caseloads and ambiguity regarding their ability to provide such support (Canary, 2008).
- Many parents perceive school personnel as authority figures, and are uncomfortable voicing an opinion that may be in conflict with the opinions of these individuals.
- A mother's involvement in the education of her child with ASD is affected most by the attempts of school personnel to encourage and provide opportunities for active involvement in her child's education (Seitsinger et al., 2007). What you do really does make a difference!
- School systems do not always involve the student in the selection of appropriate treatment targets or interventions designed to improve student skills.

## Social Validity

**Even a potentially effective treatment will not work for some families unless they feel it is appropriate.**

Social validity can be broadly defined as approval of or satisfaction with a specific intervention. Social validity is usually evaluated by someone who works with, or shares the life of, the student with ASD. Interestingly, social validity can influence whether or not the treatments are being implemented accurately. It should come as no great surprise that parents who do not approve of an intervention are less likely to implement it accurately in their home or community. You are less likely to meet your goal of a having a child generalize a skill across settings if parents report low social validity.

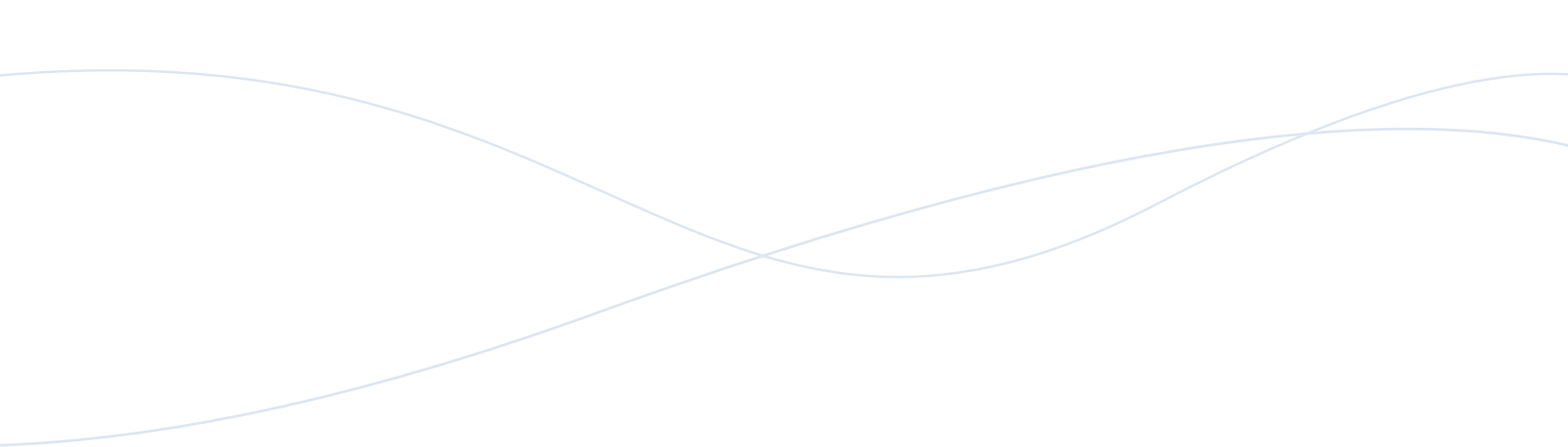
For many years, only one factor was considered when researchers conducted treatment studies—an objective measurement of the target behavior. This is understandable, but it falls short of what is necessary. We do need objective measurement of whatever behavior we are targeting, but we also need to have data on social validity.

Although extensive literature has been devoted to identifying effective interventions for students with ASD, few of these studies have examined the social validity of these interventions. That is, there is limited information regarding parents' perceptions of the effectiveness of strategies that may be implemented in school settings.

A recent investigation (Callahan et al., 2008) examining the social validity of several educational strategies (including individualized programming, data collection, research-supported treatments, active collaboration, and a focus on long-term goals) yielded some interesting outcomes to consider:

- On a positive note, high parental social validity was reported for all the strategies, with the highest ratings for strategies falling under the data collection category.
- While still rated as socially valid treatments, research-supported treatments received the lowest rating by parents. Several of the procedures included in this category were interventions (e.g., modeling, prompting, DTI) that have been shown to be effective based on the results of the National Standards Project.





Parents who had more training in these procedures were likely to rate them as highly socially valid. This underscores the importance of having an ongoing dialogue with parents about effective treatments.


Assessment of social validity should be extended to the student with ASD whenever feasible. Ask the student directly if she believes the treatment is leading to improvements in her communication, social interactions, or independence in life skills.

## Recommendations for Incorporating Family Preferences and Values

People often think evidence-based practice is about the research—and it is! But it is not about the research alone. The values and preferences of family members, including the individual with ASD when appropriate, must be respectfully addressed. Otherwise, we are not engaging in evidence-based practice.

Even if you have data to show that a current intervention results in improvements for a student, it does not mean that your work is done. Your goal is also to create a welcoming environment so parents can participate in their child's education. Further, school staff must receive training to understand that, whenever feasible, the student should participate in the educational process as well.

You already know that families are more likely to be involved in educational programming when it includes collaboration among parents and school personnel (Canary, 2008). You also understand the importance of using active strategies to incorporate the values and preferences of families into the educational process for children with ASD. Translating that knowledge and understanding into our daily activities, however, requires effort.



Schools are most likely to engage in evidence-based practice if they have explicit strategies for addressing family preferences and values. We offer recommendations as a guide for schools in developing these strategies. These recommendations include: data collection; ongoing communication; parent education and training; tackling barriers to family participation; informing families of their choices and options; addressing conflicting views; establishing appropriate family supports; and supporting parents in generalizing skills.

## Data Collection

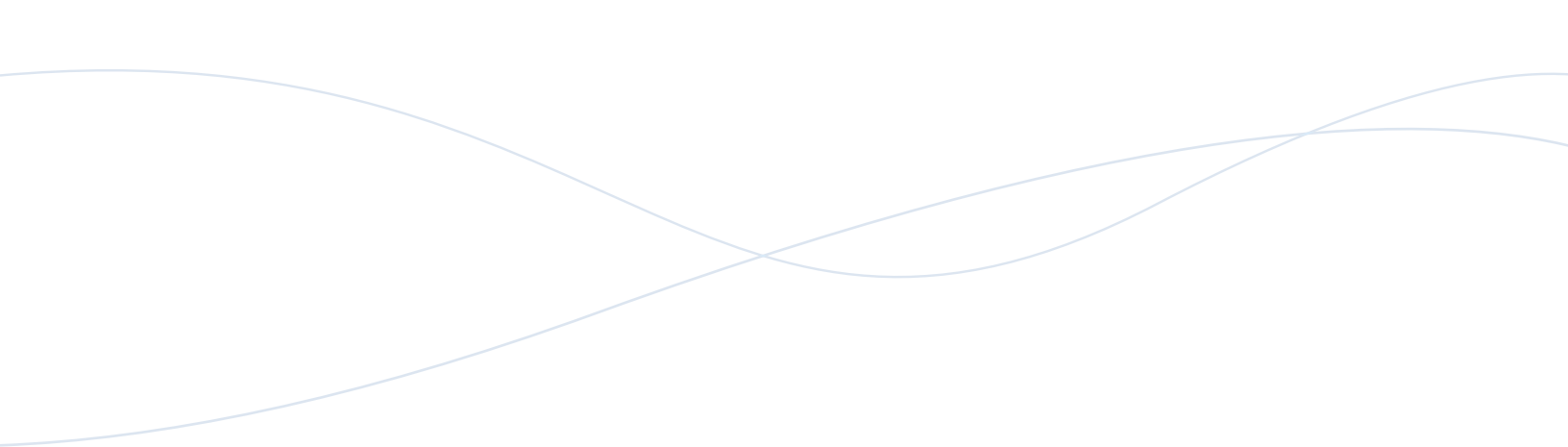
The first step in incorporating family preferences and values into the treatment process is ensuring that the educational team has a clear understanding of those values and preferences. You should gather information on a family's motivation to participate in their child's educational progress. You are already familiar with collecting data on student outcomes (see Chapter 3), but data collection must be extended to the perspective of family members as well.

It is easy to misinterpret what it means when parents are not actively participating in the education of their child with ASD. Some people assume that parents are satisfied with the supports their child receives. Others believe that parents are uninterested in their child's educational progress. Yet it should be clear by now that there are barriers that may impede parent participation in the process. You may find that you can increase family participation by considering the barriers they face and offering supports to families (Davis-McFarland, 2008). Directly assessing the family's motivation to participate is a great way to begin the process.

Don't restrict your information-gathering to the parents. Providing the student with ASD the opportunity to voice his opinion about treatment goals or intervention options is also important.

### **Several tools are available to assess factors that affect a family's motivation to participate in the educational process:**

- The *Family Needs Survey* (Bailey & Simeonsson, 1990) can provide information related to current stressors in the life of the family, and the need for support to manage those stressors (see Table 1).

- 
- Instruments such as the *Child Preference Indicators* (Moss, 2006) allow a family to share personal knowledge and expertise about their child with the educational team. This offers parents the opportunity to provide valuable input related to strategies for reinforcement, self-calming skills, and other information needed for a successful educational plan.
  - In order to gather information regarding parents' specific needs related to the implementation of research-supported treatments, you may need additional tools. Hunter and Wilczynski developed the *Autism Spectrum Disorders–Parental Participation Questionnaire (ASD-PPQ)* for this purpose (see Table 2). You can use the ASD-PPQ to gather information regarding parent knowledge and acceptability of research-supported treatments. It is important to gain insight into parents' views regarding their treatment options before you begin serving new students. For children who are already receiving services, parents can complete this form prior to regularly scheduled meetings or other interactions.
  - Student participation in the educational process should occur whenever possible. It can be helpful to identify the skills the student believes should be targeted as well as her interest in learning about different research-supported treatments. Wilczynski and Hunter developed the *Autism Spectrum Disorders–Student Participation Questionnaire (ASD-SPQ)* for this use (see Table 3). You can use the ASD-SPQ to gather information from students who are capable of participating in educational decisions that support their progress. Students who can complete this form are most likely older students with stronger communication skills.

*Please note: Comprehensive Behavioral Treatment for Young Children and Joint Attention are not listed as interventions on this form. These interventions focus on young children for whom the ASD-SPQ is not appropriate.*

You should make it clear to the family that, should they decide to complete the survey, the information will be kept in strict confidence, and that their participation in this kind of survey is purely voluntary.

**Table 1}** *Family Needs Survey*

## Family Needs Survey

(Revised, 1990b)

Child's Name: \_\_\_\_\_

Person Completing Survey: \_\_\_\_\_

Date Completed: \_\_\_\_/\_\_\_\_/\_\_\_\_

Relationship to Child: \_\_\_\_\_

Dear Parent:

Many families of young children have needs for information or support. If you wish, our staff are very willing to discuss these needs with you and work with you to identify resources that might be helpful.

Listed below are some needs commonly expressed by families. It would be helpful to us if you would check in the columns on the right any topics you would like to discuss. At the end there is a place for you to describe other topics not included in the list.

If you choose to complete this form, the information you provide will be kept confidential. If you would prefer not to complete the survey at this time, you may keep it for your records.

Would you like to discuss this topic  
with a staff person from our program?

TOPICS	No	Not Sure	Yes
<b>Information</b>			
1. How children grow and develop			
2. How to play or talk with my child			
3. How to teach my child			
4. How to handle my child's behavior			
5. Information about any condition or disability my child might have			
6. Information about services that are presently available for my child			
7. Information about the services my child might receive in the future			
<b>Family &amp; Social Support</b>			
1. Talking with someone in my family about concerns			
2. Having friends to talk to			
3. Finding more time for myself			
4. Helping my spouse accept any condition our child might have			
5. Helping our family discuss problems and reach solutions			
6. Helping our family support each other during difficult times			
7. Deciding who will do household chores, child care, and other family tasks			
8. Deciding on and doing family recreational activities			
<b>Financial</b>			
1. Paying for expenses such as food, housing, medical care, clothing, or transportation			
2. Getting any special equipment my child needs			
3. Paying for therapy, day care, or other services my child needs			
4. Counseling or help in getting a job			
5. Paying for babysitting or respite care			
6. Paying for toys that my child needs			

Family Needs Survey. Donald B. Bailey, Jr. & Rune J. Simeonsson. FPG Child Development Institute, The University of North Carolina at Chapel Hill.

Would you like to discuss this topic with a staff person from our program?

<b>TOPICS</b>	<b>No</b>	<b>Not Sure</b>	<b>Yes</b>
<b>Explaining to Others</b>			
1. Explaining my child's condition to my parents or my spouse's parents			
2. Explaining my child's condition to his or her siblings			
3. Knowing how to respond when friends, neighbors, or strangers ask questions about my child			
4. Explaining my child's condition to other children			
5. Finding reading material about other families who have a child like mine			
<b>Child Care</b>			
1. Locating babysitters or respite care providers who are willing and able to care for my child.			
2. Locating a day care program or preschool for my child			
3. Getting appropriate care for my child in a church or synagogue during religious services			
<b>Professional Support</b>			
1. Meeting with a minister, priest, or rabbi			
2. Meeting with a counselor (psychologist, social worker, psychiatrist)			
3. More time to talk to my child's teacher or therapist			
<b>Community Services</b>			
1. Meeting & talking with other parents who have a child like mine			
2. Locating a doctor who understands me and my child's needs			
3. Locating a dentist who will see my child			

Other: Please list other topics or provide any other information that you would like to discuss .

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Is there a particular person with whom you would prefer to meet?

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*Thank you for your time.  
We hope this form will be helpful to you in identifying the services that you feel are important.*

**Table 2}** *Autism Spectrum Disorders–Parental Participation Questionnaire (ASD-PPQ)*

**Parental Participation Questionnaire**

**Dear Parents and other Family Members:**

Thank you for taking the time to read and respond to this questionnaire. We encourage you to use it as an opportunity to tell us what services you believe your child needs. It also helps us to know your family better.

We believe we can provide better services for your child if we understand your views about treatment and know more about your family. We understand that not all families like to share this information. Filling out this form is completely voluntary. If you do not feel comfortable answering any of the questions below, please leave them blank.

**Student's Name:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Family Characteristics:**

1. Please tell us about the people currently living in the child's home.

Name	Age	Relationship to Child
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

If your child lives in more than one home (e.g., as a result of joint custody), please tell us about the people currently living in your child's second home.

Name	Age	Relationship to Child
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

*Autism Spectrum Disorders–Parental Participation Questionnaire (ASD-PPQ).* Melissa Hunter & Susan M. Wilczynski. National Autism Center.

2. Are there other family members or friends who care for your child? If so, please tell us their names and roles.
  
3. What language is primarily spoken in your home? Would you like an interpreter for meetings with your child's school team?
  
4. For the purpose of scheduling team meetings, what days/times typically work best for you and your family?
  
5. How would you prefer we contact you? Email? Phone? Written notes? Other? Please provide the relevant contact information below, and circle the mode of communication you prefer.
  - a. E-mail address(es):
  - b. Phone number(s):
  - c. Fax:
  - d. Webpage:
  
6. We have a few questions about other services your child receives.
  - a. Does your child receive additional treatment or support services from other providers? If so, which ones?
  
  - b. Would you like to invite other providers to attend educational meetings for your child? If so, you can invite them yourselves or we can provide you consent forms so we can contact them. Please let us know what method of notification you would prefer.

### Research-Supported Treatments

This table identifies treatments for Autism Spectrum Disorders that have been shown to be effective through research. We would like to know your views on these treatments. Please place a check mark in the appropriate box if you agree with any of the statements in the left column. You may check more than one box in each column.

	Antecedent Package	Behavioral Package	Comprehensive Behavioral Treatment for Young Children	Joint Attention	Modeling	Naturalistic Teaching Strategies	Peer Training Package	Pivotal Response Treatment	Schedules	Self-Management	Story-based Intervention
I am not familiar with this treatment.											
I would like to learn about this treatment.											
I would like to discuss this treatment option for my child.											
My child receives this treatment outside of the school.											
This treatment has been <i>effective</i> with my child in other settings.											
This treatment has been <i>ineffective</i> with my child in other settings.											
If it is available, I would like to receive training in this intervention.											
I do not want this treatment used with my child.											

**Other Treatments:** You may be aware of additional treatments that should be considered for your child. Use this space to identify additional treatments you would like to discuss with school staff. Please write on the back of this form if you need additional space.



### Available School Support Services

Each student we serve has different needs. We have a range of support services available to help our students. We would like to know your views on these support services. Please place a check mark in the appropriate box if you agree with any of the statements in the left column. You may check more than one box in each column.

	Speech Services	Occupational Therapy	Physical Therapy	Learning Support	Autism Support	Emotional Support	Title I
I am not familiar with this support service.							
I would like to learn about this support service.							
I would like to discuss this support service with school staff.							
My child receives this service outside the school.							
This support service has been <i>effective</i> in the past.							
This support service has been <i>ineffective</i> in the past.							
I do not want this support service for my child.							

**Final comments:** We are interested in any information you can provide us that will lead to appropriate educational services for your child. Use this space to identify any additional information you believe will help us meet that goal. Please write on the back of this form if you need more space.

**Table 3}** *Autism Spectrum Disorders–Student Participation Questionnaire (ASD-SPQ)*

**Student Participation Form**

**Student’s Name:** \_\_\_\_\_ **Date:** \_\_\_\_\_

Thank you for taking the time to read and respond to this questionnaire. It gives you the chance to tell us important information that could affect the way we teach you in this school. We believe your opinion is important. Not all students want to complete this questionnaire. You do not have to complete this form if you do not want to. Also, some students like help in filling out this form. Please let us know if you would like someone to help you complete this form.

**Skills to Target**

Schools try to teach students many things. Like other students in this school, we know there are things you can learn at school. Here is a list of skills students sometimes need to learn. Please put a check mark next to the skills you think you need to learn.

- 1. Completing homework \_\_\_\_\_
- 2. Paying attention in class \_\_\_\_\_
- 3. Talking to other students \_\_\_\_\_
- 4. Talking to your teachers \_\_\_\_\_
- 5. Taking care of yourself \_\_\_\_\_
- 6. Academics (class work) \_\_\_\_\_

*If you need help with academics, please write down the names of the classes you would like help with.*

- 7. Spending time with other students \_\_\_\_\_
  - a. If you need help spending time with other students, is it because other students pick on you? Please circle "yes" or "no."  
 YES    NO
  - b. If you need help spending time with other students, is it because you are not sure how to hang out with other students? Please circle "yes" or "no."  
 YES    NO

*Autism Spectrum Disorders–Student Participation Questionnaire (ASD-SPQ). Susan M. Wilczynski & Melissa Hunter. National Autism Center.*

8. Please tell us what other skills you think you need to learn. You can write on the back of this form if you need more space.

**Selection of Strategies**

There are many different ways to teach students new skills. Some students like to learn about the strategies school staff will use to teach you new skills.

1. Are you interested in learning more about strategies school staff may use to teach you new skills? Please circle "yes" or "no."


YES    NO

2. If you answered yes to question 1 above, let us know if you would like to learn more about any of the following strategies that are used to teach students. Put a check mark next to the strategies listed below. Most students are not familiar with these strategies. If you are not sure which one to check, please check them all. Then we can help you learn more about all of these strategies.

- Antecedent Package \_\_\_\_\_
- Behavioral Package \_\_\_\_\_
- Modeling \_\_\_\_\_
- Naturalistic Teaching Strategies \_\_\_\_\_
- Peer Training Package \_\_\_\_\_
- Pivotal Response Treatment \_\_\_\_\_
- Schedules \_\_\_\_\_
- Self-management \_\_\_\_\_
- Story-based Intervention Package \_\_\_\_\_

3. Please tell us if there is any additional information you would like your teachers or other school staff to know.

*Autism Spectrum Disorders-Student Participation Questionnaire (ASD-SPQ). Susan M. Wilczynski & Melissa Hunter. National Autism Center.*



Parent and student input is important, so gathering information is essential. However, there are dangers in gathering this information if you do not use it in the educational process. Here are several reasons why:

- Families may believe you do not think their time is valuable. After all, it takes time to complete these forms.
- Families may feel alienated.
- Families may be less likely to share relevant information with you in the future.

## Ongoing Communication

Students transition in and out of school systems. School staff are most likely to engage families when students first come in contact with schools. But continued collaboration between the home and school is critical for long-term success. Families should have frequent opportunities to share their opinions and concerns.

School staff need to create an open and ongoing dialogue with families. Parents should be encouraged to share both their agreements and disagreements with the educational team. This is the only way to be confident that family preferences and values are respected (Davis-McFarland, 2008).

School professionals are often so busy in their daily routines that they forget to create such an open environment. There are, however, many opportunities to maintain parent involvement in the educational process (see Table 4).

## Parent Education and Training

Students are best supported when their educators and parents work together. Think of the years of education and training you completed before serving students with special needs. After that, you received ongoing training through the school system and support from your colleagues. Still, most of us who provide services to children with special needs will find ourselves uncertain about how best to proceed from time to time.

Parents deserve the opportunity to receive training and ongoing support as well. Parents who are knowledgeable about their child's disability are more likely to be involved in their child's education, and are better able to extend the improvements you

**Table 4}** Strategies for Maintaining Parent Involvement

Opportunities for Maintaining Parent Involvement	Opportunities to Consider
Informal meetings	<ul style="list-style-type: none"> <li>• Parents may pick up their children for medical appointments</li> <li>• Parents may attend special class activities (e.g., birthday parties)</li> <li>• Parents may be involved in sports activities</li> </ul>
Formal meetings	<ul style="list-style-type: none"> <li>• IEP meetings</li> <li>• Parent-teacher conferences</li> </ul>
Information sharing	<ul style="list-style-type: none"> <li>• School-home notes</li> <li>• E-mail or phone conversations</li> </ul>
Volunteering	<ul style="list-style-type: none"> <li>• School outings</li> <li>• Fundraisers</li> <li>• Data collection in the classroom</li> <li>• Classroom assistants</li> </ul>
School-based support groups	<ul style="list-style-type: none"> <li>• Autism support groups</li> <li>• Disability support groups</li> </ul>
Advisory board	<ul style="list-style-type: none"> <li>• Capacity Development Team (see Chapter 5)</li> <li>• Parent-Teacher Association</li> </ul>
Information-gathering forms	<ul style="list-style-type: none"> <li>• Family Stress Survey</li> <li>• Child Preference Indicators</li> <li>• <i>Autism Spectrum Disorders—Parental Participation Questionnaire</i></li> <li>• <i>Autism Spectrum Disorders—Student Participation Questionnaire</i></li> </ul>

achieve with the student at school into the home or community. Thus, your students' successes may be maximized when parents receive sufficient education and training.

School staff can arrange for frequent training opportunities for interested parents who are able to participate. These trainings can be formal or informal, led by teachers, school-based therapy providers, school administrators, or outside consultants. In addition, educators can inform parents about independent training opportunities that may be available to them (see Chapter 5 for additional recommendations).

Schools can set a regular schedule (e.g., once per month) to provide families with frequent educational and training opportunities. Suggestions for training topics can be gathered by reviewing parent responses to the *Autism Spectrum Disorders—Parental Participation Questionnaire*. In addition, schools may wish to video or audiotape trainings so they can make them available for parents who are unable to attend.

## Tackle Barriers to Family Participation

As noted above, there are several factors that affect the likelihood that families will be involved in their children's education. These barriers should be identified and addressed during the educational process.

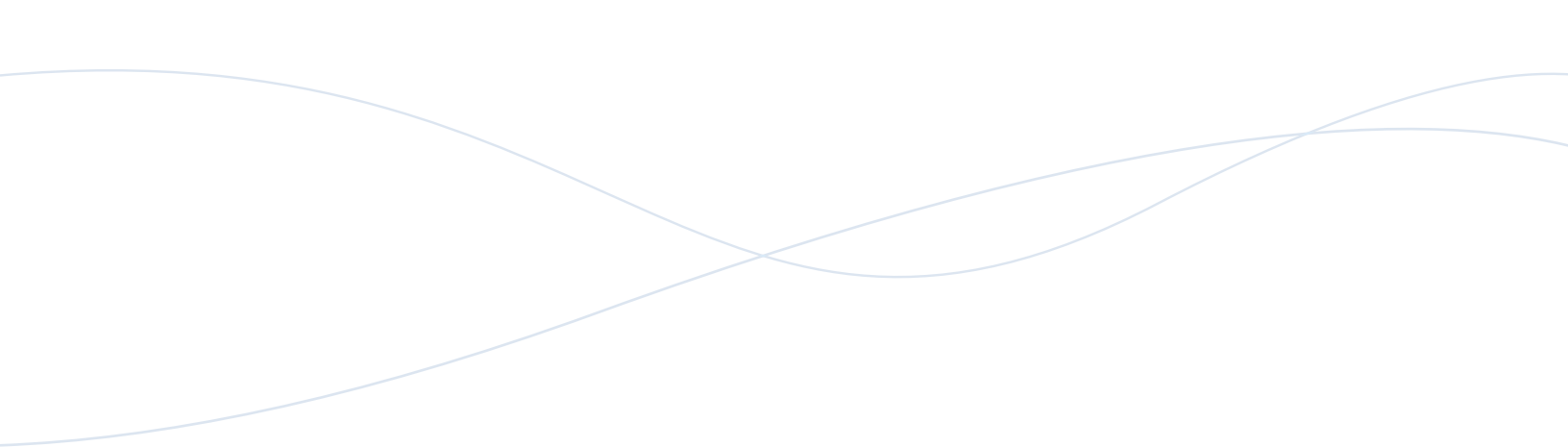
### Consider these efforts toward reducing barriers to parental participation:

- Finding the time to participate in the educational process is often very difficult for parents, particularly when the school day is often shorter than their workday. To counteract this challenge, schedule educational meetings around times that work for the family. Ask families to identify what days/times work best for them (see *Parental Participation Questionnaire*). Also, give families plenty of notice for scheduled meetings.
- Provide parents with advance draft copies of materials that may be discussed in meetings. For example, draft copies of Individualized Education Plans (IEPs) can be provided to the family for review as early as possible.

Of course, it is imperative to explain to the family that the materials they receive are "working documents" that can be modified in the meeting based on family or professional input. You will want to share

information about the school's views in advance, and avoid leaving families with the impression that all decisions have already been made.

- Both parents and students can be overwhelmed by the jargon and acronyms that professionals frequently use. Avoid the use of educational jargon to the extent possible and, when unfamiliar terms are used, ensure that attempts are made to explain the meaning to families. Providing parents and students with a short "dictionary" of commonly used educational terms may be helpful.
- When the primary language spoken in the home is not English, you should develop a plan to ensure clear communication between school and home. For example, consider providing an interpreter, offering parent training in a language other than English, and/or writing documents in the family's primary language.
- Transportation may be a challenge for some families. For example, parents may rely on public transportation, which may influence their arrival time. Meeting times may need to revolve around these schedules. If families arrive well ahead of a scheduled meeting, efforts should be made to make them comfortable. Transportation may also affect which days parents might be available. For example, a mother or a father may have access to a family car only one day of the week.

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- Parents may be concerned about their ability to find childcare for the student with ASD, or their other children. School staff may need to arrange for childcare at the school so parents can participate in meetings.
  - Unfortunately, students with ASD are often taught to passively respond to adults in the environment. School personnel will need to encourage students to voice their opinions about treatment goals and intervention options.

## **Inform Families of Choices and Options**

Recognizing the family as the primary decision maker for a child is important. But families will be active participants in the educational process only if you provide the support they need to make informed decisions (Davis-McFarland, 2008).


You already know that school personnel are responsible for making parents aware of educational options that are available for their child. But translating this knowledge into practice is more challenging than many people realize. How often do we assume that the parents have already seen and read their rights, so we hand them a written copy without discussion? If parents in this situation don't understand their rights, they are unlikely to admit it when surrounded by a group of professionals anxious to begin the meeting.

### **We offer a brief list of issues and strategies that may empower families:**

- Encourage parents to ask questions. For example, when placement decisions are made, provide parents with information regarding different placement options. They may have questions about what these options mean for their child.

Will their child be pulled from the regular classroom? If so, for how long? How much time will she spend in support services (e.g., speech-language therapy) each week? What are the benefits and risks of the different types of service options available to her? What social opportunities does she lose when she is in a more restrictive environment?

Parents are likely to have many additional questions, but they may be too intimidated to raise them in the group. Despite the fact that it will extend the length of these meetings, school staff should encourage parents to ask questions.

- 
- Invite parents to observe their children in the school. Often, students act very differently in home and school settings. This may be even more true for students on the autism spectrum because they have difficulty generalizing skills from one setting to another.

Sometimes educators and parents accuse each other of exaggerating or underestimating a child's skills. Very often, the difference in perspectives stems from true differences in skill performance across home and school settings.

By inviting parents to observe their child in the classroom, at lunch, or on the playground, it becomes easier to have an open dialogue about the student's skills and needs in the school setting. Parents may have suggestions for handling challenging behaviors that will benefit educators. Similarly, parents may be open to recommendations for generalizing a skill to home and community settings because they have seen it as a real strength when observing in the school.

- For parents who are interested, help establish communication with other families who are facing similar challenges. Parents benefit from the opportunity to ask each other questions and discuss their concerns. Parents can help each other understand the options that are available to them both in and out of the school system.

## Address Conflicting Views

Even when you have established strategies for obtaining parental input and created a welcoming environment that allows for open and ongoing dialogue, parents and schools will not always be in agreement. Conflicting perspectives can be uncomfortable for all parties involved. This can create a challenging but not insurmountable problem for the educational team and the family.

Consider the example in which a parent might identify an intervention for her child that is in conflict with the educational approach suggested by school professionals. For instance, a mother may request that her child be on a special diet while in school. Your school system has reviewed the scientific literature on the diet and does not recommend the approach because harmful medical side effects (e.g., nutritional deficiencies, loss of bone density) have sometimes been reported. How do you proceed?



**In a situation like this, we would recommend moving forward together by taking the following steps:**

- Show continued respect for parental expertise regarding a child’s needs.
- Effectively communicate your concerns for the child’s health. Provide the family with a copy of the *Findings and Conclusions* report so they can be familiar with current research in this area.
- Recommend that the family discuss medical aspects of the diet with a qualified physician. It is important to collaborate not only across home and school, but also with outside professionals.
- Encourage a data-based approach for all treatments (see Chapter 3 on professional judgment). Model the use of single-subject research design with other school-recommended treatments that are implemented. Show the parents how this can be used to evaluate the effectiveness of the interventions the family puts in place (e.g., the diet). Provide support for parents who are interested in using single-subject research design to identify the effectiveness of the intervention for their child.

In the end, as the primary caregivers for their children, parents have unique expertise related to their children’s strengths and needs. Their opinion should be carefully considered and highly valued (McNaughton, 1994).

## **Establish Appropriate Family Supports**

You can establish family supports within your building or district, and/or provide families with information about supports that are available elsewhere. Some schools establish parent support groups to offer additional support to families. These groups create opportunities for families to share information and get to know other families in similar positions.

If a school does not feel there is enough need to warrant a support group in their building, collaborating with other schools in the district or providing parents with information on community resources may be better options. Parents should not feel “pushed” into participating in a support group, however. A sizeable number of parents prefer privacy, have limited time, or feel that a support group would not be helpful.

## Support Parents in Generalizing Skills

Given that children with ASD experience difficulties generalizing skills across environments, it is essential to coordinate efforts to teach skills across multiple environments. Many learning opportunities naturally occur at home or when the family is in the community. Parents can continue their involvement in their child's education by engaging in activities at home. These can include child-directed play, creating opportunities for social interaction with other children, educational leisure activities such as trips to a museum, and the development of adaptive skill goals such as toilet training, self-care, and community safety skills (Benson et al., 2008).

### **Schools can facilitate skill development in the home and community by:**

- Providing materials that parents may need in order to work on specific skills
- Providing parents with ideas and training related to skill development in naturally occurring learning environments
- Communicating with parents about a child's current goals and progress in her educational programming
- Stressing your awareness of the importance of learning opportunities at home (When possible, teachers or therapists can make home visits to demonstrate specific strategies for parents in the home.)



## Final Considerations

As noted earlier, a school's efforts to encourage parental involvement are strongly related to the parents' level of involvement in their child's education. When school staff make clear efforts to contact parents and include them in their child's education, parents report more positive experiences with the school and are more likely to reach out to the school (Seitsinger et al., 2007).

Everyone on the educational team (e.g., teachers, specialty services, paraprofessionals, etc.) should learn how to create a welcoming environment in the school. Administrative support is critical to creating school- and district-wide goals related to parent involvement (Benson et al., 2008). School personnel will also need to consider their own feelings related to parent participation in education, and address concerns or biases as needed. Also, schools should develop training for school staff who are not accustomed to the idea of a student fully participating in the educational process, if the student has the capacity to participate.

When parents are knowledgeable about the needs of their children and receive appropriate support from school personnel, the children perform better academically (Seitsinger et al., 2007) and are likely to experience benefits in other areas of their lives. Schools must take an active role in incorporating family preferences and values into the educational process for children with ASD.

The following case example illustrates the importance of incorporating family preferences and values into the educational process. It also demonstrates the benefit of gathering information related to family preferences and values prior to the implementation of interventions.

## Case Example

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Emma is a 6-year-old girl who will begin first grade at a small elementary school in the Northeast United States in the fall. She previously attended kindergarten in a different district, and her parents have moved over the summer due to new employment for her father. The family-centered approach described below was initiated prior to the first meeting of Emma's educational team.

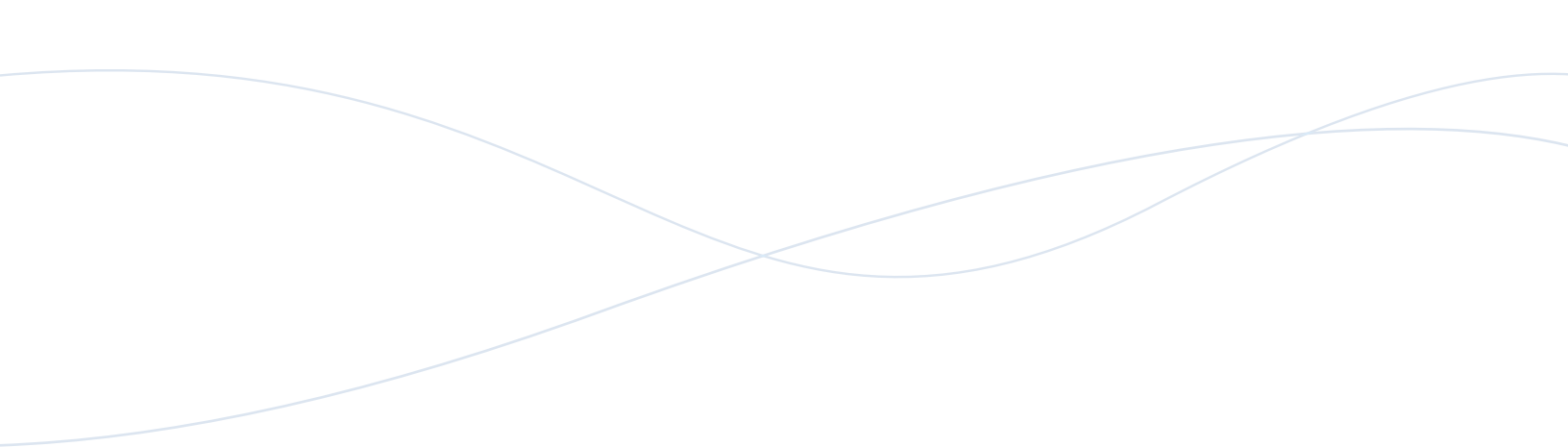
Emma's parents called the special education director of the new school district, Dr. Smith, to inform her of their move and Emma's special education needs. Dr. Smith set up an informal, face-to-face meeting with the family to introduce herself and describe the process that the district would undertake to develop an appropriate educational program for Emma. During this meeting, Emma's parents expressed concern about her previous placement, indicating that they believed services were not intense enough to meet her needs.

Emma has a complex developmental history and currently has diagnoses of cerebral palsy, seizure disorder, and autism. She is primarily nonverbal, although she does produce some sounds and says a few common words such as "mama" and "open." Her primary mode of communication is sign language, and her mother is fluent in sign. In her previous school, she received several support services, including speech-language therapy,

occupational therapy, and learning support services. Emma also had a paraprofessional who was with her in the classroom throughout the day. Her parents reported that her previous school encouraged the use of an augmentative and alternative communication device. However, they noted they were unhappy with this suggestion, given that Emma was already using sign language to communicate. Further, the communication device was cumbersome for her because of motor difficulties with one side of her body related to cerebral palsy. They also expressed concern that she would become "too dependent" on her paraprofessional.

Dr. Smith acknowledged their concerns, and explained the district's family-centered approach. She also discussed the concept of research-supported treatments. At the end of the meeting, Dr. Smith asked Emma's parents to complete a family stress survey, the Child Preference Indicators, and the *Parental Participation Questionnaire* to gather more information related to their values and preferences. (They did not ask Emma to complete the *Student Participation Questionnaire* because it is not developmentally appropriate for a 6-year-old.) Dr. Smith gave the parents a stamped, self-addressed envelope in which to return the forms.

In the meantime, she invited the family to observe various educational options that may be available to Emma, including a classroom for students with



autism, a regular education first grade classroom, learning support services, speech-language therapy, and occupational therapy. Dr. Smith gathered the necessary consent signatures from other families to allow these observations to occur.


The responses of Emma's parents to the questionnaires revealed several sources of stress for the family, with three children under the age of seven, including one child with multiple disabilities. Other stressors included their recent move to a new home, beginning new jobs, and lack of family support in the area. Other responses indicated an interest in Comprehensive Behavioral Treatment for Young Children and a number of other behavioral treatments. They also wished to increase Emma's speech-language services to promote her continued development of sounds and language skills. Based on their observations in the school, they cited the potential benefits of both the regular education classroom and the autism classroom for Emma. They did, however, report concerns about Emma's ability to interact with her same-age peers in the autism classroom.

The district conducted a comprehensive evaluation of Emma and used those results, along with the information described above, to develop a program for her. First, the autism support teacher for the district visited Emma's family at home to provide more information about the interventions which interested Emma's parents. The teacher also shared the data the school had collected to

show these treatments were being implemented accurately by school personnel. With this additional information, Emma's parents were excited about using these strategies with her.

Because the autism classroom utilized behavioral treatments, the family expressed an interest in having Emma spend a portion of her day there. They were pleased to know their concerns had been addressed when the school suggested Emma should spend a portion of her day in the regular education classroom; this would support social skills development and provide opportunities for generalization of skills. However, both the parents and the district were concerned that, although the special education teacher and staff were fluent in sign language, her regular education teacher was not. They decided to provide an interpreter for Emma in the regular education classroom to facilitate her ability to communicate effectively.

The educational team then discussed the family's need for additional speech-language services. They authorized 30 minutes of speech-language therapy for Emma four days a week. The family also received information about additional speech-language providers in the area. Finally, Emma's parents were invited to attend monthly district-sponsored trainings on various issues related to meeting the needs of children with autism. They were also offered weekly updates on Emma's progress toward educational goals.



This case example demonstrates the process school personnel can utilize to ensure that family preferences and values are incorporated into the educational process. Emma's parents reported high acceptability of her educational programming because they were involved in decision making from the very beginning. They noted the willingness of Dr. Smith to meet with them personally and that of the autism support teacher to come to their home. These supports eased their concerns and helped them to feel valued. School staff also reported that a good relationship had been established with Emma's family and were positive about her educational progress.

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# 5

## Building & Sustaining Capacity to Deliver Treatments that Work

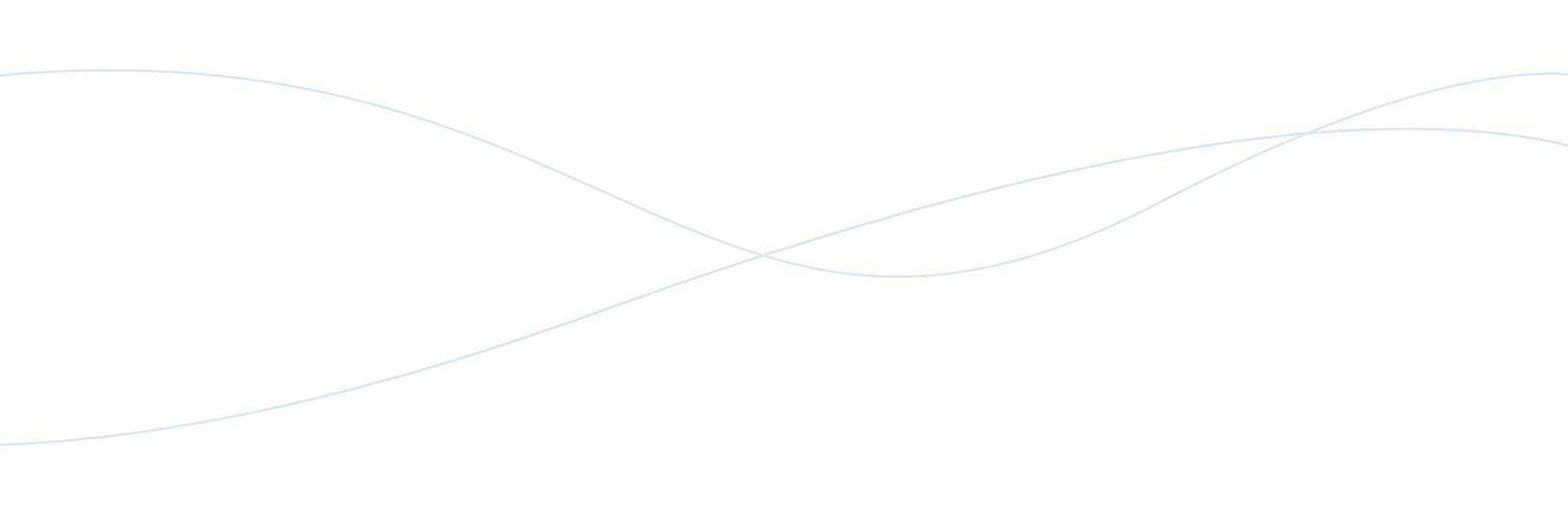
Throughout this manual, we have endeavored to provide you—front-line interventionists—with the most current and accurate information available on research-supported treatments for children and adolescents with Autism Spectrum Disorders (ASD).

Each of the preceding chapters focused on the elements we identified as critical to the development of evidence-based practice: the history and evolving understanding of autism; the Established Treatments identified by the National Standards Project; the importance of your professional judgment and data-based decision making; and the need to incorporate the values and preferences of families in treatment plans. In this final chapter, we discuss the need to build capacity for implementing effective interventions in the schools. We offer our strong recommendation to build capacity using a comprehensive, systemic approach.

Let us be clear at the outset about one very important point. We understand the “real world” situations and challenges you face, every day. We acknowledge your commitment to excellence with the students you serve. This manual, and the recommendations herein, are meant to support the work you do and to further our mutual goal of providing appropriate services by increasing evidence-based practice in the schools. We know the implementation of evidence-based practice requires significant time and resources. We also know that it will enable educators and schools to provide more efficient and effective treatments, with better outcomes for your students with ASD.

There are two approaches you may use to build the capacity to implement effective interventions for students with ASD. Specifically, you might adopt a grassroots approach or a systemic approach to creating change.

The grassroots approach typically begins and ends with one professional’s dedication to meeting the needs of an individual student. As is often the case, a teacher (or




speech-language pathologist, psychologist, or other professional in the school) may try to develop her own capacity to meet the needs of one or more of her students. This grassroots approach places tremendous pressure on individual service providers! Unfortunately, we know that this approach to developing capacity is the reality many educators face. The grassroots approach has several inherent weaknesses which will be familiar to front-line interventionists and administrators.

Developing the capacity to offer treatments to one student at a time made more sense when Autism Spectrum Disorders were viewed as “rare.” After all, if most educators would never have the opportunity to work with a student on the autism spectrum, why build systemic capacity? In the 21st century, however, autism and its related disorders are all too familiar in our classrooms. There is no question that the number of diagnosed cases of ASD has increased steadily for nearly two decades (Hertz-Picciotto & Delwiche, 2009). Schools now must prepare *all* staff to serve *all* children with ASD—including students with varying communication, social, cognitive, and adaptive skills. The grassroots approach is simply not an efficient strategy for meeting the needs of this increasingly large and diverse student population.

The complicated nature of treatment decisions requires the participation and input of all involved. As noted in Chapters 3 and 4, both initial treatment selection and the decision to continue using an intervention are complicated. When one person is solely responsible for treatment selection and continuation, decisions are more likely to be based on incomplete and potentially erroneous information. A teacher may have heard that a treatment was effective when, in fact, it has no evidence of effectiveness. A principal may invest training dollars in a workshop for the entire staff based on the opinion of one parent. This parent may report that the treatment worked for his son, but there may not be evidence the treatment should be applied to all students on the autism spectrum. It is always best to make treatment selection and continuation decisions in a systematic fashion with input from all key stakeholders.

Another inherent weakness to the grassroots approach is that it does not address the need for strategic planning. The accurate implementation of interventions often requires time, energy, and fiscal support beyond those immediately available to the front-line interventionist. Marshalling such resources requires strategic planning. This plan may involve identifying barriers to



intervention implementation, preparing training materials and treatment guides, completing the groundwork necessary for training to occur, and evaluating essential outcomes. Strategic planning and allocation of necessary resources are best handled by a team that is dedicated to producing systemic change.

Therefore, we recommend that the most efficient way to build capacity for implementing effective interventions for students with ASD is to take steps that will produce systemic change. The systemic approach addresses the needs of the entire population of students with ASD, and provides support to school service providers as a team.

Development of a strategic plan for building capacity takes time, as does any endeavor requiring the participation of a group. But it is time well spent. It is only as a team of capable, competent professionals that you can overcome the barriers you will face. Once capacity

to implement effective interventions has been developed, school professionals—working in collaboration with families—will be in a far stronger position to quickly provide interventions that have evidence of effectiveness (Adelman & Taylor, 1997).

**We present five key steps to consider as you build sustainable capacity in your school:**

- **Step 1:** Establish the Planning Team
- **Step 2:** Problem Clarification and Needs Assessment
- **Step 3:** Evaluating Outcomes
- **Step 4:** Developing a Training Plan
- **Step 5:** Sustainability

We will explore each of these steps for producing systemic change in further detail.

## Producing Systemic Change

The autism spectrum is very broad, and includes students with a wide range of skills and needs. These students are served in general and special education classrooms throughout the country.

Given the diversity in the ASD student population, school professionals will not always feel adequately prepared to provide necessary supports to these students. What strategies does your school system have in place to develop systemic capacity to support these students?

### **As you assess your current capacity, you may begin by asking:**

- Have many school personnel attended the same workshops? If so, who made the decision about securing training in this area?
- Are school professionals in agreement about when and how interventions should be implemented?
- Is there a system in place to evaluate accuracy of implementation and assess the outcomes for students?
- Is there a sense among school professionals that new ASD treatments come and go like fads?
- Has there been an organized effort to ensure all school staff have access to necessary resources?
- Who has planned to ensure this intervention can be sustained in the school?

The planning process will raise these questions, and many others. The first step is to establish a well-functioning and representative team that is committed to increasing the use of evidence-based practices.

This team holds many responsibilities including, but not restricted to, the following:

- Evaluating their current capacity
- Determining how many different groups of students will be affected and how this relates to capacity building
- Identifying barriers that may undermine the plan (e.g., availability of resources, resistance from school personnel, lack of training, etc.)
- Problem-solving collaborative strategies for reducing the impact of these barriers (Although the process of reducing barriers can be time-consuming, it cannot be rushed.)
- Establishing the training process
- Developing necessary resources
- Advancing a plan to provide ongoing support to school staff

The remainder of this chapter describes a methodology for producing and sustaining the kind of systemic change that will build capacity to accurately implement interventions.

## Step 1: Establish the Planning Team

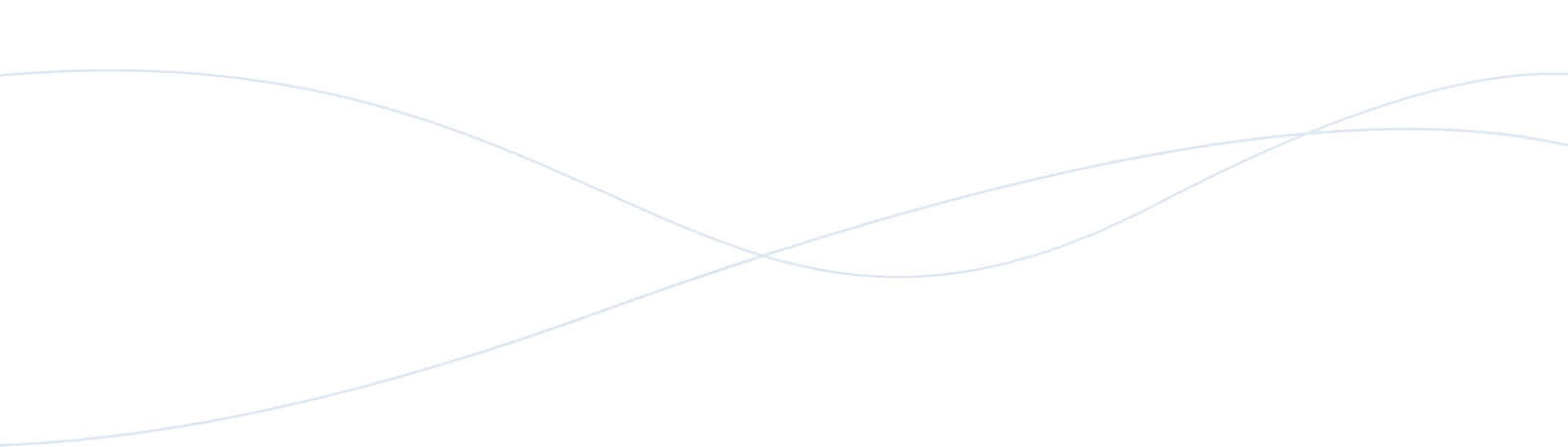
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“Never doubt that a small group of thoughtful, committed individuals can change the world. Indeed, it’s the only thing that ever has.”

— Margaret Mead

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In order to effectively produce system-wide changes, many people must contribute to and feel ownership of the change process. A planning team should be developed to begin preparation for systemic change. The diverse perspectives of planning team




members are a real advantage. The planning team will need to anticipate unique barriers to building capacity. Diverse experiences and perspectives will produce different solutions to these challenges. In addition, all school staff will likely benefit from a collaborative planning team that brings distinctive strengths to the table. Recognizing the roles and responsibilities of various school staff members is the first step in the process of capacity building, which is a continuing exercise in problem solving.

Each member of the planning team will bring specialized training and experiences to the group. In addition to their training in specific content domains (e.g., teaching, speech-language therapy, etc.), the most effective team will also include members with process-specific skills.

**These skills may include, but are not restricted to, the following areas:**

- **Data collection.** Data collection will be critical to the mission. So, at least one team member should understand efficient and effective strategies for measuring change. Team members with experience in data collection will help determine whether treatments are being implemented accurately and are leading to improved outcomes for students.
- **Leadership.** It can be beneficial to include team members with different leadership skills. For example, one member might be skilled in fostering collaborative relationships, while another might help direct the team forward in the decision-making process. Keep in mind that different leadership styles can lead to conflict if a collaborative and respectful environment is not regularly fostered by all team members.
- **Generalization.** At least one team member should be charged with ensuring the plan to build capacity is extended across relevant environments (e.g., hallways, playground, cafeteria, etc.). Ideally, this staff member will have experience providing services across multiple environments.

While there will be a natural division of responsibilities on the team, it is important from the outset for everyone to have a shared sense of commitment to the process and responsibility for a successful result.



The two main functions of the team are planning and evaluation. The steps required for planning for capacity building are laid out in detail in this chapter; evaluating outcomes is also addressed.

Your planning team should represent all of the professionals who will deliver the treatment. In addition, the team should include representatives of any group that is responsible for ensuring the treatment is implemented accurately and sustained over time. This will include instructional agents as well as support services, personnel development, and administrative services staff.

Each of these groups is discussed below.

## **Instructional Agents**

Individuals who regularly provide educational services to students with autism should be well-represented on the school-wide planning team.

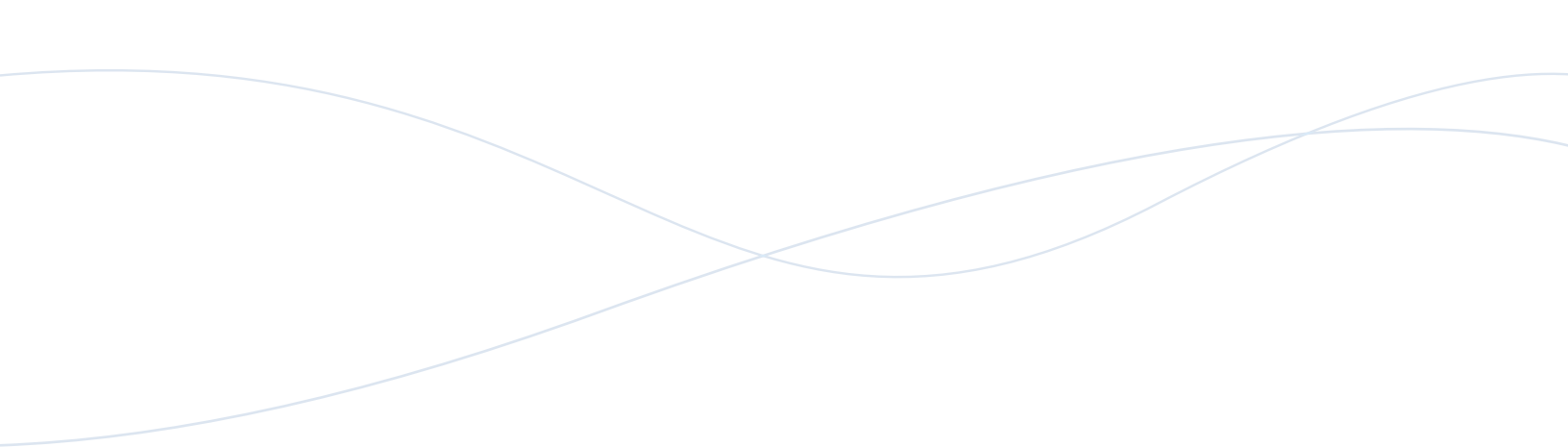
### **Keep the following points in mind as you develop your team:**

- There are benefits to including paraprofessionals as well as teachers. Paraprofessionals often spend a good deal of instructional time with the student with ASD. As front-line interventionists, they may also provide unique insight about barriers to capacity building.
- At least one instructional agent on the team must have expertise in how to modify curricular materials if new treatments are implemented.
- Another instructional agent must be able to determine how the new treatment will impact existing goals. For example, how will the new treatment relate to academic, behavioral, and social goals?

## **Support Services Staff**


In addition to instructional agents, support services are often necessary for individuals on the autism spectrum. Support services personnel often play a crucial role in helping students meet their Individualized Educational Plan (IEP) goals.





The following professionals may offer valuable perspectives to the team:

- **Behavior analysts, counselors, and psychologists.** Behavioral or mental health support is often necessary for students with ASD. In addition to the behavior problems (e.g., self-injury, aggression) that some children on the autism spectrum demonstrate, issues of depression or anxiety may present a significant impediment to successful life and school functioning for older students on the spectrum. These professionals often have training on how to increase developmentally appropriate skills as well.
- **Physical therapists.** Students with ASD may require physical therapy if they have motoric limitations that interfere with their ability to function effectively in their environments. Their targets may include improvements in motor skills, balance, and coordination.
- **Occupational therapists.** Occupational therapy may be necessary to help students on the autism spectrum participate fully in school-related activities. Treatments may need to be adapted so that these students will be more likely to make gains and progress in their treatment objectives.
- **Speech and Language therapists.** Most individuals with ASD experience some difficulties with communication. As noted in Chapter 1, these difficulties may include deficits in verbal and nonverbal communication. Even when students on the autism spectrum do not have measurable deficits in receptive or expressive skills early in life, social pragmatic skills are often impaired and become an obstacle to success for children.
- **Transportation professionals.** Like their typically developing peers, many students with ASD receive transportation services from their school system. Some of these students will require intervention plans for the transportation process. For example, students on the autism spectrum often have severe social challenges. Waiting with other children to board the bus, or riding the bus, may present difficulties for these students. Sometimes, a student with ASD is bullied or victimized in some way. Behavioral issues may also present challenges during transportation. In all of these instances, staff need to be trained and supervised in the use of approved management strategies consistent with those provided in other educational environments. A bus driver may be able to provide critical input on whether or not a student with ASD or his peers are responding to treatment.

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- **Family resource specialists.** These specialists work with the families of students with ASD to make them aware of services available in the school system, including after-school services. They often help families connect with additional services available in their communities. Support services for family members contribute to effective and durable treatment outcomes. These services offer much-needed respite and help ensure that families have the stamina and resources necessary to meet treatment goals in the home and community. Family resource specialists can also facilitate the family involvement described in Chapter 4.
  - **Youth service specialists.** Some school systems have a wide variety of youth services available. These may include tutoring programs, recreational services, or health services programs.

## **Personnel Development Staff**

These individuals are dedicated to developing capacity to meet the school's goals by providing training to school professionals. They offer a range of services, including pre-service trainings, in-service trainings, direct trainings, and post-training follow-ups. Because these professionals often have significant expertise in developing capacity in schools, it's important to include this group in the planning team process.

## **Administrative Services Staff**

Of course, administrators are essential to developing systemic change. Most people widely recognize the role of the administrator in securing necessary resources. However, the role of the administrator should extend far beyond issues of resource allocation.

The planning team must address a broad range of issues; it is important for administrators to understand what is required to produce systemic changes, and why. This will be essential as they implement a plan to develop and sustain capacity. School administrators have more experience in managing systemic changes than any other school professionals. Their unique insight will likely ground the planning team so that real change can occur.

Administrators are accountable for—and should be involved in—evaluating whether the efforts to produce systemic change in evidence-based practice actually lead to improved outcomes for students with ASD. Administrators, along with all other members of the planning team, must be familiar with the treatments that are selected, the steps that must be completed in order to build capacity to implement those interventions, the key components of determining if the treatment is being accurately implemented, and the methods for evaluating whether a treatment is producing favorable outcomes.

## Step 2: Problem Clarification and Needs Assessment

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“There are moments...when it is incumbent upon those known for their wisdom and clarity of vision to survey the problem, with all its complexities...in a bold drive toward new horizons.”

— Anwar Sadat

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### Problem Clarification

Once the planning team is in place, its work begins with problem clarification. The team must clarify the exact nature of the problem it faces as a system. It does so by moving through the three components of problem clarification:

- 1. Current capacity evaluation:** Determine the extent to which the school currently has sufficient capacity to implement effective interventions
- 2. Problem definition:** Describe the nature and the scope of the problem
- 3. Systemic identification:** Identify which systems will be affected by their efforts to produce systemic change

Let's consider each of these components in more detail.

## Current Capacity Evaluation

When you transition from a grassroots approach to a systemic approach, your planning team will need to evaluate each member of the school staff who serves students with ASD. It's important to understand the perceived knowledge, skills, and treatment integrity (i.e., extent to which an intervention or interventions are being accurately implemented) of each of these staff. We developed the *Research-Supported Treatments–Teacher Report Form* (RST-TRF) to help you collect this information from staff members (see Table 1).

Keep in mind that self-reporting may not accurately identify the exact level of knowledge, skill, or treatment integrity for research-supported treatments in the school. Service providers in all agencies may sometimes incorrectly believe that they {a} know the essential components of an intervention or {b} accurately implement these interventions. Despite this fact, the RST-TRF can be useful; it can help you identify perceived strengths or weaknesses in your school's capacity. The RST-TRF can also help identify essential resources for developing system-wide capacity (e.g., candidates who may serve as a master teacher or consultant). If school staff consistently report that they lack knowledge about research-supported treatments, you have identified deficits that must be addressed.

The RST-TRF is helpful for school systems that use a grassroots approach to building capacity. It may also be helpful when a school has adopted what we call a "train-and-hope" strategy to systemic capacity building. Consider the following example. A school wants to build capacity among its staff. As part of its plan, it sends a few school personnel to a two-day workshop. The goal is for these staff members to become experts on the intervention; they can then serve as consultants to other school staff. So, these staff members were "trained," and then everyone "hoped" the school's capacity would improve. Unfortunately, capacity building often requires more than attendance at a workshop. You must ensure that staff who are given the responsibility to implement an intervention (or to teach others to accurately provide treatment services) actually have the capacity to do so. The RST-TRF can help identify areas where past or current training resources are insufficient to produce appropriate levels of mastery of treatments.

If your school system has already adopted a systemic approach like the one described in the rest of this chapter, you already have a clear understanding of the school's capacity to implement selected interventions. The RST-TRF may still be beneficial to secure input from new staff entering the system, or to monitor staff self-assessments on a regular basis.

**Table 1}** Research-Supported Treatments – Teacher Report Form (RST-TRF)

**Research-Supported Treatments – Teacher Report Form**

This table identifies treatments for Autism Spectrum Disorders that have been shown to be effective through research. We would like to know more about your knowledge and use of these treatments. Please check the box for the statement that most accurately describes your level of familiarity or competence with each of these ASD treatments.

The last item is for teachers to identify appropriate staff. Please use the back of this form if you need additional room.

	Antecedent Package	Behavioral Package	Comprehensive Behavioral Treatment for Young Children	Joint Attention	Modeling	Naturalistic Teaching Strategies	Peer Training Package	Pivotal Response Treatment	Schedules	Self-Management	Story-based Intervention
I am not familiar with this treatment.											
I know how to use this treatment but have not used it before.											
I know the "basics" about this treatment but could not explain it to others.											
I know this treatment well enough to teach others the "basics."											
I could implement this treatment tomorrow.											
I could teach someone to implement this treatment.											
I have used this treatment in the past.											
I have data to show that I can accurately implement this treatment.											
The following people can accurately implement this treatment in my classroom.											

**Other Treatments:** You may accurately implement treatments that are not identified on this form. Please identify any additional treatments for which you could provide training to others in the school system.

## Problem Definition

Your planning team was convened to increase the school's capacity to use research-supported treatments. Now, the team must clearly define the nature and scope of the task ahead.

**Consider these questions as you explore how to identify which treatments to develop:**

- 1.** Do you plan to develop school-wide capacity to provide many or all of the research-supported treatments? Eleven Established Treatments have been identified (see Chapter 2). Developing capacity to implement many or all of these interventions is a major commitment for educational systems. It will require a detailed plan for its implementation, and may take an extensive period of time to complete.
- 2.** Will you build capacity in more than one area simultaneously, or sequentially? If you build capacity simultaneously, are there sufficient resources to develop the capacity to implement all the interventions with a high degree of accuracy? If you build capacity sequentially, can the needs of the students with ASD be adequately addressed while you await the second, third, or fourth intervention?
- 3.** Will different school professionals develop capacity with two or more research-supported treatments? If so, will they be expected to serve as consultants or master teachers for other school staff? What supports are in place to encourage their development as trainer-of-trainers?

Another important consideration in capacity building involves whom you serve. Which populations will you target with the selected treatments?

- ☛ Should the treatment be targeted for all students with ASD?
- ☛ Should the treatment be targeted for students of a particular age?
- ☛ Should the treatment be targeted for students with specific skill deficits?
- ☛ Should the treatment be targeted for students with behavioral excesses?
- ☛ Should the treatment be targeted for students with specific diagnoses?
- ☛ Are there any additional variables that might influence the scale on which these treatments might be applied?


## Trainer of Trainers

Master teachers or consultants often follow a training-of-trainers (TOT) model. The TOT model involves building capacity through training and technical assistance. A trainer fosters a collaborative learning environment. The trainer must be able to prepare training materials, deliver instruction, and provide follow-up sessions (e.g., coaching and booster sessions) to support the teacher's generalization of knowledge and skills to the students he serves.

Training extends beyond lecture to structured experiential learning (e.g., role-plays, direct delivery of instruction with individualized supports from the trainer, etc.). The trainer must be culturally sensitive

and able to provide constructive feedback that promotes a positive learning experience.

The TOT model is often applied in educational settings. Trainers often have knowledge and skills regarding the implementation of an effective intervention prior to their interest in serving in this role. However, knowledge and skills are not enough. Trainers must themselves receive sufficient training to develop appropriate materials, teaching activities, and strategies for fostering a collaborative teaching environment.



Many interventions can be applied with the vast majority of students on the autism spectrum. However, you may need to use your professional judgment along with the information provided in the *Findings and Conclusions* report to identify the best strategy for building capacity in your school. For example, you may know that joint attention skills are often targeted with the youngest students with ASD. Your planning team may make the decision to develop capacity to implement joint attention skills for preschool teachers and support staff. In contrast, intervention strategies included in the Behavioral Package treatment category have been successfully applied to students of all different age groups. Your planning team may determine that all educators in the school should have the capacity to implement Behavioral Package treatment strategies.

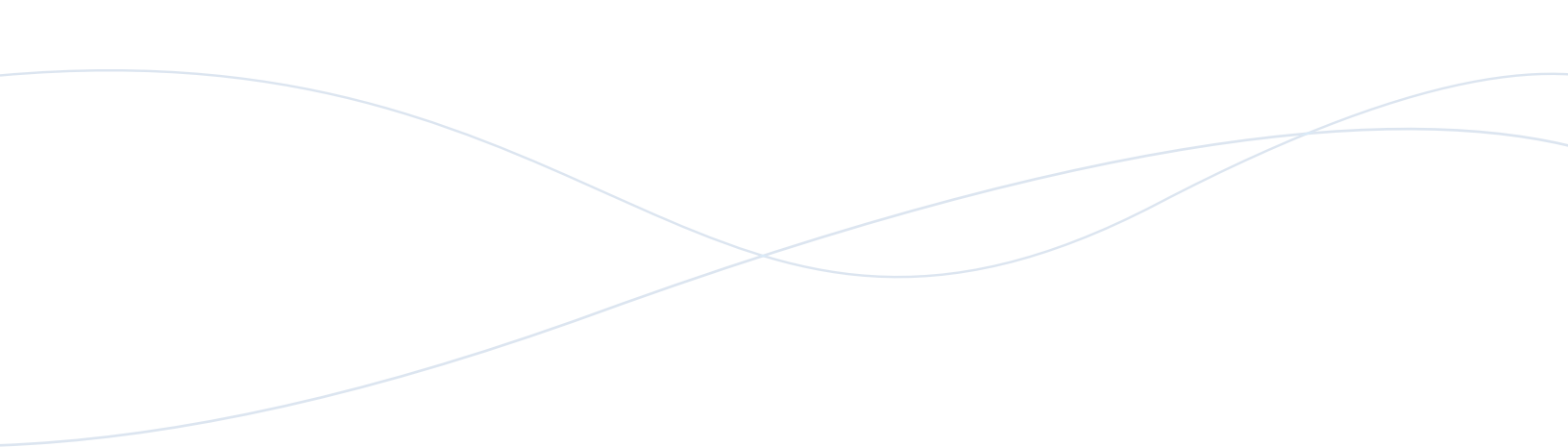
### **System Identification**

After the team evaluates current capacity and clearly defines the problem, it must determine which systems will be involved in the treatment. For example, the team must identify which instructional services, support services, personnel development, or administrators will be most affected by the decision to increase capacity. You began this process when you established your team. But you must re-examine this issue because not *all* of the individuals most affected on a daily basis will be represented on the planning team. Strategies for securing input and developing collaboration between the planning team and the professionals on the front line are essential. This is why a needs assessment is a necessary process.

### **Needs Assessment**

Before beginning formal staff training, it's important for your planning team to conduct a needs assessment. This will identify barriers to implementing the treatments you have identified. A needs assessment allows the team to systematically assess the school staff's perceived needs and barriers. A needs assessment can be completed through a survey or interviews. In the end, it should provide an indicator of what will be required to move the school forward toward an evidence-based approach to practice.





The needs assessment helps front-line interventionists provide critical input into the capacity-building process. Without getting “buy-in” from a broad range of front-line interventionists, it will be difficult to produce meaningful long-term change (Sims & Sims, 2004).


Following is a review of possible barriers to consider as your planning team completes a needs assessment. Although the purpose of the needs assessment is restricted to evaluating current perspectives, we have also offered strategies for reducing these barriers.

■ **Barrier 1: Differences between the existing and proposed interventions.**

Barriers to treatment implementation are more likely when a greater discrepancy exists between the treatment being utilized and the treatment being adopted. Most of us are more likely to complete training and then implement an intervention with a high degree of accuracy if the effort required is minimal. We should expect the same to be true for all front-line interventionists. The planning team should evaluate the degree of change required with any new treatment, and then identify meaningful ways to acknowledge or reward the increased demands placed on school staff.

For example, consider the difference between using Schedules and simple Self-management systems. Both involve {a} breaking a task into component parts, {b} having students indicate when a task component has been completed, and {c} delivering reinforcers at the conclusion of the task. The two treatments differ in that the student monitors his own progress and self-reinforces when Self-management is used. Given how minor the difference is between these treatments, school staff already using schedules are not likely to resist adding Self-management to their repertoire of Established Treatments.

But now consider how different Peer Training is from Schedules. Peer Training requires identifying socially skilled peers and then teaching them to facilitate social and play interactions with a child with ASD. In addition to implementing a teaching protocol with the typically developing peers, this process requires ongoing monitoring of both the peers and the student with ASD. In this case, it is likely that school staff will be more resistant to adding a treatment like Peer Training, given how different this process is from their previous experience with Schedules.

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- **Barrier 2: Additional time required to implement new treatments.** We all feel that we have too much to do and too little time to do it. The needs assessment must consider how training and implementation requirements will add to an educator's time demands. Ignoring this reality can undermine plans to introduce new interventions.

Consider the following factors that may influence resistance from school staff:

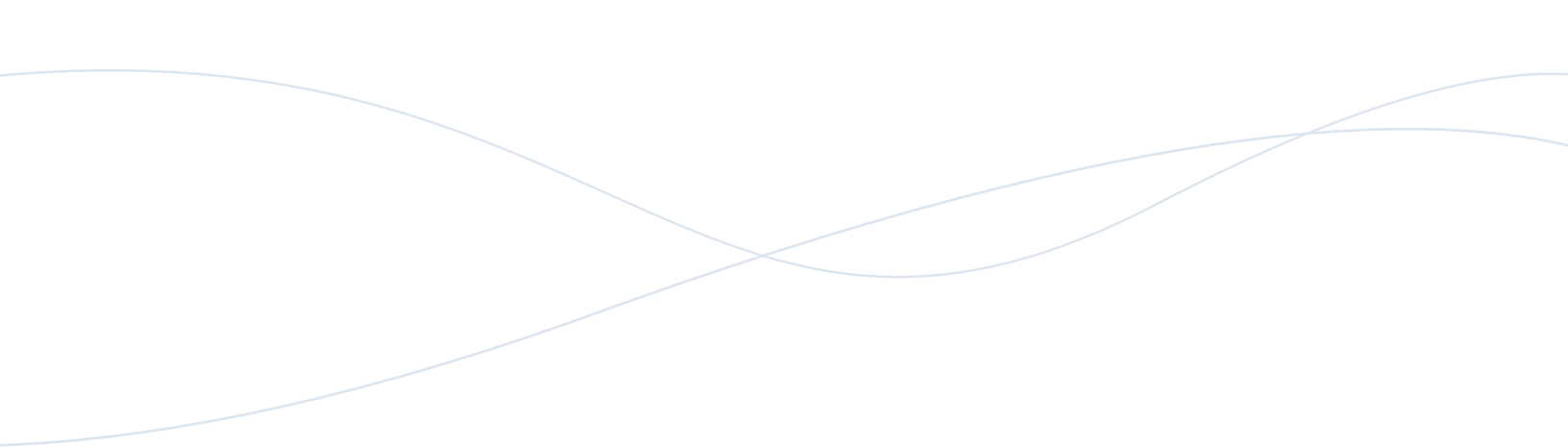
- ▶ Who would be involved in implementing the intervention? What training would they require? Remember, the amount of training necessary will be related to the amount of previous experience staff members have in implementing a given treatment. It will obviously take longer to train staff with less experience.

Training often involves a didactic component, an experiential component, and sustained coaching from a consultant or master teacher. School staff are more likely to be resistant if they are expected to complete all their regular activities while receiving this training. The planning team may need to develop a strategy for addressing the staffing needed to manage everyday tasks while all components of training are delivered.

- ▶ What would be involved in preparing the materials? Preparation of materials may be very time-consuming. Materials may involve pictures, objects, worksheets, checklists, or any other stimuli used to teach students. If the school develops multiple sets of materials that are readily available to all educators involved in implementing a new treatment, it will require less time for the front-line interventionist, and will likely reduce resistance.

The planning team may also need to consider what modifications to materials may be necessary for students with additional disabilities (e.g., cerebral palsy) or co-morbid conditions (e.g., pica, the ingestion of inedible objects). Staff may also need to evaluate materials for developmental appropriateness (e.g., the toys used in Peer Training may be very different in a preschool classroom than in a second grade classroom). Note that you may not be able to anticipate all modifications. Establishing a consultation team can help front-line interventionists address modifications of materials on an ongoing basis.

Transportability and "replaceability" (how easy it is to replace materials) are two more issues to consider when materials are prepared. Materials may



need to be transported across settings within the school system, or across home and school environments. The planning team should anticipate that materials may be lost or destroyed when they are transported. More than one copy of materials will be necessary because {a} more than one staff member may need to use the same materials and {b} materials may be lost or destroyed.

- **Barrier 3: Treatment acceptability.** It is important to know if front-line interventionists find a new treatment acceptable. If a staff person doesn't approve of a new treatment, how likely will she be to implement it accurately? When making plans to produce systemic changes, it is best to evaluate the acceptability of a new treatment for all individuals who will be implementing it.

There are several tools you can use to assess treatment acceptability. For example, the *Intervention Rating Profile–15* is a 15-item questionnaire designed to evaluate the acceptability of treatments in school settings (Martens, Witt, Elliott, & Darveaux, 1985). Each item is rated on a six-point scale ranging from strongly disagree to strongly agree. Scores above 52.5 indicate a treatment is acceptable. A variety of treatment acceptability measures have been developed (Carter, 2007) and schools may elect to use one or more of these tools based on teacher preference for these instruments.

There are several reasons a treatment might be considered unacceptable. For example, some treatments may be considered unacceptable on ethical grounds or because they are inconsistent with school policy. However, treatments are sometimes deemed unacceptable based on insufficient or inaccurate information. You can address resistance related to treatment acceptability by ensuring that front-line interventionists have an accurate understanding of the essential components of any intervention they may be expected to implement. Remember that it is important to openly discuss all treatment acceptability concerns.

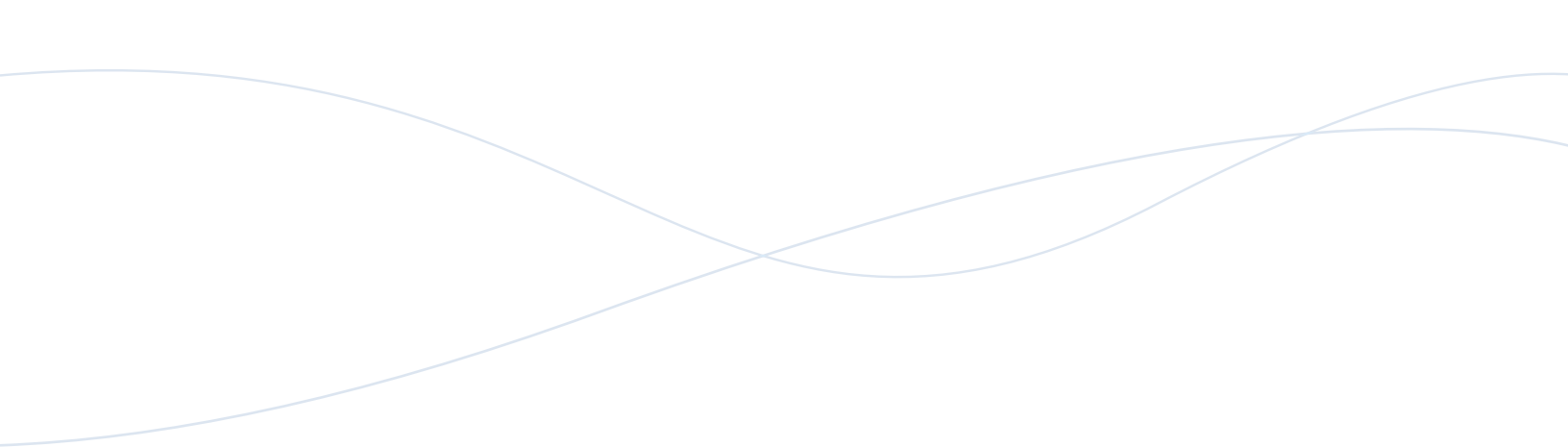
- **Barrier 4: History of treatment delivery.** School staff may have a natural resistance to new treatments based on their history of delivering interventions. First, school staff may already have a commitment to the interventions they currently implement. Second, front-line interventionists may be skeptical if novel treatment approaches have been adopted in the past (without sufficient support) and then discarded. More discussion follows on these two reasons for resistance.

## Effort as a Barrier

Change is hard! Changing from an existing treatment to a new treatment always requires more effort than sticking with what is already in place. We first need to assess how much effort will be required to change from the current educational practices to the new treatment.

It takes time to become proficient at implementing a new intervention, and it taps into your energy reserves as you become an expert. Until they become proficient, front-line interventionists will feel fatigued from the additional effort required to put a new intervention in place. The planning team may need to estimate the length of time it takes for the average staff member to become proficient at implementing the new intervention.

You may be able to reduce resistance if you initiate a motivational system for school staff who are developing new skills. This may involve a formal recognition of the sustained effort front-line interventionists are investing, or something as simple as informally mentioning your respect for an individual educator's efforts.



► **Commitment to current interventions**

School professionals often have specialized training for the children they serve. Some professionals may be trained in specific educational techniques during their formal coursework and later continue their education through additional coursework or training seminars.

When front-line interventionists have extensive training in a treatment that has evidence of effectiveness, it works to the school's advantage. Why would they resist further use of this treatment? But what happens when previous training involves a treatment that does *not* have research support?

Front-line interventionists tend to believe in the treatments they have been trained to use—whether or not there is any evidence of effectiveness. This may be particularly true when the treatment has been used in the past and the educator had a “sense” that it was effective. This is one of the reasons data collection is so important (see Chapter 3). If high-quality data have not been collected, we have only our beliefs on which to base our decisions. We are all inclined to believe that our efforts produce favorable outcomes. We should not be surprised, then, when we find resistance among front-line interventionists.

Our history in using specific techniques makes us more biased against alternatives—even when there is evidence the treatment is truly effective. In order to convince someone that he should switch from a current educational practice to a new Established Treatment, you must provide clear and compelling evidence. We hope the *Findings and Conclusions* report of the National Standards Project in the Appendix of this manual assists you with this task.

► **Skepticism**

Some professionals are resistant to change because they have “been through this before.” Unfortunately, many school professionals have seen numerous treatments become popular and then fade away during their tenure. It's hard to be convinced that you should modify the educational services you are comfortable providing if you think the “new” treatment is a fad. This is one reason to avoid fads altogether. But it is an entirely different matter when Established Treatments are identified as the goal of systemic change. There are now evidence-based practice guidelines like those in the *Findings and Conclusions*

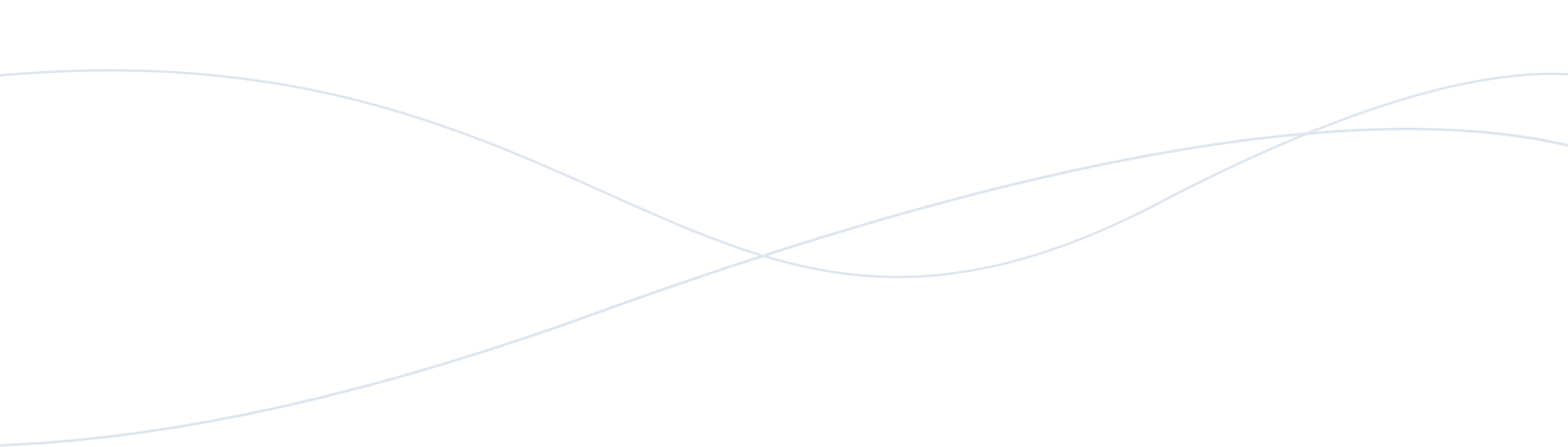
report that can help you determine which treatments should be a primary focus of systemic change.

The *Findings and Conclusions* report may not be enough to address entrenched resistance based on skepticism. In this case, staff may become motivated to use Established Treatments (i.e., those that are demonstrated to be effective) to avoid naturally occurring negative outcomes. For example, what school professional is not motivated to avoid a due process hearing? School professionals who do not use Established Treatments will be more likely to find themselves in the uncomfortable situation of trying to defend the use of alternate treatments. Although most school professionals will be motivated to increase their capacity to implement effective interventions in order to improve student outcomes, we recognize that nearly everyone is motivated to avoid a legal dispute.

Further, engaging in evidence-based practice is now legally mandated and a part of the ethical and training guidelines for many professionals. The No Child Left Behind Act (2001) includes over 100 references to using educational services that are based on scientific research. The Individuals with Disabilities Education Improvement Act (2004) also states that instructional practices should be scientifically supported. In addition, ethical guidelines like those put out by the National Association of School Psychologists (NASP) or training guidelines like those developed by the Network of Autism Training and Technical Assistance Programs (NATTAP) may also influence staff willingness to embrace the changes required to engage in evidence-based practice for students on the autism spectrum.

- **Barrier 5: Organizational Climate.** Organizational climate refers to the “atmosphere” within the school system. Is there an open and ongoing dialogue among professionals representing different service systems in the school? We know that many different systems will be affected by systemic change—are these systems really ready to change?

Convening the planning team is the first step in building capacity. But the team alone does not guarantee the systemic change you will need to engage in evidence-based practice for students with ASD. If the meeting of the newly established planning team is the first time a diverse group of professionals has



come together to produce change in the school, you should expect that the planning stage will take some time.

If the tone of the school system is one of open dialogue, the needs assessment is likely to result in accurate information that your planning team can act on. On the other hand, if the school system is closed to change, school professionals may not feel as comfortable acknowledging their limitations. In addition, your planning team will probably have a more difficult time working together effectively to address the barriers to treatment implementation identified during the needs assessment.

How do school professionals respond to the needs assessment? Does it spur conversation among individuals outside the planning team? Are the planning team members motivated to address the concerns and needs of their colleagues?

Cultivating an open organizational climate often begins with the administrators. It is nearly impossible to create a more open organizational climate if administrators do not seek feedback from the bottom up, or if they are not open to suggestions for improving educational services. When administrators actively participate on the planning team, they send a clear message—administration is interested in the concerns raised by front-line interventionists.

However, the responsibility for an open system does not lie exclusively with administrators. All school professionals contribute to a sense of openness or closeness. There is an entire field of study devoted to modifying organizational climates. Although we cannot do justice to the topic here, we can make a few recommendations for improving the organizational climate of a school system that is not yet sufficiently open to the idea of change.

Moving organizational climate toward acceptance of systemic change begins with the planning team. Take the time to assess the value that each planning team member places on transitioning from existing educational services to research-supported treatments. The team must be able to openly discuss resistance to change and work collaboratively to problem-solve strategies before it can address barriers outside the group.

We have already identified a number of reasons why school professionals may be resistant to making systemic changes to their schools. You can begin

improving the organizational climate by acknowledging that these reasons {a} are often very legitimate and {b} may be motivated by a desire to provide the best educational services available (e.g., a teacher who is concerned that teaching a self-management system to a student will take time away from teaching that student other new skills). Without recognizing the very real challenges school professionals face in their efforts to improve services for their students, you will not be able to have an open dialogue about how to develop a sustainable plan.

In addition to encouraging open dialogue about the potential barriers to implementing Established Treatments, and developing solutions to those barriers, there are a number of other ways to improve the organizational climate. So many school professionals are truly dedicated to helping their students reach their greatest potential. However, even the most committed educators can become worn down by daily demands. You may sometimes need to remind one another why you entered this profession. You can often reduce barriers to producing systemic change by simply asking each other to remember that you *will* improve student outcomes by using treatments that have evidence of effectiveness.

Finally, think of the entire school staff as a team. This will allow you to adopt

strategies that promote effective team-building.

**According to Webber and Scheuermann (2008), the following strategies encourage effective communication:**

- ▶ Listen well.
- ▶ Speak in a lively way, fluently, and with confidence.
- ▶ Use the language of feelings and positive one-liners.
- ▶ Use self-disclosure to help build relationships and keep communication lines open.
- ▶ Interpret behavior and use body language to enhance your message.
- ▶ Express open-mindedness.
- ▶ Give constructive feedback.
- ▶ Genuinely reinforce people when they do what you asked.

**Webber and Scheuermann (2008) also advise against the following communication strategies:**

- ▶ Being overly punitive
- ▶ Displays of impatience
- ▶ Expression of over-concern
- ▶ Arguing
- ▶ Ridiculing or belittling
- ▶ Making false promises
- ▶ Rejecting the individual



## Step 3: Evaluating Outcomes

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“If you can not measure it, you can not improve it.”

–Lord Kelvin

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Before the planning team develops a training plan, you should establish your intended goals. Why are you developing the capacity to implement the new Established Treatment? This process should involve evaluating changes for students and for the entire school organization.

### Evaluating Outcomes for Students

The reason to go through all the effort of producing systemic changes is to help students reach their potential. The planning team members should develop a process for evaluating whether student outcomes actually improve as a result of implementing the new treatments. Strategies for evaluating student outcomes are covered in depth in Chapter 3. Here we will merely point out that measuring change requires operationally defining your intended outcomes. The target goals should be defined in a specific, observable, and measurable form. In addition, systematic application of single-subject research design will be necessary to determine if the intervention is effective with given students.

These strategies can be used to determine if a given student improves once an intervention has been put into place. In addition to building systemic capacity for implementing effective interventions, the planning team should develop systemic capacity for evaluating student outcomes. Student outcomes must be measured individually, and decisions about treatment continuation or modification should be made on a case-by-case basis. However, the planning team should aggregate the results across students to determine if an intervention is producing improvements for students with ASD throughout the school.

When student outcomes are not favorable, one of the first questions you should ask is, “Are these interventions being implemented with a high degree of accuracy?” This question is explored below.

## Evaluating Outcomes for the School Organization

One of the reasons you implement system-wide changes is to enable educators to provide Established Treatments with a high degree of procedural accuracy. Procedural accuracy is also known as treatment integrity, treatment fidelity, or procedural fidelity. No matter what term you use, the goal is to determine the extent to which you are correctly implementing an intervention. There are several reasons to assess procedural accuracy.

First, if school staff deviate from the way an intervention is supposed to be implemented, they are no longer using the agreed-upon treatment. Professionals sometimes feel they should modify a treatment based on what is convenient, what seems reasonable given the available resources, or for a variety of other reasons.

It's helpful to ask ourselves, "Would I feel comfortable if my healthcare provider modified a necessary medical procedure based on convenience or availability of resources?" Most of us would not feel comfortable with the healthcare system adjusting the dialysis machine or the chemical composition of chemotherapy treatments for the reasons stated above. Similarly, most parents don't feel very comfortable if educators make a decision to modify an Established Treatment—even if the motivations are pure.

Second, the school made the decision to build capacity for implementing research-supported treatments for a reason—there is evidence that they work! Is there any evidence that the modified strategy works just as well? If not, it is generally best not to make modifications to the treatment. This is not to say that modification can never be considered. Should modifications to a treatment be needed, consider the suggestions in "Accommodations" in the upcoming Sustainability section.


## Developing Guidelines/ Manuals

Some Established Treatments have treatment guidelines or manuals commercially available; others do not. The planning team must develop treatment guidelines or manuals that provide instruction to all of the professionals in the school system on how to deliver the treatment.

Treatment guidelines or manuals should clearly explain the procedures that will be used, and they should do so in accessible terms. Procedures should be broken down into component parts so that {a} educators can implement the intervention and {b} another school professional can assess the extent to which the procedures are being accurately implemented. Ideally, the treatment is supplemented with scripts and/or video. The procedures may include practical examples of situations front-line professionals are likely to face.

These guidelines or manuals should clearly outline the materials needed to implement the intervention. They should also identify the roles and responsibilities of all front-line interventionists.

As noted previously, educators should make every effort to implement an intervention exactly as it was put into practice in the studies that support its use. However, we have also acknowledged that individual modification may be necessary on rare occasions. You should anticipate permissible modifications of the procedures outlined in the guidelines or manuals. You should also develop a plan to address the need for further modifications that were not anticipated. For further details, see “Accommodations” in the upcoming Sustainability section.



The planning team should develop a strategy for evaluating procedural accuracy. The goal of evaluating procedural accuracy is to improve performance (Fixsen et al., 2005).

Procedural accuracy assessments involve breaking down an intervention into its component parts. A list of activities that are required for accurate implementation is then generated. Treatment integrity checklists can be completed as self-assessments (e.g., the teacher records his own implementation behavior) or by another professional (e.g., the school psychologist records the teacher's implementation).

You can find some treatment integrity checklists in books (Leaf & McEachin, 1999) or on websites ([www.autisminternetmodules.org/user\\_mod.php](http://www.autisminternetmodules.org/user_mod.php)); please note that you must sign in before you can access the modules which contain implementation checklists. However, these treatment integrity checklists may not reflect the way your school will be adopting an intervention. These tools are a useful starting point, but internal

collaboration with ongoing support from consultants is recommended (Sanetti & Kratochwill, 2009).

All professionals will deviate from the way they are supposed to implement an intervention from time to time. None of us is perfect. Anyone who has ever implemented an intervention has drifted away from the way the treatment is supposed to be implemented—even when they are giving it their best effort. That's one of the reasons why treatment integrity protocols are important. In addition to developing treatment integrity protocols, schools can also improve procedural accuracy by regularly reviewing the guidelines or manuals developed by the planning team (as discussed on the previous page).

Development of treatment integrity checklists and treatment guidelines or manuals often occurs simultaneously with training (see Step 4). That is because it is hard to develop these tools with the level of specificity required to answer all treatment-related questions until you have sufficient training.

## Step 4: Developing a Training Plan

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“It’s all to do with training: you can do a lot if you’re properly trained.”

– Elizabeth II


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When a school system first determines that it must address capacity issues to implement interventions, training is often the first step considered. Hopefully, you can now see that a great deal of work must occur *before* a training plan is developed. While all these steps (previously described) are important and necessary, they do not in any way minimize the need for a complete training plan, which is crucial for success. The training plan should include two phases: {a} obtaining initial training and {b} providing coaching.

### Obtaining Initial Training

Unless members of the school staff have expertise in a particular treatment (e.g., they have completed certification in the intervention, received extensive training in graduate school, etc.), the planning team should arrange for additional training through outside consultants or specialists. These professionals should be able to clearly identify the level of training necessary for the school to produce the desired systemic changes. More complex interventions require more extensive training. Less complex interventions will require less training time, but will still require a great deal of attention to detail.

The literature on the training of adult learners tells us that simply engaging an outside consultant to talk to the staff about a treatment will not result in the level of proficiency needed—even if they provide a good deal of detail. Adults benefit from direct training, and this should be a component of every training plan. Hands-on training is essential.



Initial training may require multiple sessions. For example, some trainers will progressively introduce new and more complicated strategies only after front-line professionals have practiced skills learned in the earlier phases of training in the actual school setting.

Developing a plan for initial training may be easier for some interventions than for others. For example, if you are interested in Pivotal Response Training, a quick web search leads you to the Koegel Autism Center at the University of California—Santa Barbara. Much of the information you need about training can be accessed on this website. You can find training materials, video clips, and the PRT certification process. In contrast, there is no single source for joint attention training. You may need to begin by identifying a list of professionals with experience training school staff to use behavioral strategies. You can then contact these individuals to determine their expertise in training school staff or parents on joint attention strategies.

## Coaching

If only we could develop capacity to accurately implement effective interventions after attending a one- or two-day workshop! Unfortunately, the adult learner literature suggests this is unlikely. Didactic training alone is insufficient if the goal is to develop a high degree of mastery in educational settings (Fixsen et al., 2005). More experiential learning with ongoing feedback is necessary.

Coaching refers to the availability of an expert to provide on-site feedback based on real-world application of a new treatment. The coach assesses the front-line interventionist's use of the treatment in practice, then provides feedback and support. As noted previously, learning to implement new interventions can be exhausting. It requires significant time and effort, and may be emotionally draining. Good coaches provide more than constructive feedback; they also support the front-line interventionist!

### Developing Timelines

Developing a plan to produce system-wide improvements in school services cannot happen overnight. In addition to developing a plan to {a} address barriers, {b} measure intended outcomes, {c} produce a procedural guideline, and {d} establish a training plan, the planning team must produce a timeline for developing the capacity to implement Established Treatments. Each step of the process should be clearly tied to an expected deadline. Without a timeline, most training plans will either be unnecessarily delayed or rushed to completion without sufficient consideration given to accurately completing each step.

## Step 5: Sustainability

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“Sustainability requires cooperation.”

–Tom Seager

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The planning team’s responsibilities do not end once they have developed a strategy for building capacity. The process we have described is time and labor intensive. However, it will not produce the needed outcomes for students with ASD if efforts are not made to sustain these system-wide changes.

We have already noted the ongoing need for training. The planning team must either make a long-term commitment to work to sustain these changes, or develop a second “sustainability committee” dedicated to this purpose.



### The sustainability committee must:

- Identify ongoing training needs. Even though educators have received initial training and coaching support, the training plan should include “booster” training sessions. This will increase the likelihood that school staff will implement interventions with a high degree of procedural accuracy.
- Identify resources required to address ongoing training needs and maintain a high degree of procedural accuracy in the implementation of the intervention. The process of identifying necessary resources may evolve over time, and the sustainability committee must establish a system for evaluating ongoing needs. It is not unusual to discover that additional resources are necessary once a treatment is actually put in place.
- Identify new barriers to treatment implementation. The sustainability committee must also determine if existing barriers are being addressed. Barriers may emerge in surprising ways. Sometimes, people who like the idea of producing change in the abstract begin resisting when the efforts required to improve service delivery impact their daily activities.
- Ensure that changes have resulted in positive outcomes for the students.
- Determine how to manage requests to deviate from the procedures outlined in the procedural guidelines/manuals. The sustainability committee must have the technical skills to either {a} ensure that procedural modifications that were not anticipated are later addressed in a manner that is consistent with the identified treatment or {b} identify when outside consultation is necessary.

Ongoing leadership paired with sustained ownership of the systemic changes are necessary to meet the long-term goal of providing better educational services to all students (Adelman & Taylor, 1997).



## Accommodations

In almost all cases, a treatment can be implemented with individual students using exactly the same procedures which were employed in the research that demonstrated the treatment was effective. However, this does not mean that accommodations should never be made.

As noted in Chapter 3, an educator may implement an intervention that does not produce favorable results. If procedural accuracy has been calculated and the intervention has been implemented with a high degree of accuracy (e.g., greater than 80%), it becomes clear that something must be changed. In some cases, a different treatment may be selected. Or, school professionals may identify modifications to the treatment that should be considered based on their professional judgment and/or parental input.

In other cases, modifications must be made based on factors that are unique to the child. For example, modifications may be required for a child with physical limitations.

The planning team should anticipate reasons for which accommodations may be necessary and develop a plan for addressing these accommodations. As noted previously, the manual or guideline developed for each intervention should address acceptable deviations and the exact conditions under which these accommodations should be considered.

A team of school professionals with expertise in the initial intervention and/or the proposed accommodation can be assembled. The team can review the proposed accommodation and then offer support to the staff implementing the modified treatment. The data-based approach advocated in Chapter 3 should then be applied to the modified treatment. In this way, an ineffective intervention will not be maintained and a strong rationale is provided for sustaining an effective modification.



## Unique Considerations

Each school system is unique. For example, in some parts of the country, a single school may provide services for students of all age groups in the region who have been diagnosed with ASD. In a different part of the country, a school may be one of dozens serving students in a restricted age group (e.g., elementary school).

Each of these schools may need to adapt the capacity-building strategies identified in this chapter, based on their unique needs. For example, a large school district may build capacity across multiple schools simultaneously. In this case, it may be necessary to establish an internal planning team that sends representatives to a larger district-wide planning team. This school's planning team will need to collaborate with the district-wide planning team throughout the capacity-building process. We encourage all planning teams to identify distinctive factors and unique challenges they may face.

We hope the capacity-building example that follows clarifies the ways a school system can meet the unique needs of its constituents while building the capacity to implement interventions that work!

## Case Study: Developing Capacity— Elizabeth Public School District

Systemic changes have been documented in educational systems using the proposed methods outlined in this chapter. Many of these methods were applied in the Elizabeth Public Schools (EPS) system to improve service delivery for students with ASD (Hernandez, 2008).


EPS had been sending its most challenging students with ASD to out-of-district placement facilities. The school system made major modifications to the way it served students on the autism spectrum starting in 2004.

### **EPS underwent this process in four phases:**

- 4.** Needs Identification (November 2004 – May 2005)
- 5.** Development (May 2005 – August 2005)
- 6.** Implementation (September 2005 – August 2006)
- 7.** Growth (September 2006 – December 2006)

During the Needs Identification phase, school personnel reached the conclusion that developing an ASD model classroom would be a viable option. This phase was strongly influenced by the school system's recognition that it may not be providing the most appropriate program to all students within the system and that effective treatment options could be developed. The creation of a district behaviorist position increased resources and identified a vehicle for regular input from staff regarding student needs.

In the Development phase, the school system identified a strategy for developing a model classroom. This process included everything from budget and educational cost considerations to evaluating staff willingness to participate in the new classroom. The



school system also addressed the need to establish clear training procedures. Training sessions included teachers, speech-language pathologists, Child Study Team members and administrators. A plan was established to develop capacity beyond the model classroom and to include educators in different classrooms. This allowed the team to focus not only on the immediate needs of students in its care, but to plan for transitioning out of the model classroom and providing services to students with different needs.

The Implementation phase focused on the challenging realities of implementing a complicated treatment program. As a result of good planning earlier in the process, a consultation system was available to front-line interventionists. Not only did these consultants provide ongoing training, but they also helped educators better address the concerns of parents. Cultural awareness of staff was supported during this phase because more than half of the students were from homes in which English was not the primary language. Case managers met with staff and built a sense of solidarity as problems were identified and solutions to barriers were addressed. During this phase, the school system also recognized the need to plan for further growth. Staff were trained in data collection procedures that fit smoothly into the daily activities of the classroom. Procedural accuracy was emphasized in a supportive way.

In the Growth phase, additional classrooms were developed. Efforts were made to continue supporting staff, being responsive to family needs, maintaining a high degree of procedural accuracy, and recognizing the needs of individuals with ASD in the district.

The staff identified and overcame a large number of barriers that could have delayed or derailed their plans to implement a research-supported treatment program. By establishing a collaborative tone, staff continued to address those barriers as effectively as possible. Although new challenges will continue to present themselves, the school system accomplished systemic changes to support students with ASD.



## Final Considerations

You have learned that evidence-based practice requires the integration of research findings with {a} professional judgment and data-based clinical decision making, {b} the values and preferences of families, including the student with ASD, and {c} developing capacity to implement interventions with a high degree of integrity. Even when everyone agrees that a given treatment is appropriate, we are not engaging in evidence-based practice unless we can implement an intervention accurately.

Building capacity is a complicated process, and it's not easy to accurately implement Established Treatments. When necessary, we can build capacity to implement effective interventions one child at a time. After all, we do have an obligation to use research-supported treatments for each and every student with ASD we serve. Given the reality of an ever-growing number of students with ASD, approaching our need to provide treatments that work on a large-scale (systemic) basis is likely to be the most efficient strategy.

School systems will be best served by establishing a strong team to plan for system-wide improvements in service delivery. The team must take a systemic approach that considers the needs of all parties involved. It must address barriers that result from staffing concerns, and respond to the need for appropriate resources. The team must also establish clear procedural guidelines, along with a plan to sustain improvements.

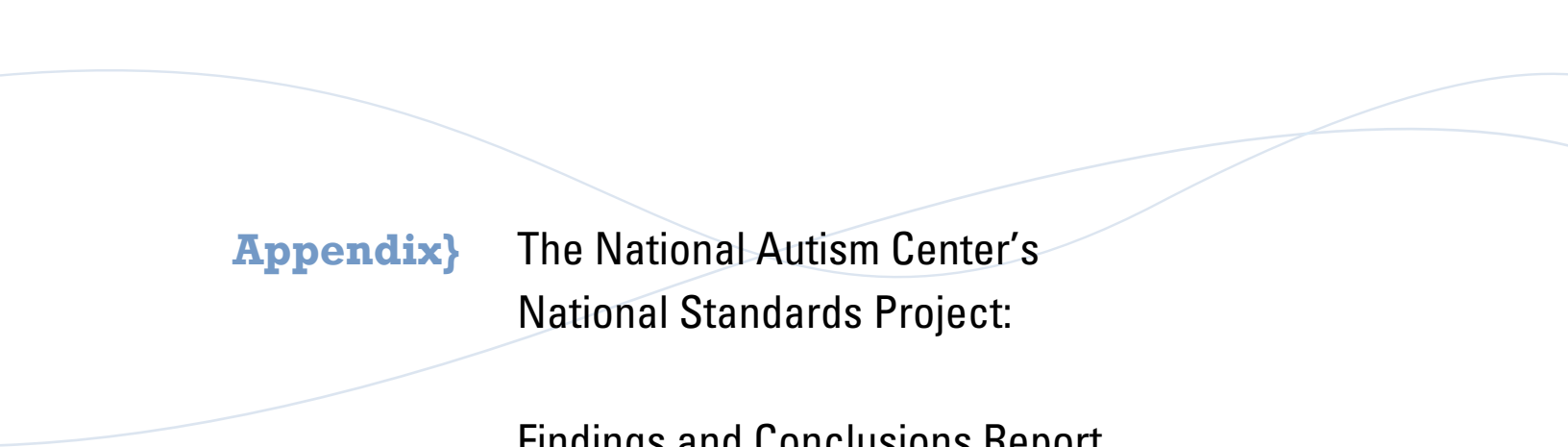
Systemic efforts to improve services for students on the autism spectrum are possible—as demonstrated by the Elizabeth Public School District of New Jersey!

## Recommended Readings}

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**Appendix}** The National Autism Center's  
National Standards Project:

Findings and Conclusions Report

This is the full text of the *Findings and Conclusions* report which has been independently distributed in this exact format.

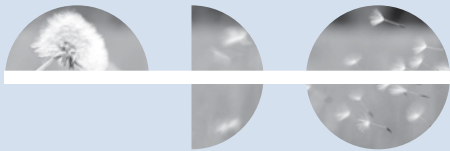




The National Autism Center's

# National Standards Project

## Findings and Conclusions



ADDRESSING THE NEED FOR EVIDENCE-  
BASED PRACTICE GUIDELINES FOR  
AUTISM SPECTRUM DISORDERS





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41 Pacella Park Drive  
Randolph, Massachusetts 02368

We have endeavored to build consensus among experts from diverse fields of study and theoretical orientation. We collaboratively determined the strategies used to evaluate the literature on the treatment of Autism Spectrum Disorders. In addition, we jointly determined the intended use of this document. We used a systematic process to provide all of our experts multiple opportunities to provide feedback on both the process and the document. Given the diversity of perspectives held by our experts, the information contained in this report does not necessarily reflect the unique views of each of its contributors on every point. We are pleased with the spirit of collaboration these experts brought to this process.



## IN MEMORY OF EDWARD G. CARR, PH.D., BCBA

*This report is dedicated to the memory of Dr. Ted Carr, an internationally recognized leader in the treatment of Autism Spectrum Disorders and in the field of Positive Behavior Supports.*

*From the outset, Ted was a major contributor to the National Standards Project. He played a pivotal role in shaping the methodology used in the Project. Ted understood that the value of the National Standards Project was based not only on the scientific validity of its design and implementation, but also on its social validity within the broader community. We are grateful to Ted for his insightful input, and his persistent focus on ensuring that this document be useful to families, educators, and service providers.*

*Throughout his career, Ted often led the charge for the intelligent care and compassionate and respectful treatment of individuals with Autism Spectrum Disorders and other developmental disabilities. We at the National Autism Center, along with countless organizations and professionals throughout the world, will miss him and keenly feel his loss.*

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## Acknowledgments

There are many challenges in undertaking a project of this nature. A series of complex decisions must be made over the course of several years that influence the usefulness of the final document. I would like to take the opportunity to thank the extraordinary number of professionals, family members, and organizations that have made this task easier.

I have had the good fortune to receive feedback from family members and individuals on the autism spectrum at the numerous conferences at which I have discussed the National Standards Project. Your input has influenced both the process we have used and this final document. I hope you continue to provide us feedback as we develop future editions of the National Standards Project. I have also received feedback at these conferences from professionals representing different fields of expertise and theoretical orientations. These professionals grapple with the very complicated process of providing best practices in homes, schools, and communities. Thank you for your assistance and your sustained input to the National Standards Project.

I am also grateful to the professionals and lay members of the autism community who provided very detailed feedback at various stages of this project. It would be hard to overstate the importance of your contributions. Your disparate views aided in the development of the review process and the completion of this document. Many of you are identified in our contributors section. I appreciate the consistent support of our expert panelists and conceptual reviewers who contributed tirelessly throughout this process. The input of families and professionals was also essential to the development of this project.

The National Standards Project could not have been completed without an important group of organizations and individuals. We appreciate both their willingness to underwrite the costs associated with the project and their consistent neutrality regarding the outcomes reported in this document. May Institute has supported the National Standards Project from its inception. Most costs associated with the first plenary session which began the development of this project were provided by the Autism Education Network (AEN). Without the support of Michelle Waterman and Janet Lishman of AEN, the early development of this project would have been far more challenging. Additional costs for the project were underwritten by the California Department of Developmental Services. We also appreciate the support and feedback we received from the Oversight and Advisory Committees through the California Department of Developmental Services and the professionals involved in the "Autism Spectrum Disorders: Guidelines for Effective Interventions" document that will be available soon.



Susan M. Wilczynski, Ph.D., BCBA

Executive Director, National Autism Center

Chair, National Standards Project

## Contributors

### Pilot Teams

#### Team 1

Gina Green, Ph.D., BCBA-D

Joseph N. Ricciardi, Psy.D., ABPP, BCBA

#### Team 2

Brian A. Boyd, Ph.D.

Kara Anne Hume, Ph.D.

Mara V. Ladd, Ph.D.

Samuel L. Odom, Ph.D.

Hanna C. Rue, Ph.D.

### Research Assistants

Lauren E. Christian, M.A.

Jesse Logue, B.A.

### Document Commentators

Jennifer D. Bass, Psy.D.

Bridget Cannon-Hale, M.S.W.

Nancy DeFilippis, B.A.

Natalie DeNardo, B.A.

Marcia Eichelbeger, B.S.

Stefanie Fillers, B.A., BCABA

Mary Elisabeth Hannah, M.S.Ed., BCBA

Kerry Hayes, B.A.

Deborah Lacey

Kelli Leahy, B.A.

Linda Lotspeich, M.D.

Dana Pellitteri, B.A.

Nicole Prindeville, B.A.

Hanna C. Rue, Ph.D.

Annette Wragge, M.Ed.

*We also thank a number of families who provided input but did not wish to have their names made public.*

### Computer Consultant

Jeffrey K. Oresik, M.S.

### Editors

Heidi A. Howard, M.P.A.

Patricia Ladew, B.S.

Eileen G. Pollack, M.A.

### Graphic Designer

Juanita Class

### Statistical Consultant

Tammy Greer, Ph.D.

### Advisors

Carl J. Dunst, Ph.D.

Dean L. Fixsen, Ph.D.

Gina Green, Ph.D., BCBA-D

Catherine E. Lord, Ph.D.

Dennis C. Russo, Ph.D., ABPP, ABPP

### Expert Panelists

Susan M. Wilczynski, Ph.D., BCBA (*Chair*)

Jane I. Carlson, Ph.D., BCBA

Edward G. Carr, Ph.D., BCBA

Marjorie H. Charlop, Ph.D.

Glen Dunlap, Ph.D.

Gina Green, Ph.D., BCBA-D

Alan E. Harchik, Ph.D., BCBA-D

Robert H. Horner, Ph.D.

Ronald Huff, Ph.D.

Lynn Kern Koegel, Ph.D., CCC-SLP

Robert L. Koegel, Ph.D.

Ethan S. Long, Ph.D., BCBA-D

Stephen C. Luce, Ph.D., BCBA-D

James K. Luiselli, Ed.D., ABPP, BCBA-D

Samuel L. Odom, Ph.D.

Cathy L. Pratt, Ph.D.

Robert F. Putnam, Ph.D., BCBA

Joseph N. Ricciardi, Psy.D., ABPP, BCBA

Raymond G. Romanczyk, Ph.D., BCBA-D

Ilene S. Schwartz, Ph.D., BCBA

Tristram H. Smith, Ph.D.

Phillip S. Strain, Ph.D.

Bridget A. Taylor, Psy.D., BCBA

Susan F. Thibadeau, Ph.D., BCBA-D

Tania M. Trembl, M.Ed., BCBA

### Conceptual Model Reviewers

Brian A. Boyd, Ph.D.

Anthony J. Cuvo, Ph.D.

Ronnie Detrich, Ph.D., BCBA

Wayne W. Fisher, Ph.D.

Lauren Franke, Psy.D., CCC-SP

William Frea, Ph.D.

Lynne Gregory, Ph.D.

Kara Anne Hume, Ph.D.

Penelope K. Knapp, M.D.

John R. Lutzker, Ph.D.

David McIntosh, Ph.D.

Gary Mesibov, Ph.D.

Patricia A. Prelock, Ph.D., CCC-SLP

Sally J. Rogers, Ph.D.

Mark D. Shriver, Ph.D.

Brenda Smith Myles, Ph.D.

Coleen R. Sparkman, M.A., CCC-SLP

Aubyn C. Stahmer, Ph.D., BCBA-D

Pamela J. Wolfberg, Ph.D.

John G. Youngbauer, Ph.D.

---

## Article Reviewers

Amanda N. Adams, Ph.D., BCBA  
 Amanda K. Albertson, M.A.  
 Keith D. Allen, Ph.D., BCBA  
 Angela M. Arnold-Seritepe, Ph.D.  
 Judah B. Axe, Ph.D., BCBA  
 Jennifer D. Bass, Psy.D.  
 Barbara Becker-Cottrill, Ed.D.  
 Stacy Lynn Bliss Fudge, Ph.D.  
 Brian A. Boyd, Ph.D.  
 James E. Carr, Ph.D., BCBA  
 Stephanie Chopko, M.A.  
 Costanza Colombi, Ph.D.  
 Shannon E. Crozier, Ph.D., BCBA  
 Elizabeth Delpizzo-Cheng, Ph.D., BCBA, NCSP  
 Ronnie Detrich, Ph.D., BCBA  
 Melanie D. Dubard, Ph.D., BCBA  
 Stephen E. Eversole, Ed.D., BCBA-D  
 Adam B. Feinberg, Ph.D., BCBA-D  
 Laura F. Fisher, Psy.D.  
 Wayne W. Fisher, Ph.D.  
 William Frea, Ph.D.  
 William A. Galbraith, Ph.D., BCBA  
 Katherine T. Gilligan, M.S., BCBA  
 Gina Green, Ph.D., BCBA-D  
 Tracy D. Guiou, Ph.D., BCABA  
 Neelima Gutti, B.S.  
 Lisa M. Hagermoser Sanetti, Ph.D.  
 Alan E. Harchik, Ph.D., BCBA-D  
 Patrick F. Heick, Ph.D., BCBA-D  
 Thomas S. Higbee, Ph.D., BCBA  
 Kara Anne Hume, Ph.D.  
 Maree Hunt, Ph.D.  
 Melissa D. Hunter, Ph.D.  
 Heather Jennett, Ph.D., BCBA  
 Kristen N. Johnson-Gros, Ph.D., NCSP  
 Debra M. Kamps, Ph.D.  
 Amanda M. Karsten, M.A.  
 Shannon Kay, Ph.D., BCBA  
 Courtney L. Keegan, M.Ed., BCBA  
 Penelope K. Knapp, M.D.  
 Daniel J. Krenzer, M.S.  
 Mara V. Ladd, Ph.D.  
 Courtney M. LeClair, M.A.  
 Celia Lie, Ph.D.  
 Ethan S. Long, Ph.D., BCBA-D  
 James K. Luiselli, Ed.D., ABPP, BCBA-D  
 Elizabeth A. Lyons, Ph.D., BCBA  
 Gwen Martin, Ph.D., BCBA  
 Britney N. Mauldin, M.S.  
 Judy A. McCarty, Ph.D., NCSP, BCBA  
 J. Christopher McGinnis, Ph.D., NCSP, BCBA  
 Christine McGrath, Ph.D., NCSP  
 Victoria Moore, Psy.D.  
 Oliver C. Mudford, Ph.D., BCBA  
 Dipti Mudgal, Ph.D.  
 Samuel L. Odom, Ph.D.  
 Gary M. Pace, Ph.D., BCBA-D  
 Heather Peters, Ph.D.  
 Marisa Petrucelli, Psy.D.  
 Katrina J. Phillips, Ph.D., BCBA  
 Patricia A. Prelock, Ph.D., CCC-SLP  
 Jane E. Prochnow, Ed.D.  
 Robert F. Putnam, Ph.D., BCBA  
 Sarah G. Reck, B.A.  
 Henry S. Roane, Ph.D., BCBA  
 Lise Roll-Peterson, Ph.D., BCBA  
 Hannah C. Rue, Ph.D.  
 Dennis C. Russo, Ph.D., ABPP, ABPP  
 Jana M. Sarno, M.A.  
 Stephanie L. Schmitz, Ed.S.  
 Mark D. Shriver, Ph.D.  
 Jennifer M. Silber, Ph.D., BCBA  
 Torri Smith Tejral, M.S., BCBA  
 Tristram H. Smith, Ph.D.  
 Debborah E. Smyth, Ph.D.  
 Aubyn C. Stahmer, Ph.D.  
 CarrieAnne St. Armand, M.B.A., M.S., BCBA  
 Ravit R. Stein, Ph.D.  
 Catherine E. Sumpster, Ph.D.  
 Bridget A. Taylor, Psy.D., BCBA  
 Susan F. Thibadeau, Ph.D., BCBA-D  
 Matthew J. Tincani, Ph.D.  
 Jennifer Wick, M.A.  
 Susan M. Wilczynski, Ph.D., BCBA  
 Pamela S. Wolfe, Ph.D.  
 April S. Worsdell, Ph.D., BCBA

# 1

## Introduction

### About the National Standards Project

The National Standards Project, a primary initiative of the National Autism Center, addresses the need for evidence-based practice guidelines for Autism Spectrum Disorders (ASD).

The National Standards Project seeks to:

- provide the strength of evidence supporting educational and behavioral treatments that target the core characteristics of these neurological disorders
- describe the age, diagnosis, and skills/behaviors targeted for improvement associated with treatment options
- identify the limitations of the current body of research on autism treatment
- offer recommendations for engaging in evidence-based practice for ASD

#### *Who will benefit from national standards?*

*We believe that parents, caregivers, educators, and service providers who must make complicated decisions about treatment selection will benefit from national standards.*



## About the National Autism Center

The National Autism Center is dedicated to serving children and adolescents with Autism Spectrum Disorders (ASD) by providing reliable information, promoting best practices, and offering comprehensive resources for families, practitioners, and communities.

An advocate for evidence-based treatment approaches, the National Autism Center identifies effective programming and shares practical information with families about how to respond to the challenges they face. The Center also conducts applied research as well as develops training and service models for practitioners. Finally, the Center works to shape public policy concerning ASD and its treatment through the development and dissemination of national standards of practice.

Guided by a Professional Advisory Board, the Center brings concerned constituents together to help individuals with Autism Spectrum Disorders and their families pursue a better quality of life.

# 2

## Overview of the National Standards Project

### What is the Purpose?

The National Standards Project serves three primary purposes:

- 1.** To identify the level of research support currently available for educational and behavioral interventions used with individuals (below 22 years of age)<sup>1</sup> with Autism Spectrum Disorders (ASD). These interventions address the core characteristics of these neurological disorders. Knowing levels of research support is an important component in selecting treatments that are appropriate for individuals on the autism spectrum.
- 2.** To help parents, caregivers, educators, and service providers understand how to integrate critical information in making treatment decisions. Specifically, evidence-based practice involves the integration of research findings with {a} professional judgment and data-based clinical decision-making, {b} values and preferences of families, and {c} assessing and improving the capacity of the system to implement the intervention with a high degree of accuracy.
- 3.** To identify limitations of the existing treatment research involving individuals with ASD.

We hope that the National Standards Project will help individuals with ASD, their families, caregivers, educators, and service providers to select treatments that support people on the autism spectrum in reaching their full potential.

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<sup>1</sup> For the purpose of this report, we use the phrase “individuals with Autism Spectrum Disorders” to refer to individuals on the autism spectrum who are under 22 years of age.

# What was the Process?

## Developing the Model

The National Standards Project began with the development of a model for evaluating the scientific literature involving the treatment of ASD by a working group consisting of Pilot Team 1 and outside consultation from methodologists<sup>2</sup>. The process for the initial development of the National Standards Project is outlined in Flowchart 1. We developed a model based on an examination of evidence-based practice guidelines from other health and psychology fields<sup>3</sup> as well as from 25 experts (see expert panel) attending planning sessions for the National Standards Project. This model was sent to the original experts as well as an additional 20 experts (see conceptual reviewers) who represent diverse fields of study and theoretical orientations. The model was modified based on their feedback and then served as the foundation for data collection procedures.

## Identifying the Research

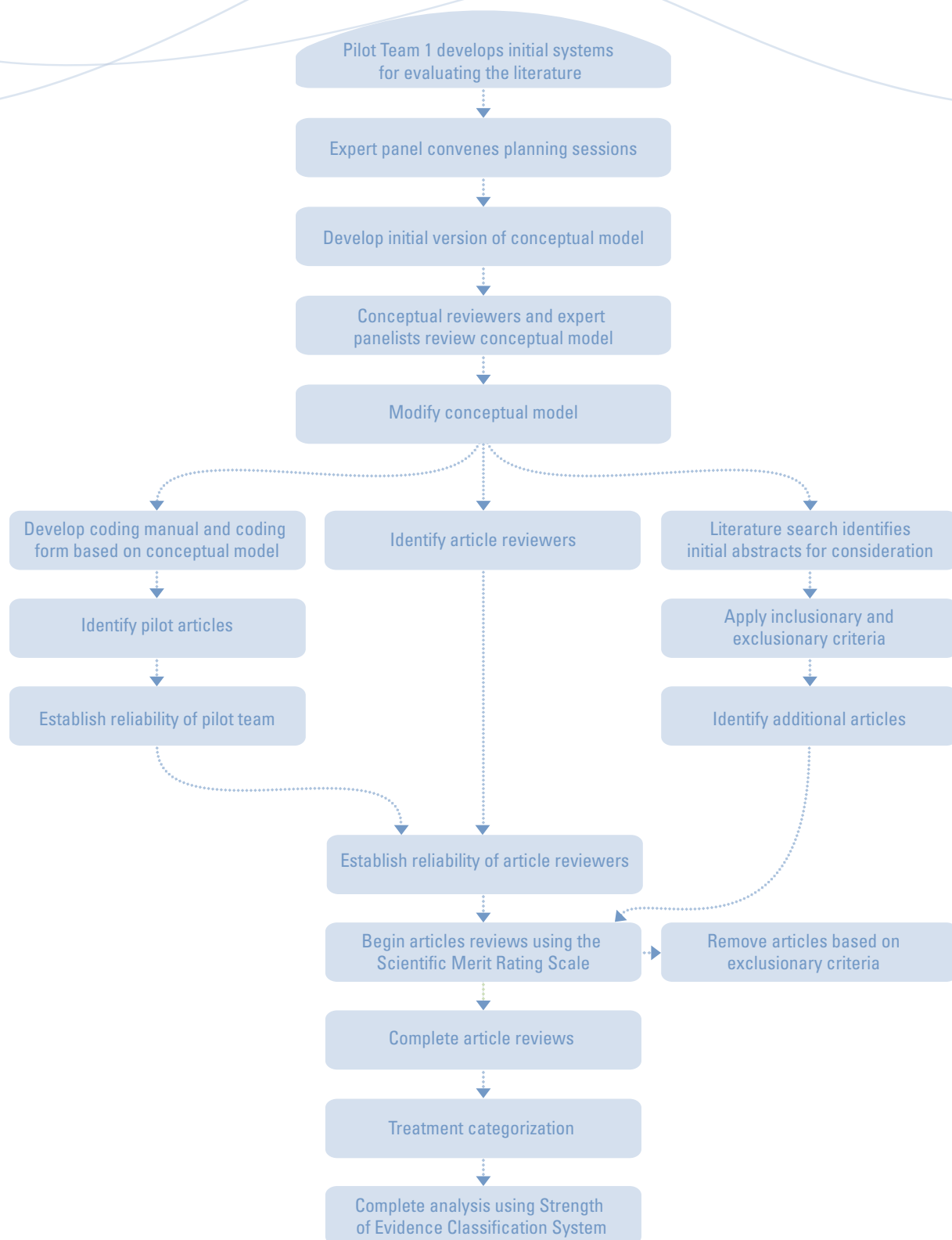
Prior to data collection, we identified the ASD treatment articles that should be included in our review. These treatments were generally designed to address the core features of these neurological disorders. A number of these studies also addressed the associated features of ASD. The studies were conducted in a wide variety of settings such as universities, university-based clinics, medical settings, and schools and were conducted by a broad range of professionals (e.g., psychologists, speech-language

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<sup>2</sup> The pilot team relied on the following sources: Sidman (1960); Johnston & Pennypacker (1993); Kazdin (1982; 1998); New York State Department of Health, Early Intervention Program (1999) and; Task Force on Promotion and Dissemination of Psychological Procedures (1995).

<sup>3</sup> These systems were developed based on an examination of previous evidence-based practice guidelines including the Agency for Healthcare Research and Quality (West, King, Carey, Lohr, McKoy et al., 2002), American Psychological Association Presidential Task Force on Evidence-Based Practice (2003), and the Task Force on Evidence-Based Interventions in School Psychology (APA, 2005). These were also based on an examination of publications about evidence-based practice by authors {a} Chambless, Baker, Baucom, Beutler, Calhoun, Crits-Christoph, et al., (1998) and {b} Horner, Carr, Halle, McGee, Odom, & Wolery (2005).

## Flowchart 1} Process of the Initial Development of the National Standards Project





pathologists, educators, occupational or physical therapists). Search engines produced a total of 6,463 abstracts for consideration; an additional 644 abstracts were identified by our experts, attendees to national autism conferences, and project participants who reviewed recent book chapters. These abstracts were compared against our inclusion/exclusion criteria (see Appendix 1). An additional 413 articles were removed by trained field reviewers (described below). We included 724 peer-reviewed articles in our final review. Because more than one study was published in several of these articles, a total of 775 research studies were reviewed and analyzed.

## Ensuring Reliability

To ensure a high degree of agreement (i.e., reliability) among reviewers, the coding of articles began with observer calibration. That is, a pilot team reviewed articles and made modifications to a coding manual until interobserver agreement reached an acceptable level (>80%). All field reviewers then received a copy of the coding manual, the coding form, and a pilot article to code. Field reviewers who reached an acceptable level of agreement (>80%) were invited to review articles for the National Standards Project.

## About the Scientific Merit Rating Scale

We developed the Scientific Merit Rating Scale as a means of objectively evaluating whether the methods used in each study were strong enough to determine whether or not a treatment was effective for participants on the autism spectrum. This information allows us to determine if the results are believable enough that we would expect similar results in other studies that used equal or better research methodologies.

We then applied each of the dimensions (listed below) included in the Scientific Merit Rating Scale in the same way to each article. This allowed us to consistently answer questions relevant to the scientific merit of each study specifically related to individuals with ASD. Table 1 briefly describes some of the questions answered with the Scientific Merit Rating Scale. (A detailed outline of the Scientific Merit Rating Scale is available in Appendix 2.)

### The five dimensions of the Scientific Merit Rating Scale include:

1. experimental rigor of the research design;
2. quality of the dependent variable;
3. evidence of treatment fidelity;
4. demonstration of participant ascertainment; and
5. generalization data collected.

**Table 1}** Examples of Questions Addressed with the Scientific Merit Rating Scale

**Rating}** Scores fall between 0 and 5 with higher scores representing higher indications of scientific merit specific to the ASD population

<b>Design:</b> <i>Two classes of research design were considered</i>		<b>Measurement of Dependent Variable:</b> <i>Two types of data were considered</i>		<b>Measurement of Independent Variable</b>	<b>Participant Ascertainment</b>	<b>Generalization of Tx Effect(s)</b>
<b>Group</b>	<b>Single-subject</b>	<b>Test, scale, checklist, etc.</b>	<b>Direct behavioral observation</b>			
Answers questions such as:	Answers questions such as:	Answers questions such as:	Answers questions such as:	Answers questions such as:	Answers questions such as:	Answers questions such as:
How many participants were included? How many groups were included? Were relevant data lost? What was the research design?	How many comparisons were made? How many data points were collected? How many participants were included? Were relevant data lost?	Was the protocol standardized? What are the psychometric properties? Were the evaluators blind and/or independent?	What type of measurement was used? Is there evidence of reliability? How much data were collected?	Is there evidence the treatment was implemented accurately? How much treatment fidelity data were collected? Is there evidence of reliability for treatment fidelity?	Who delivered the diagnosis? Was the diagnosis confirmed? Were psychometrically sound instruments used? Were DSM or ICD criteria used?	Were objective data collected? Were maintenance and/or generalization data collected?

Each category was weighted. Dimensions that have been consistently acknowledged as essential in research since the first studies were published were given stronger weights. Factors that have most recently been considered important were given lesser weights. The weights assigned were as follows: Research Design (.30) + Dependent Variable (.25) + Participant Ascertainment (.20) + Procedural Integrity (.15) + Generalization (.10).

## Treatment Effects Ratings

In addition, each study was examined to determine if the treatment effects were: {a} beneficial, {b} ineffective, {c} adverse, or {d} unknown.

- Beneficial is identified when there is sufficient evidence that we can be confident favorable outcomes resulted from the treatment.
- Unknown was identified when there was not enough information to allow us to confidently determine the treatment effects.

- Ineffective is identified when there is sufficient evidence that we can be confident favorable outcomes did not result from the treatment.
- Adverse is identified when there is sufficient evidence that the treatment was associated with harmful effects.

Appendix 3 outlines the criteria for treatment effects.

The reason separate scores are required to determine scientific merit and treatment effects is they tap into separate but equally important concerns related to each study. For example, a study could have a very strong research design (high scientific merit) but show that the treatment was actually ineffective. Decision-makers should be aware of a finding of this type.

Similarly, a study could have a relatively weak research design (lower scientific merit) but show that the treatment was effective. Scientists would not necessarily believe the treatment was actually effective in this case because the outcomes could be due to some factor other than the treatment (e.g., the passage of time, some unknown variable that was not accounted for in the study, etc.).

Once we coded all studies, we combined the results of the Scientific Merit Rating Scale and the Treatment Effects Ratings to identify the level of research support that is currently

available for each educational and behavioral intervention we examined. We identified 38 treatments<sup>4</sup>. The term “treatment” may represent either intervention strategies (i.e., therapeutic techniques that may be used in isolation) or intervention classes (i.e., a combination of different intervention strategies that have core characteristics in common). Whenever possible, we combined intervention strategies into treatment classes in order to lend clarity to the effectiveness of the treatment. When this was not possible, we reported results on isolated intervention strategies. The experts involved in the project provided feedback when reviewing earlier drafts of this report. That is, they were given the opportunity to provide input three times before the final 38 treatments were identified.

After we identified the treatments, we applied the Strength of Evidence Classification System criteria.

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<sup>4</sup> Reliability in the form of interobserver agreement was .92 for treatment categorization.

## Strength of Evidence Classification System

The Strength of Evidence Classification System can be used to determine how confident we can be about the effectiveness<sup>5</sup> of a treatment. Ratings reflect the level of quality, quantity, and consistency of research findings for each type of intervention. There are four categories in the Strength of Evidence Classification System.<sup>6</sup> Table 2 identifies the criteria associated with each of the ratings.

**These general guidelines can be used to interpret each of these categories:**

- **Established.** Sufficient evidence is available to confidently determine that a treatment produces favorable outcomes for individuals on the autism spectrum. That is, these treatments are established as effective.
- **Emerging.** Although one or more studies suggest that a treatment produces favorable outcomes for individuals with ASD, additional high quality studies must consistently show this outcome before we can draw firm conclusions about treatment effectiveness.
- **Unestablished.** There is little or no evidence to allow us to draw firm conclusions about treatment effectiveness with individuals with ASD. Additional research may show the treatment to be effective, ineffective, or harmful.
- **Ineffective/Harmful.** Sufficient evidence is available to determine that a treatment is ineffective or harmful for individuals on the autism spectrum.

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<sup>5</sup> Professionals often describe a treatment as “effective” when it has been shown to work in real world settings such as home, school, and community. For the purposes of this report, the word “effective” refers to studies conducted in real world, clinical, and research settings.

<sup>6</sup> The Strength of Evidence Classification System was modified to its current four-point format to ease interpretation of outcomes for the general public. Although the Strength of Evidence Classification System was modified from a six-point format, the interpretation of outcomes remains identical across formats. For example, all treatments that were previously identified as having sufficient evidence of effectiveness did not vary across the two systems.

**Table 2} Strength of Evidence Classification System**

<b>Established</b>	<b>Emerging</b>	<b>Unestablished</b>	<b>Ineffective/Harmful</b>
<p>Several<sup>a</sup> published, peer-reviewed studies</p> <ul style="list-style-type: none"> <li>• Scientific Merit Rating Scales scores of 3, 4, or 5</li> <li>• Beneficial treatment effects for a specific target</li> </ul> <p>These may be supplemented by studies with lower scores on the Scientific Merit Rating Scale.</p>	<p>Few<sup>b</sup> published, peer-reviewed studies</p> <ul style="list-style-type: none"> <li>• Scientific Merit Rating Scale scores of 2</li> <li>• Beneficial treatment effects reported for one dependent variable for a specific target</li> </ul> <p>These may be supplemented by studies with higher or lower scores on the Scientific Merit Rating Scale.</p>	<p>May or may not be based on research</p> <ul style="list-style-type: none"> <li>• Beneficial treatment effects reported based on very poorly controlled studies (scores of 0 or 1 on the Scientific Merit Rating Scale)</li> <li>• Claims based on testimonials, unverified clinical observations, opinions, or speculation</li> <li>• Ineffective, unknown, or adverse treatment effects reported based on poorly controlled studies</li> </ul>	<p>Several<sup>a</sup> published, peer-reviewed studies</p> <ul style="list-style-type: none"> <li>• Scientific Merit Rating Scales scores of 3</li> <li>• No beneficial treatment effects reported for one dependent measure for a specific target (Ineffective)</li> </ul> <p style="text-align: center;">OR</p> <ul style="list-style-type: none"> <li>• Adverse treatment effects reported for one dependent variable for a specific target (Harmful)</li> </ul> <p>Note: Ineffective treatments are indicated with an "I" and Harmful treatments are indicated with an "H"</p>
<p><sup>a</sup> Several is defined as 2 group design or 4 single-subject design studies with a minimum of 12 participants for which there are no conflicting results or at least 3 group design or 6 single-subject design studies with a minimum of 18 participants with no more than 1 study reporting conflicting results. Group and single-case design methodologies may be combined.</p> <p><sup>b</sup> Few is defined as a minimum of 1 group design study or 2 single-subject design studies with a minimum of 6 participants for which no conflicting results are reported.* Group and single-subject design methodologies may be combined.</p> <p>*Conflicting results are reported when a better or equally controlled study that is assigned a score of at least 3 reports either {a} ineffective treatment effects or {b} adverse treatment effects.</p>			

# 3

## Outcomes

### Established Treatments

We identified 11 treatments as Established (i.e., they were established as effective) for individuals with Autism Spectrum Disorders (ASD). Established Treatments are those for which several well-controlled studies have shown the intervention to produce beneficial effects. There is compelling scientific evidence to show these treatments are effective; however, even among Established Treatments, universal improvements cannot be expected to occur for all individuals on the autism spectrum.

The following interventions are Established Treatments:

- Antecedent Package
- Behavioral Package
- Comprehensive Behavioral Treatment for Young Children
- Joint Attention Intervention
- Modeling
- Naturalistic Teaching Strategies
- Peer Training Package
- Pivotal Response Treatment
- Schedules
- Self-management
- Story-based Intervention Package

Each of these treatments is defined below. Whenever possible, we provided examples of treatment strategies associated with each Established Treatment. These examples should also be considered Established Treatments for individuals with ASD. The number of studies conducted that contributed to this rating is listed in brackets after the treatment name.

## Established Treatments with definitions and examples:

- **Antecedent Package** {99 studies}. These interventions involve the modification of situational events that typically precede the occurrence of a target behavior. These alterations are made to increase the likelihood of success or reduce the likelihood of problems occurring. Treatments falling into this category reflect research representing the fields of applied behavior analysis (ABA), behavioral psychology, and positive behavior supports.

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Examples include but are not restricted to: behavior chain interruption (for increasing behaviors); behavioral momentum; choice; contriving motivational operations; cueing and prompting/prompt fading procedures; environmental enrichment; environmental modification of task demands, social comments, adult presence, intertrial interval, seating, familiarity with stimuli; errorless learning; errorless compliance; habit reversal; incorporating echolalia, special interests, thematic activities, or ritualistic/obsessional activities into tasks; maintenance interspersal; noncontingent access; noncontingent reinforcement; priming; stimulus variation; and time delay.

- **Behavioral Package** {231 studies}. These interventions are designed to reduce problem behavior and teach functional alternative behaviors or skills through the application of basic principles of behavior change. Treatments falling into this category reflect research representing the fields of applied behavior analysis, behavioral psychology, and positive behavior supports.

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Examples include but are not restricted to: behavioral sleep package; behavioral toilet training/dry bed training; chaining; contingency contracting; contingency mapping; delayed contingencies; differential reinforcement strategies; discrete trial teaching; functional communication training; generalization training; mand training; noncontingent escape with instructional fading; progressive relaxation; reinforcement; scheduled awakenings; shaping; stimulus-stimulus pairing with reinforcement; successive approximation; task analysis; and token economy.

Treatments involving a complex combination of behavioral procedures that may be listed elsewhere in this document are also included in the behavioral package category. Examples include but are not restricted to: choice + embedding + functional communication training + reinforcement; task interspersal with differential reinforcement; tokens + reinforcement + choice + contingent exercise + overcorrection; noncontingent reinforcement + differential reinforcement; modeling + contingency management; and schedules + reinforcement + redirection + response prevention. Studies targeting verbal operants also fall into this category.

● **Comprehensive Behavioral Treatment for Young Children** {22 studies}. This treatment reflects research from comprehensive treatment programs that involve a combination of applied behavior analytic procedures (e.g., discrete trial, incidental teaching, etc.) which are delivered to young children (generally under the age of 8). These treatments may be delivered in a variety of settings (e.g., home, self-contained classroom, inclusive classroom, community) and involve a low student-to-teacher ratio (e.g., 1:1). All of the studies falling into this category met the strict criteria of: {a} targeting the defining symptoms of ASD, {b} having treatment manuals, {c} providing treatment with a high degree of intensity, and {d} measuring the overall effectiveness of the program (i.e., studies that measure subcomponents of the program are listed elsewhere in this report).

These treatment programs may also be referred to as ABA programs or behavioral inclusive program and early intensive behavioral intervention.

● **Joint Attention Intervention** {6 studies}. These interventions involve building foundational skills involved in regulating the behaviors of others. Joint attention often involves teaching a child to respond to the nonverbal social bids of others or to initiate joint attention interactions.

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Examples include pointing to objects, showing items/activities to another person, and following eye gaze.

● **Modeling** {50 studies}. These interventions rely on an adult or peer providing a demonstration of the target behavior that should result in an imitation of the target behavior by the individual with ASD. Modeling can include simple and complex behaviors. This intervention is often combined with other strategies such as prompting and reinforcement.

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Examples include live modeling and video modeling.



### ● **Naturalistic Teaching Strategies**

{32 studies}. These interventions involve using primarily child-directed interactions to teach functional skills in the natural environment. These interventions often involve providing a stimulating environment, modeling how to play, encouraging conversation, providing choices and direct/natural reinforcers, and rewarding reasonable attempts.

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Examples of this type of approach include but are not limited to focused stimulation, incidental teaching, milieu teaching, embedded teaching, and responsive education and prelinguistic milieu teaching.

### ● **Peer Training Package** {33 studies}.

These interventions involve teaching children without disabilities strategies for facilitating play and social interactions with children on the autism spectrum. Peers may often include classmates or siblings. When both initiation training and peer training were components of treatment in a study, the study was coded as “peer training package.” These interventions may include components of other treatment packages (e.g., self-management for peers, prompting, reinforcement, etc.).

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Common names for intervention strategies include peer networks, circle of friends, buddy skills package, Integrated Play Groups™, peer initiation training, and peer-mediated social interactions.

### ● **Pivotal Response Treatment** {14 studies}. This treatment is also referred to as PRT, Pivotal Response Teaching, and Pivotal Response Training. PRT focuses on targeting “pivotal” behavioral areas—such as motivation to engage in social communication, self-initiation, self-management, and responsiveness to multiple cues, with the development of these areas having the goal of very widespread and fluently integrated collateral improvements. Key aspects of PRT intervention delivery also focus on parent involvement in the intervention delivery, and on intervention in the natural environment such as homes and schools with the goal of producing naturalized behavioral improvements.


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This treatment is an expansion of Natural Language Paradigm which is also included in this category.

### ● **Schedules** {12 studies}. These interventions involve the presentation of a task list that communicates a series of activities or steps required to complete a specific activity. Schedules are often supplemented by other interventions such as reinforcement.

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Schedules can take several forms including written words, pictures or photographs, or work stations.



● **Self-management** {21 studies}. These interventions involve promoting independence by teaching individuals with ASD to regulate their behavior by recording the occurrence/non-occurrence of the target behavior, and securing reinforcement for doing so. Initial skills development may involve other strategies and may include the task of setting one's own goals. In addition, reinforcement is a component of this intervention with the individual with ASD independently seeking and/or delivering reinforcers.

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Examples include the use of checklists (using checks, smiley/frowning faces), wrist counters, visual prompts, and tokens.

● **Story-based Intervention Package** {21 studies}. Treatments that involve a written description of the situations under which specific behaviors are expected to occur. Stories may be supplemented with additional components (e.g., prompting, reinforcement, discussion, etc.).

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Social Stories™ are the most well-known story-based interventions and they seek to answer the “who,” “what,” “when,” “where,” and “why” in order to improve perspective-taking.

The Established Treatments identified in this document arise from diverse theoretical orientations or fields of study.

However, certain trends emerged from an examination of these Established Treatments. Approximately two-thirds of the Established Treatments were developed exclusively from the behavioral literature (e.g., applied behavior analysis, behavioral psychology, and positive behavioral supports). Of the remaining one-third, 75% represent treatments for which research support comes predominantly from the behavioral literature.

Additional contributions were made from the non-behavioral literature emanating from the fields of speech-language pathology and special education. These researchers often gave strong emphasis to developmental considerations. Less than 10% (i.e.,

Story-based Intervention Package) of the total number of Established Treatments arose from the theory of mind perspective. Interestingly, even these interventions often included a behavioral component.

This pattern of findings suggests that treatments from the behavioral literature have the strongest research support at this time. Yet it is important to recognize that treatments based on alternative theories, in isolation or combined with behavioral interventions, should continue to be examined empirically. Further, it demonstrates that all treatment studies can be compared against a common methodological standard and show evidence of effectiveness. Despite the preponderance of evidence associated with the behavioral literature, it is important to acknowledge the important contributions non-behavioral approaches are

making at present, and to fund research examining both the behavioral and non-behavioral literature as we move forward.

## Detailed Summary of Established Treatments

Most treatments are not intended to address every treatment target (i.e., skills to be increased or behaviors to be decreased). Similarly, they may not be developed with the expectation that they will target every age or diagnostic group. For example, joint attention is a skill set that typically develops in very young children. Knowing this, we would expect to see most of the research on joint attention conducted with infants, toddlers, or preschool-aged children. In fact, this is exactly what our review shows. However, whenever a treatment could reasonably be effective for different treatment targets, age groups, or diagnostic groups, researchers should set as a goal to extend research into these different targets or groups.

Table 3 shows which Established Treatments have demonstrated favorable outcomes for each treatment target, age group, or diagnostic group. Although not all Established Treatments should be expected to apply to each of these areas, many of these interventions could be applied to a broader array of treatments. A brief summary follows.

### Treatment Targets

Established Treatments have demonstrated favorable outcomes for many treatment targets. See Appendix 4 for definitions for each of the treatment targets.

- Antecedent Package, Behavioral Package, and Comprehensive Behavioral Treatment for Young Children have demonstrated favorable outcomes with more than half of the skills that are often targeted to be increased (see Table 3 for examples).
- Behavioral Package has demonstrated favorable outcomes with three-quarters of the behaviors that are often targeted to decrease (see Table 3 for examples).
- Other Established Treatments have demonstrated favorable outcomes with a smaller range of treatment targets. In many cases, this provides a rich opportunity to extend research findings.

## Age Groups

Established Treatments have demonstrated favorable outcomes with many age groups.

- Behavioral Package has demonstrated favorable outcomes with all age groups.
- Antecedent Package, Comprehensive Behavioral Treatment for Young Children, Modeling, and Self-management have demonstrated favorable outcomes with two-thirds of all age groups.
- Naturalistic Teaching Strategies have demonstrated favorable outcomes with one-half of all age groups.
- Only one Established Treatment has been associated with favorable outcomes for the early adult age group. Further investigation is necessary for this age group.
- Other Established Treatments have demonstrated favorable outcomes with a small range of age groups. In many cases, this provides a rich opportunity to extend research findings.

## Diagnostic Groups

Established Treatments have demonstrated favorable outcomes with many diagnostic groups.

- Behavioral Package, Comprehensive Behavioral Treatment for Young Children, Joint Attention Intervention, Modeling, Naturalistic Teaching Strategies, and Peer Training Package have demonstrated favorable outcomes with most diagnostic groups.
- A few Established Treatments (i.e., Modeling and Story-based Intervention Package) have been associated with favorable outcomes for Asperger's Syndrome. Further investigation is necessary for this diagnostic group.
- Other Established Treatments have demonstrated favorable outcomes with a smaller range of diagnostic groups. In many cases, this provides a rich opportunity to extend research findings.

**Table 3}** Established Treatments with Favorable Outcomes Reported

<b>Skills Increased</b>				
<b>Academic</b>	<b>Communication</b>	<b>Higher Cognitive Functions</b>	<b>Interpersonal</b>	<b>Learning Readiness</b>
Behavioral Package	Antecedent Package Behavioral Package CBTYC Joint Attention Modeling NTS Peer Training PRT	CBTYC Modeling	Antecedent Package Behavioral Package CBTYC Joint Attention Modeling NTS Peer Training PRT Self-management Story-based	Antecedent Package Behavioral Package NTS
<b>Motor</b>	<b>Personal Responsibility</b>	<b>Placement</b>	<b>Play</b>	<b>Self-Regulation</b>
CBTYC	Antecedent Package Behavioral Package CBTYC Modeling	CBTYC	Antecedent Package Behavioral Package CBTYC Modeling NTS Peer Training PRT	Antecedent Package Behavioral Package Schedules Self-management Story-based

<b>Behaviors Decreased</b>			
<b>Problem Behaviors</b>	<b>Restricted, Repetitive, Nonfunctional Behavior, Interests, or Activities</b>	<b>Sensory/Emotional Regulation</b>	<b>General Symptoms</b>
Antecedent Package Behavioral Package CBTYC Modeling Self-management	Behavioral Package Peer Training	Antecedent Package Behavioral Package Modeling	CBTYC

<b>Ages</b>					
<b>0-2</b>	<b>3-5</b>	<b>6-9</b>	<b>10-14</b>	<b>15-18</b>	<b>19-21</b>
Behavioral CBTYC Joint Attention NTS	Antecedent Behavioral CBTYC Joint Attention Modeling NTS Peer Training PRT Schedules Self-management	Antecedent Behavioral CBTYC Modeling NTS Peer Training PRT Schedules Self-management Story-based	Antecedent Behavioral Modeling Peer Training Schedules Self-management Story-based	Antecedent Behavioral Modeling Self-management	Behavioral

<b>Diagnostic Classification</b>		
<b>Autistic Disorder</b>	<b>Asperger's Syndrome</b>	<b>PDD-NOS</b>
Antecedent Behavioral CBTYC Joint Attention Modeling NTS	Peer Training PRT Schedules Self-management Story-based	Modeling Story-based
		Behavioral Package CBTYC Joint Attention Modeling NTS Peer Training

Antecedent=Antecedent Package; Behavioral=Behavioral Package; CBTYC=Comprehensive Behavioral Treatment for Young Children; Joint Attention=Joint Attention Intervention; NTS=Naturalistic Teaching Strategies; Peer Training=Peer Training Package; PRT=Pivotal Response Treatment; Story-based=Story-based Intervention Package


## Emerging Treatments

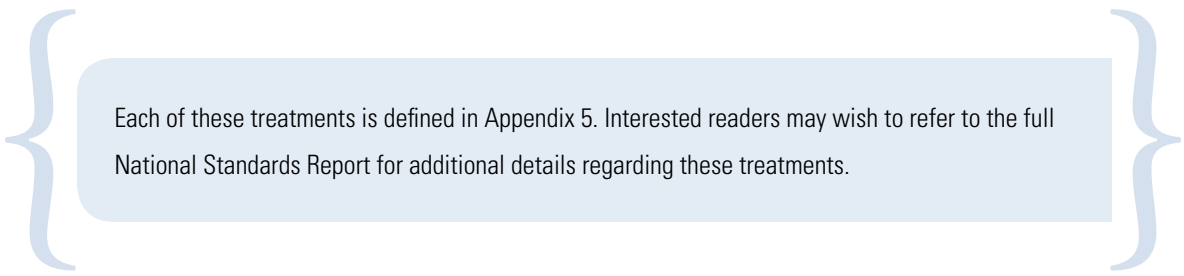
Emerging Treatments are those for which one or more studies suggest the intervention may produce favorable outcomes. However, additional high quality studies that consistently show these treatments to be effective for individuals with ASD are needed before we can be fully confident that the treatments are effective. Based on the available evidence, we are not yet in a position to rule out the possibility that Emerging Treatments are, in fact, not effective.

A large number of studies fall into the “Emerging” level of evidence. We believe scientists should find fertile ground for further research in these areas. The number of studies conducted that contributed to this rating is listed in parentheses after the treatment name.

**The following treatments have been identified as falling into the Emerging level of evidence:**

- Augmentative and Alternative Communication Device {14 studies}
- Cognitive Behavioral Intervention Package {3 studies}
- Developmental Relationship-based Treatment {7 studies}
- Exercise {4 studies}
- Exposure Package {4 studies}
- Imitation-based Interaction {6 studies}
- Initiation Training {7 studies}
- Language Training (Production) {13 studies}
- Language Training (Production & Understanding) {7 studies}
- Massage/Touch Therapy {2 studies}
- Multi-component Package {10 studies}

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- Music Therapy {6 studies}
  - Peer-mediated Instructional Arrangement {11 studies}
  - Picture Exchange Communication System {13 studies}
  - Reductive Package {33 studies}
  - Scripting {6 studies}
  - Sign Instruction {11 studies}
  - Social Communication Intervention {5 studies}
  - Social Skills Package {16 studies}
  - Structured Teaching {4 studies}
  - Technology-based Treatment {19 studies}
  - Theory of Mind Training {4 studies}



Each of these treatments is defined in Appendix 5. Interested readers may wish to refer to the full National Standards Report for additional details regarding these treatments.



## Unestablished Treatments

Unestablished Treatments are those for which there is little or no evidence in the scientific literature that allows us to draw firm conclusions about the effectiveness of these interventions with individuals with ASD. There is no reason to assume these treatments are effective. Further, there is no way to rule out the possibility these treatments are ineffective or harmful.

The following treatments have been identified as falling into the Unestablished level of evidence:

- Academic Interventions {10 studies}
- Auditory Integration Training {3 studies}
- Facilitated Communication {5 studies}

*Note: The National Standards Project followed strict inclusionary/exclusionary criteria. As a result, we eliminated a large number of studies on the treatment of Facilitated Communication that {a} involved adults 22 years of age or older, {b} involved individuals with infrequently occurring co-morbid conditions, and {c} focused on the adult facilitators (as opposed to the individuals with ASD). Although our results indicate Facilitated Communication is an “Unestablished Treatment,” we believe it is necessary to make readers aware that a number of professional organizations have adopted resolutions advising against the use of facilitated communication. These resolutions are often related to concerns regarding “immediate threats to the individual civil and human rights of the person with autism...” (American Psychological Association, 1994).*

● Gluten- and Casein-Free Diet {3 studies}

*Note: Early studies suggested that the Gluten- and Casein-Free diet may produce favorable outcomes but did not have strong scientific designs. Better controlled research published since 2006 suggests there may be no educational or behavioral benefits for these diets. Further, potential medically harmful effects have begun to be reported in the literature. We recommend reading the following studies before considering this option:*

1. Arnold, G. L., Hyman, S. L., Mooney, R. A., & Kirby, R. S. (2003). Plasma amino acids profiles in children with autism: Potential risk of nutritional deficiencies, *Journal of Autism and Developmental Disabilities*, 33, 449-454.
2. Heiger, M. L., England, L. J., Molloy, C. A., Yu, K. F., Manning-Courtney, P., & Mills, J. L. (2008). Reduced bone cortical thickness in boys with autism or autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 38, 848-856.

● Sensory Integrative Package {7 studies}

Each of these treatments is defined in Appendix 5. Interested readers may wish to refer to the full National Standards Report for additional details regarding these treatments.

There are likely many more treatments that fall into this category for which no research has been conducted or, if studies have been published, the accepted process for publishing scientific work was not followed. There are a growing number of treatments that have not yet been investigated scientifically. These would all be Unestablished Treatments. Further, any treatments for which studies were published exclusively in non-peer-reviewed journals would be Unestablished Treatments.



## Ineffective/Harmful Treatments

Ineffective or Harmful Treatments are those for which several well-controlled studies have shown the intervention to be ineffective or to produce harmful outcomes, respectively. At this time, there are no treatments that have sufficient evidence specific to the ASD population that meet these criteria.

This outcome is not entirely unexpected. When preliminary research findings suggest a treatment is ineffective or harmful, researchers tend to change the focus of their scientific inquiries into treatments that may be effective. That is, research often stops once there is a suggestion that the treatment does not work or that it is harmful. Further, research showing a treatment to be ineffective or harmful may be available with different populations (e.g., developmental disabilities, general populations, etc.). Ethical researchers are not going to then apply these ineffective or harmful treatments specifically to children or adolescents on the autism spectrum just to show that the treatment is equally ineffective or harmful with individuals with ASD.

See the Evidence-based Practice section to learn how practitioners' knowledge of interventions outside the ASD population should be integrated into the decision-making process.

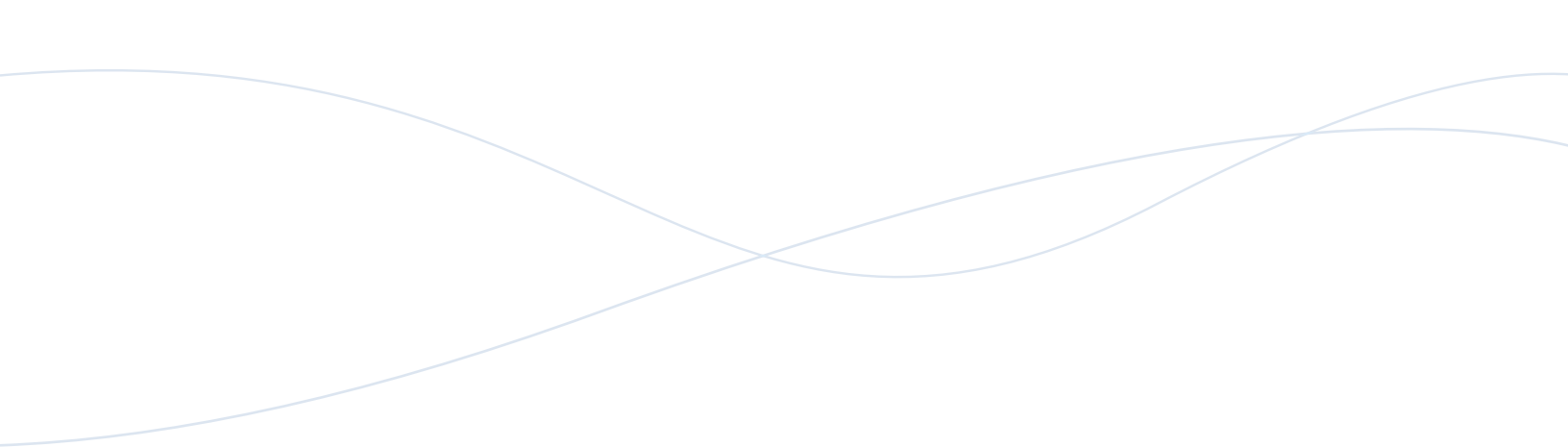
# 4

## Recommendations for Treatment Selection

Treatment selection is complicated and should be made by a team of individuals who can consider the unique needs and history of the individual with Autism Spectrum Disorder (ASD) along with the environments in which he or she lives. We do not intend for this document to dictate which treatments can or cannot be used for individuals on the autism spectrum.

Having stated this, we have been asked by families, educators, and service providers to recommend how our results might be helpful to them in their decision-making. As an effort to meet this request, we provide suggestions regarding the interpretation of our outcomes. In all cases, we strongly encourage decision-makers to select an evidence-based practice approach.

Research findings are not the sole factor that should be considered when treatments are selected. The suggestions we make here refer only to the “research findings” component of evidence-based practice and should be only one factor considered when selecting treatments.



### Recommendations based on research findings:

- Established Treatments have sufficient evidence of effectiveness. We recommend the decision-making team give serious consideration to these treatments because {a} these treatments have produced beneficial effects for individuals involved in the research studies published in the scientific literature, {b} access to treatments that work can be expected to produce more positive long-term outcomes, and {c} there is no evidence of harmful effects. However, it should not be assumed that these treatments will universally produce favorable outcomes for all individuals on the autism spectrum.
- Given the limited research support for Emerging Treatments, we generally do not recommend *beginning* with these treatments. However, Emerging Treatments should be considered promising and warrant serious consideration if Established Treatments are deemed inappropriate by the decision-making team. There are several very legitimate reasons this might be the case (see examples in the Professional Judgment or Values and Preferences sections of Chapter 5).
- Unestablished Treatments either have no research support or the research that has been conducted does not allow us to draw firm conclusions about treatment effectiveness for individuals with ASD. When this is the case, decision-makers simply do not know if this treatment is effective, ineffective, or harmful because researchers have not conducted any or enough high quality research. Given how little is known about these treatments, we would recommend considering these treatments *only* after additional research has been conducted and this research shows them to produce favorable outcomes for individuals with ASD.

These recommendations should be considered along with other sources of critical information when selecting treatments (see Chapter 5).

# 5

## Evidence-based Practice

One of the primary objectives of this document is to identify evidence-based treatments. We are not alone in this activity. The National Standards Project is a natural extension of the efforts of the National Research Council {2001}, the New York State Department of Health, Early Intervention Division {1999}, and other related documents produced at state and national levels.

Knowing which treatments have sufficient evidence of effectiveness is likely to—and should—influence treatment selection. Evidence-based practice, however, is more complicated than simply knowing which treatments are effective. Although we argue that knowing which treatments have evidence of effectiveness is essential, other critical factors must also be taken into consideration.

**We have identified the following four factors of evidence-based practice:**

- **Research Findings.** The strength of evidence ratings for all treatments being considered must be known. Serious consideration should be given to Established Treatments because there is sufficient evidence that {a} the treatment produced beneficial effects and {b} they are not associated with unfavorable outcomes (i.e., there is no evidence that they are ineffective or harmful) for individuals on the autism spectrum.

Ideally, treatment selection decisions should involve discussing the benefits of various Established Treatments. Despite the fact there is compelling evidence to suggest these treatments generally produce beneficial effects for individuals on the autism spectrum, there are reasons alternative treatments (e.g., Emerging Treatments) might be considered. A number of these factors are listed below.

- **Professional Judgment.** The judgment of the professionals with expertise in Autism Spectrum Disorders (ASD) must be taken into consideration. Once treatments are selected, these professionals have the responsibility to collect data to determine if a treatment is effective. Professional judgment may play a particularly important role in decision-making when:
  - A treatment has been correctly implemented in the past and was not effective or had harmful side effects. Even Established Treatments are not expected to produce favorable outcomes for all individuals with ASD.

- ▶ The treatment is contraindicated based on other information (e.g., the use of extra-stimulus prompts for a child with a prompt dependency history).
  - ▶ A great deal of research support might be available beyond the ASD literature and should be considered when required. For example, if an adolescent with ASD presents with anxiety or depression, it might be necessary to identify what treatments are effective for anxiety or depression for the general population. The decision to incorporate outside literature into decision-making should only be made after practitioners are familiar with the ASD-specific treatments. Research that has not been specifically demonstrated to be effective with individuals with ASD should be given consideration along with the ASD-specific treatments only if compelling data support their use and the ASD-specific literature has not fully investigated the treatment.
  - ▶ The professional may be aware of well-controlled studies that support the effectiveness of a treatment that were not available when the National Standards Project terminated its literature search.
- **Values and Preferences.** The values and preferences of parents, careproviders, and the individual with ASD should be considered. Stakeholder values and preference may play a particularly important role in decision-making when:
- ▶ A treatment has been correctly implemented in the past and was not effective or had harmful side effects.
  - ▶ A treatment is contrary to the values of family members.
  - ▶ The individual with ASD indicates that he or she does not want a specific treatment.
- **Capacity.** Treatment providers should be well positioned to correctly implement the intervention. Developing capacity and sustainability may take a great deal of time and effort, but all people involved in treatment should have proper training, adequate resources, and ongoing feedback about treatment fidelity. Capacity may play a particularly important role in decision-making when:
- ▶ A service delivery system has never implemented the intervention before. Many of these treatments are very complex and require precise use of techniques that can only be developed over time.
  - ▶ A professional is considered the “local expert” for a given treatment but he or she actually has limited formal training in the technique.
  - ▶ A service delivery system has implemented a system for years without a process in place to ensure the treatment is still being implemented correctly.

# 6

## Limitations

Like other projects of this nature, there are limitations to the National Standards Project. Readers should be familiar with these limitations in order to use this document most effectively.

We have identified the following limitations:

- This document focuses exclusively on research involving individuals with Autism Spectrum Disorders (ASD) who are under 22 years of age.
  - This document does not include a review of the literature for children “at risk” for ASD. New evidence suggests that very young children who are eventually diagnosed with autism have a genetic predisposition that alters their interactions with the typical learning environment.<sup>7</sup> This area is especially important because providing effective interventions (e.g., behavioral interventions) to these infants may be the first critical step to altering early brain development<sup>8</sup> so that the neural circuitry regulating social and communication functions more effectively.
  - This document does not include a review of the adult ASD literature.
  - This document is not an exhaustive review of all treatments for all individuals. There are treatments that might have solid research support for related populations (e.g., developmental disabilities, anxiety, depression, etc.) but have limited or no evidence of research support for individuals with ASD in the National Standards Report. See Chapter 5 for how this might influence treatment selection.
- As noted in the treatment classification section of this report, determining the categories for treatments presents a real challenge. This is equally true whenever comprehensive reviews of the literature are completed for any diagnostic group. Some of our experts suggested making the unit of analysis larger for some categories; others suggested making the unit of analysis smaller for most categories. In the end, we attempted to develop categories that “made sense.” We expect that

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<sup>7</sup> Klin, A., Lin, D.J., Gorrindo, P., Ramsay, G., & Jones, W. (2009). Two-year-olds with autism orient to non-social contingencies rather than biological motion. *Nature*, 1-7. doi:10.1038/nature07868.

<sup>8</sup> Dawson, G. (2008). Early behavioral intervention, brain plasticity, and the prevention of autism spectrum disorders. *Development and Psychopathology*, 20, 775-803.



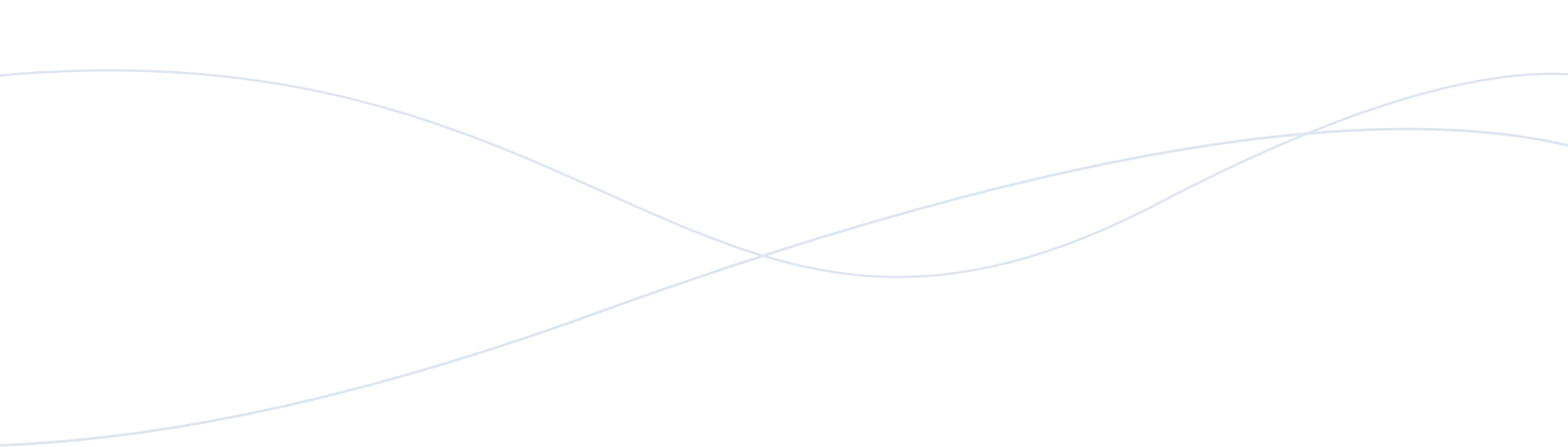
many readers may be interested in more detailed analysis using a smaller unit of analysis, or data using on a different arrangement of treatment categories based on a larger unit of analysis. We look forward to your feedback to guide the next version of the National Standards Project.

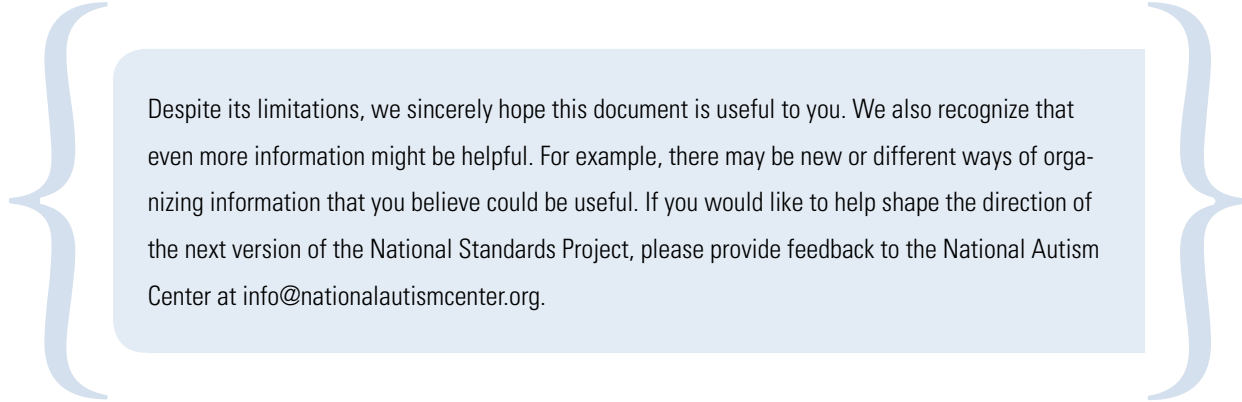
- This review included an examination of most group and single-subject research design studies but did not include every type of study.
  - ▶ For this report, we only looked at research that was designed to answer questions about the measurable effectiveness of an intervention based on quantifiable data. We did not look at research that was designed to explore questions about the perceived quality of an intervention or the experiences of the children based on qualitative data.
  - ▶ There are studies relying on single-case or group design methods that were not included in this review because they fell outside the commonly agreed-upon criteria for evaluating the effectiveness of study outcomes. The experts involved in the development of these Standards made the decision to include only those methodologies that are generally agreed-upon by scientists as sufficient for answering the question, “Is this treatment effective?”
- ▶ We only included studies that have been published in professional journals. It is likely that some researchers conducted studies that provided different or additional data that have not been published. This could influence the reported quality, quantity, or consistency of research findings.
- When establishing interobserver agreement (IOA), field reviewers were asked to examine the coding manual and rate the pilot article they received. Ideally, we would have conducted a training session before they began rating the articles. Also, the pilot articles were selected randomly. Now that we have identified articles with the highest, moderate, and lowest ratings for both single-subject and group research designs, we will use these articles for establishing IOA in future versions of the National Standards Project.
- We did not include articles reviewed in languages other than English. This has the potential to influence the ratings reported in this document. For example, a study that was not included in this review was published in French on Integrated Play Groups™ (Richard & Goupil, 2005). We hope to include volunteer field reviewers from across the world who can effectively review the non-English literature in the next version of the National Standards Project.

- The National Standards Project did not evaluate the extent to which treatment approaches have been studied in “real world” versus laboratory settings. We hope to shed light on this issue in future versions of the National Standards Project.
- One of the primary purposes of the National Standards Project was to identify the level of research support currently available for a range of educational and behavioral interventions. We did not set as our goal the determination of the level of intensity required for delivery of these interventions. The next version of the National Standards Project may provide further analysis in this area. In the interim, we believe treatment providers should continue to follow the recommendations for intensity of services provided by the National Research Council regarding children less than 8 years of age. Specifically,

“ The committee recommends that educational services begin as soon as a child is suspected of having an autistic spectrum disorder. Those services should include a minimum of 25 hours a week, 12 months a year, in which the child is engaged in systematically planned, and developmentally appropriate educational activity toward identified objectives. What constitutes these hours, however, will vary according to a child’s chronological age, developmental level, specific strengths and weaknesses, and family needs. Each child must receive sufficient individualized attention on a daily basis so that adequate implementation of objectives can be carried out effectively. The priorities of focus include functional spontaneous communication, social instruction delivered throughout the day in various settings, cognitive development and play skills, and proactive approaches to behavior problems. To the extent that it leads to the acquisition of children’s educational goals, young children with an autistic spectrum disorder should receive specialized instruction in a setting in which ongoing interactions occur with typically developing children. ”

We argue that unless compelling reasons exist to do otherwise, intervention services should be comprised of Established Treatments and they should be delivered following the specifications outlined in the literature (e.g., appropriate use of resources, staff to student ratio, following the prescribed procedures, etc.).

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- Writing a report of this type can be quite time-consuming. The National Standards Project terminated the literature review phase in September of 2007. Additional studies have been published in the interim that are not reflected in the current report. This means that if a review were conducted today, the strength of evidence ratings for a given treatment may have improved or be altered. We intend to regularly update this document to assist decision-makers in their selection of treatments. In the meantime, professionals should familiarize themselves with the literature published since the fall of 2007.
  - Ideally, research answers important questions beyond treatment effectiveness. This report does not review the following areas that may be important in selecting treatments:
    - ▶ Cost-effectiveness;
    - ▶ Social validity;
    - ▶ Studies examining mediating or moderating variables. Mediating variables can help explain why a treatment is effective. Moderating variables can make a difference in the likelihood a treatment is effective for a given subpopulation; and
    - ▶ Research supporting Established Treatments may have been developed in analog settings (e.g., highly structured research settings), which may not reflect real world settings accurately.



Despite its limitations, we sincerely hope this document is useful to you. We also recognize that even more information might be helpful. For example, there may be new or different ways of organizing information that you believe could be useful. If you would like to help shape the direction of the next version of the National Standards Project, please provide feedback to the National Autism Center at [info@nationalautismcenter.org](mailto:info@nationalautismcenter.org).

# 7

## Future Directions

### Future Directions for the Scientific Community

One of the goals of the National Standards Project is to identify limitations of the existing literature base. We believe we have done so in two ways: {a} we have identified areas benefiting from or requiring future investigation and {b} we have developed the Scientific Merit Rating Scale and Strength of Evidence Classification System, against which future research can be compared. We expand on these issues below.

There is room for additional research for all treatments. It will be important to extend the current research base for Established Treatments to all reasonable treatment goals, age groups, and diagnostic groups. Additional research must be conducted for treatments falling in the Emerging and Unestablished Treatment categories to determine if {a} the treatments are effective and {b} the treatments are ineffective or harmful. High quality research is perhaps most important for treatments falling into the Unestablished Treatments category.




## Future Directions with Methodology

Five dimensions were identified for the Scientific Merit Rating Scale: {a} research design, {b} dependent variable, {c} treatment fidelity, {d} participant ascertainment, and {e} generalization (see Table 3). We identified these dimensions based on the most recent scientific standards that are being advocated in behavioral and social science research. However, scientific standards change over time.

For example, there were no psychometrically sound instruments specifically designed to diagnose Autism Spectrum Disorders (ASD) available when the earliest studies included in this review were conducted. If there had been, the instruments would look very different today based on changes in the diagnostic criteria over the years. For this reason, it is not surprising that many older studies did not achieve the highest possible ratings in this area.

Similarly, it is only recently that evidence of treatment fidelity has been consistently emphasized by the scientific community. This means that although many studies may do an excellent job of describing the procedures used, they still received low ratings on their ability to provide evidence that they completed all procedures exactly as prescribed. This leaves room for improvement in the scientific literature in either the research design or the extent to which scientists report on these important variables.

We encourage researchers to strive to meet the most rigorous standards of scientific merit in future research. We hope the Scientific Merit Rating Scale will assist them



in doing so. But it is also essential that journal editors recognize the importance of the five dimensions of scientific merit identified in this report. Important information may sometimes be cut from articles due to space limitations. We hope that researchers will be able to point to the Scientific Merit Rating Scale as an example of critical information that should never be removed from scholarly work.

The Strength of Evidence Classification System may be expanded over time to reflect additional scientific lines of inquiry. For example, it is reasonable to use alternate criteria for different research designs, which is why we did so in the current version of the Strength of Evidence Classification System. However, if qualitative research is included in the next version of the National Standards Project, the current version of the Strength of Evidence Classification System would be insufficient to accurately evaluate these studies.

# Future Directions for the National Standards Report

We aim to address many of the limitations of the current National Standards Report in future documents.

For example, we expect:

- To review literature covering the lifespan. This will include a special section on children “at risk” for ASD.
- To reconsider the inclusion of qualitative studies or other types of peer-reviewed studies that are currently excluded.
- To modify treatment classification based on feedback from the many experts in the autism community.
- To examine the extent to which treatments have been studied in “real world” versus laboratory settings.
- To add reviewers who can accurately interpret peer-reviewed articles published in non-English journals.

With additional funding, we hope to help address questions related to cost effectiveness, social validity, studies examining mediating variables, and effectiveness of treatments in real world settings.

We suspect that this report will raise additional questions that we hope to address in future publications. Our ultimate goal is to answer relevant questions related to evidence-based practice in response to the changing expectations of professionals and the needs of families, educators, and service providers.

## Appendix 1} Inclusionary and Exclusionary Criteria

### Inclusionary Criteria

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The National Standards Project is a systemic review of the behavioral and educational treatment literature involving individuals with Autism Spectrum Disorders (ASD) under the age of 22. For the purposes of this review, Autism Spectrum Disorders were defined to include Autistic Disorder, Asperger's Syndrome, and Pervasive Developmental Disorder—Not Otherwise Specified (PDD-NOS).

### Exclusionary Criteria

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Participants who were identified as “at risk” for an ASD or who were described as having “autistic characteristics” or “a suspicion of ASD” were not included in this review.

Studies were included if the treatments could have been implemented in or by school systems, including toddler, early childhood, home-based, school-based, and community-based programs.

Studies in which parents, care providers, educators, or service providers were the sole subject of treatment were not included in the review. If these adults were one subject but data were also available regarding changes in child behavior or skills, the study was retained, but only those results pertaining to the child's behavior or skills were included in the review.

Articles were only included in the review if they had been published in peer-reviewed journals.

Studies examining biochemical, genetic, and psychopharmacological treatments were excluded (see exception below). These treatments have not historically focused on the core characteristics of ASD. We made the decision to include curative diets because professionals are often expected to implement curative diets across a variety of settings with a high degree of fidelity and the treatment is intended to address the core characteristics of ASD.

Results for study participants who were diagnosed with both ASD and co-morbid conditions that do not commonly co-occur with ASD were excluded from this review because their results could skew the outcomes.

Articles were excluded if they did not include empirical data, if there were no statistical analyses available for studies using group research design, if there was no linear graphical presentation of data for studies using single-case research design, or if the studies relied on qualitative methods.

Studies were excluded if their sole purpose was to identify mediating or moderating variables.

Articles were excluded if all participants were over the age of 22 or if a study included participants both over and under the age of 22, but separate analyses were not conducted for individuals under the age of 22. We anticipate the next version of the National Standards Project will expand the focus of the review to include treatments involving participants across the lifespan.

Articles were excluded from the National Standards Project if they were published exclusively in languages other than English.



## Appendix 2} Scientific Merit Rating Scale

SMRS} Rating 5						
Research Design		Measurement of Dependent Variable		Measurement of Independent Variable <i>(procedural integrity or treatment fidelity)</i>	Participant Ascertainment	Generalization of Tx Effect(s)
Group	Single-subject <sup>a</sup>	Test, scale, checklist, etc.	Direct behavioral observation			
Number of groups: two or more Design: Random assignment and/or no significant differences pre-Tx Participants: n > 10 per group or sufficient power for lower number of participants Data Loss: no data loss	A minimum of three comparisons of control and treatment conditions Number of data points per condition: > five Number of participants: > three Data loss: no data loss possible	Type of measurement: Observation-based Protocol: standardized Psychometric properties solid instrument Evaluators: blind and independent	Type of measurement: continuous or discontinuous with calibration data showing low levels of error Reliability: IOA $\geq$ 90% or kappa > .75 Percentage of sessions: Reliability collected in $\geq$ 25% Type of conditions in which data were collected: all sessions	Implementation accuracy measured at $\geq$ 80% Implementation accuracy measured in 25% of total sessions IOA for treatment fidelity $\geq$ 80%	Diagnosed by a qualified professional Diagnosis confirmed by independent and blind evaluators for research purposes using at least one psychometrically solid instrument DSM or ICD criteria or commonly accepted criteria during the identified time period reported to be met	Objective data Maintenance data collected AND Generalization data collected across at least two of the following: setting, stimuli, persons

SMRS} Rating 4

Research Design		Measurement of Dependent Variable		Measurement of Independent Variable <i>(procedural integrity or treatment fidelity)</i>	Participant Ascertainment	Generalization of Tx Effect(s)
Group	Single-subject <sup>a</sup>	Test, scale, checklist, etc.	Direct behavioral observation			
Number of groups: two or more  Design: Matched groups; No significant differences pre-Tx; or better design  Participants: n > 10 per group or sufficient power for lower number of participants  Data Loss: some data loss possible	A minimum of three comparisons of control and treatment conditions  Number of data points per condition: > five  Number of participants: > three  Data loss: some data loss possible	Type of measurement: Observation-based measurement  Protocol: standardized  Psychometric properties sufficient  Evaluators: blind  OR  independent	Type of measurement: continuous or discontinuous with no calibration data  Reliability: IOA $\geq$ 80% or kappa > .75  Percentage of sessions: Reliability collected in $\geq$ 25%  Type of conditions in which data were collected: all sessions	Implementation accuracy measured at $\geq$ 80%  Implementation accuracy measured in 20% of total session for focused interventions only  IOA for treatment fidelity: not reported	Diagnosis provided/confirmed by independent and blind evaluators for research purposes using at least one psychometrically sufficient instrument	Objective data  Maintenance data collected  AND  Generalization data collected across at least one of the following: setting, stimuli, persons

**SMRS} Rating 3**

Research Design		Measurement of Dependent Variable		Measurement of Independent Variable <i>(procedural integrity or treatment fidelity)</i>	Participant Ascertainment	Generalization of Tx Effect(s)
Group	Single-subject <sup>a</sup>	Test, scale, checklist, etc.	Direct behavioral observation			
Number of groups: two or more  Design: Pre-Tx differences controlled statistically or better design  Data loss: some data loss possible	A minimum of two comparisons of control and treatment conditions  Number of data points per condition: > three  Number of participants: > two  Data loss: some data loss possible	Type of measurement: Observation-based measurement  Protocol: non-standardized or standardized  Psychometric properties adequate  Evaluators: neither blind nor independent required	Type of measurement: continuous or discontinuous with no calibration data  Reliability: IOA $\geq$ 80% or kappa > .4  Percentage of sessions: Reliability collected in $\geq$ 20%  Type of conditions in which data were collected: all or experimental sessions only	Implementation accuracy measured at $\geq$ 80%  Implementation accuracy measured in 20% of partial session for focused interventions only  IOA for treatment fidelity: not reported	Diagnosis provided/confirmed by independent  OR  blind evaluator for research purposes using at least one psychometrically adequate instrument  OR  DSM criteria confirmed by a qualified diagnostician or independent and/or blind evaluator	Objective data  Maintenance data collected  OR  Generalization data collected across at least one of the following: setting, stimuli, persons

SMRS} Rating 2

Research Design		Measurement of Dependent Variable		Measurement of Independent Variable <i>(procedural integrity or treatment fidelity)</i>	Participant Ascertainment	Generalization of Tx Effect(s)
Group	Single-subject <sup>a</sup>	Test, scale, checklist, etc.	Direct behavioral observation			
Number of groups and Design: If two groups, pre-Tx difference not controlled or better research design OR a one group repeated measures pre-test/post-test design Data Loss: significant data loss possible	A minimum of two comparisons of control and treatment conditions Number of data points per Tx condition: > three Number of participants: > two Data loss: significant data loss possible	Type of measurement: Observation-based or subjective Protocol: non-standardized or standardized Psychometric properties modest Evaluators: neither blind nor independent required	Type of measurement: continuous or discontinuous with no calibration data Reliability: IOA $\geq$ 80% or kappa > .4 Percentage of sessions: Not reported Type of conditions in which data were collected: not necessarily reported Operational definitions are extensive or rudimentary	Control condition is operationally defined at an inadequate level or better Experimental (Tx) procedures are operationally defined at a rudimentary level or better Implementation accuracy measured at $\geq$ 80% Implementation accuracy regarding percentage of total or partial sessions: not reported IOA for treatment fidelity: not reported	Diagnosis with at least one psychometrically modest instrument OR diagnosis provided by a qualified diagnostician or blind and/or independent evaluator with no reference to psychometric properties of instrument	Subjective data Maintenance data collected AND Generalization data collected across at least 1 of the following: setting, stimuli, persons

**SMRS} Rating 1**

Research Design		Measurement of Dependent Variable		Measurement of Independent Variable <i>(procedural integrity or treatment fidelity)</i>	Participant Ascertainment	Generalization of Tx Effect(s)
Group	Single-subject <sup>a</sup>	Test, scale, checklist, etc.	Direct behavioral observation			
Number of groups and Design: two group, post-test only or better research design OR retrospective comparison of one or more matched groups Data loss: significant data loss possible	A minimum of two comparisons of control and treatment conditions Number of participants: > one Data loss: significant data loss possible	Type of measurement: Observation-based or subjective Protocol: non-standardized or standardized Psychometric properties weak Evaluators: Neither blind nor independent required	Type of measurement: continuous or discontinuous with no calibration data Type of conditions in which data were collected: not necessarily reported Operational definitions are extensive or rudimentary	Control condition is operationally defined at an inadequate level or better Experimental (Tx) procedures are operationally defined at a rudimentary level or better IOA and procedural fidelity data are unreported	Diagnosis provided by {a} review of records OR {b} instrument with weak psychometric support	Subjective or subjective supplemented with objective data Maintenance data collected OR Generalization data collected across at least one of the following: setting, stimuli, persons

**SMRS} Rating 0**

Does not meet criterion for a score of 1	Does not meet criterion for a score of 1	Does not meet criterion for a score of 1	Does not meet criterion for a score of 1	Does not meet criterion for a score of 1	Does not meet criterion for a score of 1	Does not meet criterion for a score of 1
--	--	--	--	--	--	--

<sup>a</sup> For all designs except alternating treatments design (ATD). For an ATD, the following rules apply:

- {5} Comparison of baseline and experimental condition; ≥ five data points per experimental condition, follow-up data collected, carryover effects minimized through counterbalancing of key variables (e.g., time of day), and condition discriminability; n ≥ three; no data loss
- {4} Comparison of baseline and experimental condition; ≥ five data points per experimental condition; carryover effects minimized through counterbalancing of key variables (e.g., time of day), OR condition discriminability; n ≥ three; some data loss possible
- {3} ≥ five data points per condition, carryover effects minimized counterbalancing of key variables OR condition discriminability; n ≥ two; some data loss possible
- {2} ≥ five data points per condition; n ≥ two; significant data loss possible
- {1} ≥ five data points per condition; n ≥ one; significant data loss possible
- {0} Does not meet criterion for a score 1

## Appendix 3} Treatment Effects

Beneficial Treatment Effects Reported	Unknown Treatment Effects Reported	Ineffective Effects Reported	Adverse Treatment Effects Reported
<p><b>Single:</b> A functional relation is established and is replicated at least two times</p>	<p><b>For all research designs:</b> The nature of the data does not allow for firm conclusions about whether the treatment effects are beneficial, ineffective, or adverse</p>	<p><b>Single:</b> A functional relation was not established and</p> <ul style="list-style-type: none"> <li>{a} results were not replicated but at least two replications were attempted</li> <li>{b} a minimum of five data points were collected in baseline and treatment conditions</li> <li>{c} a minimum of two participants were included</li> <li>{d} a fair or good point of comparison (e.g., steady state) existed</li> </ul>	<p><b>Single:</b> A functional relation is established and is replicated at least two times</p> <p>The treatment resulted in greater deficit or harm on the dependent variable based on a comparison to baseline conditions</p>
<p><b>ATD:</b> Moderate or strong separation between at least two data series for most participants</p> <p>Carryover effects were minimized</p> <p>A minimum of five data points per condition</p>		<p><b>ATD:</b> No separation was reported and baseline data show a stable pattern of responding during baseline and treatment conditions for most participants</p>	<p><b>ATD:</b> Moderate or strong separation between at least two data series for most participants</p> <p>Carryover effects were minimized</p> <p>A minimum of five data points per condition</p> <p>Treatment conditions showed the treatment produced greater deficit or harm for most or all participants when compared to baseline</p>
<p><b>Group:</b> Statistically significant effects reported in favor of the treatment</p>		<p><b>Group:</b> No statistically significant effects were reported with sufficient evidence an effect would likely have been found*</p> <p>*The criterion includes: {a} there was sufficient power to detect a small effect {b} the type I error rate was liberal, {c} no efforts were made to control for experiment-wise Type I error rate, and {d} participants were engaged in treatment</p>	<p><b>Group:</b> Statistically significant finding reported indicating a treatment resulted in greater deficit or harm on any of the dependent variables</p>

## Appendix 4} Treatment Target Definitions

### Skills Targeted for Increase

---

#### ***Academic***

Tasks required for success with school activities

#### ***Communication***

Tasks that involve nonverbal or verbal methods of sharing experiences, emotions, information

#### ***Higher Cognitive Functions***

Tasks that require complex problem-solving skills outside the social domain

#### ***Interpersonal***

Tasks that require social interaction with one or more individuals

#### ***Learning Readiness***

Tasks that serve as the foundation for successful mastery of complex skills in other domains

#### ***Motor Skills***

Tasks that require coordination of muscle systems to produce a specific goal involving either fine motor or gross motor skills

#### ***Personal Responsibility***

Tasks that involve activities embedded into every-day routines

#### ***Placement<sup>1</sup>***

Identification of a placement into a particular setting

#### ***Play***

Tasks that involve non-academic and non-work related activities that do not involve self-stimulatory behavior or require interaction with other people

#### ***Self-Regulation***

Tasks that involve the management of one's own behaviors in order to meet a goal

### Skills Targeted for Decrease

---

#### ***General Symptoms***

General Symptoms includes a combination of symptoms that may be directly associated with ASD or may be a result of psychoeducational needs that are sometimes associated with ASD

#### ***Problem Behaviors***

Behaviors that can be harmful to the individual or others, result in damage to objects, or interfere with the expected routines in the community

#### ***Restricted, Repetitive, Nonfunctional patterns of behavior, interests, or activity (RRN)***

Limited, frequently repeated, maladaptive patterns of motor activity, speech, and thoughts

#### ***Sensory or Emotional Regulation (SER)***

Sensory and emotional regulation refers to the extent to which an individual can flexibly modify his or her level of arousal or response to function effectively in the environment

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<sup>1</sup> Although placement is not a "skill," it represents an important accomplishment toward which intervention programs strive.

## Appendix 5} Names and Definitions of Emerging and Unestablished Treatments

### Emerging Treatments

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#### *Augmentative and Alternative*

##### *Communication Device (AAC)*

These interventions involved the use of high or low technologically sophisticated devices to facilitate communication. Examples include but are not restricted to: pictures, photographs, symbols, communication books, computers, or other electronic devices.

#### *Cognitive Behavioral Intervention Package*

These interventions focus on changing everyday negative or unrealistic thought patterns and behaviors with the aim of positively influencing emotions and/or life functioning.

#### *Developmental Relationship-based Treatment*

These treatments involve a combination of procedures that are based on developmental theory and emphasize the importance of building social relationships. These treatments may be delivered in a variety of settings (e.g., home, classroom, community). All of the studies falling into this category met the strict criteria of: {a} targeting the defining symptoms of ASD, {b} having treatment manuals, {c} providing treatment with a high degree of intensity, and {d} measuring the overall effectiveness of the program (i.e., studies that measure subcomponents of the program are listed elsewhere in this report). These treatment programs may also be referred to as the Denver Model, DIR (Developmental, Individual Differences, Relationship-based)/Floortime, Relationship Development Intervention, or Responsive Teaching.

#### *Exercise*

These interventions involve an increase in physical exertion as a means of reducing problems behaviors or increasing appropriate behavior.

#### *Exposure Package*

These interventions require that the individual with ASD increasingly face anxiety-provoking situations while preventing the use of maladaptive strategies used in the past under these conditions.

#### *Imitation-based Interaction*

These interventions rely on adults imitating the actions of a child.

#### *Initiation Training*

These interventions involve directly teaching individuals with ASD to initiate interactions with their peers.

#### *Language Training (Production)*

These interventions have as their primary goal to increase speech production. Examples include but are not restricted to: echo relevant word training, oral communication training, oral verbal communication training, structured discourse, simultaneous communication, and individualized language remediation.



***Language Training (Production & Understanding)***

These interventions have as their primary goals to increase both speech production and understanding of communicative acts. Examples include but are not restricted to: total communication training, position object training, position self-training, and language programming strategies.

***Massage/Touch Therapy***

These interventions involve the provision of deep tissue stimulation.

***Multi-component Package***

These interventions involve a combination of multiple treatment procedures that are derived from different fields of interest or different theoretical orientations. These treatments do not better fit one of the other treatment “packages” in this list nor are they associated with specific treatment programs.

***Music Therapy***

These interventions seek to teach individual skills or goals through music. A targeted skill (e.g., counting, learning colors, taking turns, etc.) is first presented through song or rhythmic cuing and music is eventually faded.

***Peer-mediated Instructional Arrangement***

These interventions involve targeting academic skills by involving same-aged peers in the learning process. This approach is also described as peer tutoring.

***Picture Exchange Communication System***

This treatment involves the application of a specific augmentative and alternative communication system based on behavioral principles that are designed to teach functional communication to children with limited verbal and/or communication skills.

***Reductive Package***

These interventions rely on strategies designed to reduce problem behaviors in the absence of increasing alternative appropriate behaviors. Examples include but are not restricted to water mist, behavior chain interruption (without attempting to increase an appropriate behavior), protective equipment, and ammonia.

***Scripting***

These interventions involve developing a verbal and/or written script about a specific skill or situation which serves as a model for the child with ASD. Scripts are usually practiced repeatedly before the skill is used in the actual situation.

***Sign Instruction***

These interventions involve the direct teaching of sign language as a means of communicating with other individuals in the environment.

***Social Communication Intervention***

These psychosocial interventions involve targeting some combination of social communication impairments such as pragmatic communication skills, and the inability to successfully read social situations. These treatments may also be referred to as social pragmatic interventions.

***Social Skills Package***

These interventions seek to build social interaction skills in children with ASD by targeting basic responses (e.g., eye contact, name response) to complex social skills (e.g., how to initiate or maintain a conversation).

***Structured Teaching***

Based on neuropsychological characteristics of individuals with autism, this intervention involves a combination of procedures that rely heavily on the physical organization of a setting, predictable schedules, and individualized use of teaching methods. These procedures assume that modifications in the environment, materials, and presentation of information can make thinking, learning, and understanding easier for people with ASD if they are adapted to individual learning styles of autism and individual learning characteristics. All of the studies falling into this category met the strict criteria of: {a} targeting the defining symptoms of ASD; {b} having treatment manuals; {c} providing treatment with a high degree of intensity; and {d} measuring the overall effectiveness of the program (i.e., studies that measure subcomponents of the program are listed elsewhere in this report). These treatment programs may also be referred to as TEACCH (Treatment and Education of Autistic and related Communication-handicapped CHildren).

***Technology-based Treatment***

These interventions require the presentation of instructional materials using the medium of computers or related technologies. Examples include but are not restricted to Alpha Program, Delta Messages, the Emotion Trainer Computer Program, pager, robot, or a PDA (Personal Digital Assistant). The theories behind Technology-based Treatments may vary but they are unique in their use of technology.

***Theory of Mind Training***

These interventions are designed to teach individuals with ASD to recognize and identify mental states (i.e., a person's thoughts, beliefs, intentions, desires and emotions) in oneself or in others and to be able to take the perspective of another person in order to predict their actions.

## Unestablished Treatments

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### *Academic Interventions*

These interventions involve the use of traditional teaching methods to improve academic performance. Examples include but are not restricted to: “personal instruction”; paired associate; picture-to-text matching; The Expression Connection; answering pre-reading questions; completing cloze sentences; resolving anaphora; sentence combining; “special education”; speech output and orthographic feedback; and handwriting training.

### *Auditory Integration Training*

This intervention involves the presentation of modulated sounds through headphones in an attempt to retrain an individual’s auditory system with the goal of improving distortions in hearing or sensitivities to sound.

### *Facilitated Communication*

This intervention involves having a facilitator support the hand or arm of an individual with limited communication skills, helping the individual express words, sentences, or complete thoughts by using a keyboard of words or pictures or typing device.

### *Gluten- and Casein-Free Diet*

These interventions involve elimination of an individual’s intake of naturally occurring proteins gluten and casein.

### *Sensory Integrative Package*

These treatments involve establishing an environment that stimulates or challenges the individual to effectively use all of their senses as a means of addressing overstimulation or understimulation from the environment.

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41 Pacella Park Drive  
Randolph, Massachusetts 02368

Phone 877 - 313 - 3833  
Fax 781 - 437 - 1401

Email [info@nationalautismcenter.org](mailto:info@nationalautismcenter.org)  
Web [www.nationalautismcenter.org](http://www.nationalautismcenter.org)

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ISBN 978-0-9836494-1-0 \$24.95  
52495 >



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