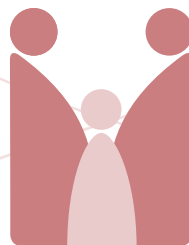


The National Autism Center's

# A Parent's Guide to Evidence-Based Practice and Autism



PROVIDING INFORMATION AND  
RESOURCES FOR FAMILIES OF CHILDREN  
WITH AUTISM SPECTRUM DISORDERS





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## 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. It is May Institute's Center for the Promotion of Evidence-based Practice. Together, the Center and May Institute are committed to identifying and applying universal standards for the treatment of autism.

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 Report was published in 2009 to share these findings. (See Appendix for the *Findings and Conclusions* report.)

We offer this parent manual to help fulfill the National Autism Center's mission to advocate for evidence-based practice and to assist parents as they make difficult decisions about how best to help their children with ASD reach their full potential.





# **I**ntroduction: **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 the only professionals who need to stay current with advances in research and best practices in their fields of expertise. A broad range of health and educational providers must also face this problem. Without keeping updated on what research tells us about the effectiveness of different treatments for autism, these professionals cannot really help you be certain that your child will receive the most appropriate services.

The National Autism Center has developed this manual as a means of helping parents learn about evidence-based practice. Knowledge of research findings is one of the most important components of evidence-based practice, which involves 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

## Parent-to-Parent

We believe parents have a unique perspective on ASD. Their experiences and views can serve as an important resource and guide for other parents. We encourage you to get support from, and give support to, other parents within your community.

You will find these “Parent-to-Parent” sections throughout the manual. Each one includes an important perspective that one of our parent authors wants to share with you. The first one comes in this introduction:

When you have a child with ASD, you get exposed to technical jargon that professionals use. Sometimes it can feel overwhelming and you think, “Do I have to go back to school and get a degree in this?” It’s an unfortunate reality that professionals use a lot of jargon.

The authors of the chapters in this manual are no exception. They all tried to explain what they mean whenever they use technical jargon. Even so, there may still be times when you feel overwhelmed as you come across several technical terms in a row. Please don’t let this stop you from using this manual! If you feel stressed, put the manual aside for a little while, but come back to it. You don’t have to know all of these terms. The most important goal is for you to understand these concepts well enough to advocate on your child’s behalf so that s/he gets access to the services that will best help him or her grow as a person.



# Outline of Chapters

## Chapter 1} Autism Spectrum Disorders

Most readers of this manual will already have a good understanding of Autism Spectrum Disorders (ASDs). But autism and related disorders are complex, and we all benefit from understanding just how broad the spectrum can be. To further complicate things, many children will show different symptoms over time or will experience additional challenges with issues like anxiety and/or depression.


We begin our manual by reviewing the defining and associated features of ASD. In Chapter 1, we also describe many disorders that may be confused with ASD or that may co-occur with ASD. This information is important to all parents because most children on the spectrum change as they develop. As a parent, you need to be aware of symptoms that may be associated with ASD as your child gets older, as well as other symptoms that may be the result of a co-occurring disorder. This should allow you to seek professional help to best help your child succeed.

## Chapter 2} Research Findings

Everyone wants to use treatments that work. Yet identifying effective interventions can be challenging. Consider this: many people promoting interventions now use the phrase “evidence-based practice” —even when there is no scientifically sound research that supports their use. 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 in detail and provide illustrative examples to clarify the uses of these interventions.



In addition to the 11 Established Treatments identified through the National Standards Project, we provide information about biomedical treatments for ASD based on a current review of the literature.

## **Chapter 3} Professional Judgment**

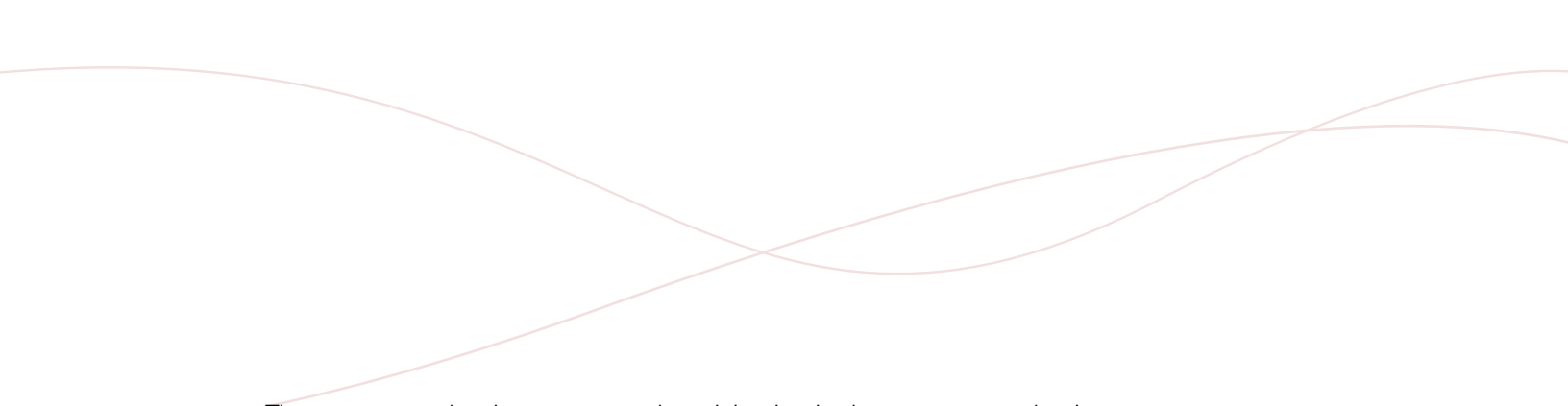
Evidence-based practice is a complex process that requires the knowledge and skills of well-trained professionals. The judgment of professionals who work with your child is extremely important to the treatment selection process. Both their unique experience working with your child and their overall experience providing treatments that have worked in the past with other children on the autism spectrum should inform the treatment selected for your child.

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 for your child, it is necessary to collect data. These data should be collected in a way that allows the professional and you to quickly determine if the intervention is effective. Data will also let your child's clinical and school team quickly make changes to treatments if the intervention is not producing the desired improvements.

Chapter 3 offers a more complete discussion of the importance of professional judgment and the role data collection should play in this process. This should allow you to better understand how to use the data collected by professionals working with your child.

## **Chapter 4} Values and Preferences of Families**

The people most affected by ASD are individuals on the spectrum and their families. Family members and/or the person with ASD should participate in intervention selection for a number of reasons. First, children and adults on the spectrum should be afforded the dignity of participating in this process unless they are incapable of doing so. Second, parents know what treatments are or are not feasible in the home and community settings. Third, families may hold certain values that may influence treatment selection. For example, eye contact with an adult therapist is one of the first skills addressed in many treatment programs—but in some cultures, children making eye contact with an adult is a sign of disrespect. In this case, the value held by the family should influence the selection of the treatment goal.



There are many barriers to parental participation in the treatment selection process. Some of these barriers come from the challenges parents face related to transportation, access to child care, language barriers, or difficult work schedules. Other barriers involve parents being uncertain if they have a role in the process or not knowing how to approach professionals about this important topic.

In Chapter 4, we offer a review of these challenges and some strategies for addressing them.

## **Chapter 5} Capacity**

How do you find professionals who can help your child reach his or her potential? This is a challenge faced by parents all over the country. Chapter 5 is designed to help you consider many factors that will influence your decision about which professional or organization should provide services to your child. You'll want to consider their commitment to evidence-based practice, their experience, and their plan to promote ongoing training for their staff. Also, what strategies does the professional or organization have to ensure that your family can provide input and is satisfied with the services your child receives?

In Chapter 5, we suggest a range of topics you may want to consider as you select the professionals and organizations that serve your child.

## **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.

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# 1 Understanding Autism Spectrum Disorders

Tremendous progress has been made in the field of autism over the last 50 years. Years ago, parents were often told to institutionalize and forget about their child on the spectrum. Parents who sought more information about Autism Spectrum Disorders (ASDs) had few resources available to them.

Today, we find information about 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 has discussed the importance of autism diagnosis, cause, and cure, and has earmarked federal dollars for research and treatment initiatives that will be instrumental in furthering the field in the years to come. Despite widespread access to information, parents are sometimes left uncertain or confused because they often receive incomplete, inaccurate, or conflicting information. We seek to provide information that is supported by research and best practice to help if you have had this experience.

ASDs are a group of developmental disabilities that appear early in a child's life. These disorders are identified based on the presence of difficulties in three major areas: communication, social interaction, and behavior (repetitive behaviors or fixated interests). People diagnosed with ASD, much like everyone else, may experience life in very different ways. Some people on the autism spectrum have very severe symptoms and others have less severe symptoms. For any given person on the autism spectrum, there can be tremendous variability in the intensity of these symptoms at different times. For example, the intensity or frequency of these symptoms may change over time or vary based on situational factors, such as being at home, in the community, or at school.

## Defining Autism Spectrum Disorders

Professionals use the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) to diagnose ASD. Currently, the DSM-IV-TR (American Psychiatric Association [APA], 2000) includes five diagnostic categories that fall under the umbrella of Pervasive Developmental Disorders (PDD). PDD is the term professionals currently use to describe ASD.

### The five major diagnoses that fall under the PDD/ASD umbrella are:

- Autism, or Autism Disorder
- Asperger's Syndrome, or Asperger's Disorder
- Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)
- Rett's Disorder
- Childhood Disintegrative Disorder

These disorders begin before age 3 and typically last in some form throughout a person's life. Symptoms may change, and often improve, as children receive effective treatment (see Chapter 2 for a description of these "Established Treatments"). Despite the fact that there is currently no known cure for ASD, many children can make remarkable progress. In fact, first grade teachers had a hard time telling the difference between children on and off the spectrum when they had the chance to carefully observe the children who responded most favorably to intensive behavioral intervention in early childhood. Research has shown that early intervention can greatly improve life outcomes for many individuals with ASD and should be initiated as early as possible—even before a formal diagnosis is given (Centers for Disease Control and Prevention [CDC], 2009b).

We begin this chapter by familiarizing you with facts about ASD and defining the five disorders included on the autism spectrum. We will then focus on common misunderstandings about ASD and what parents might expect in different developmental phases of childhood. Next, we focus on other disorders that are sometimes confused with ASD or that co-occur with ASD. Lastly, we examine the impact of ASD on families.

## Current Facts about ASD

The CDC (2009a) offers the following facts and statistics about ASD:

- ASDs affect an average of one in every 110 children nationwide.
- ASDs are four-to-five times more likely in boys than girls, and occur across all racial, ethnic, and socioeconomic groups that have been studied.
- At this time, it is estimated that approximately 10 percent of children with an ASD also have an identifiable genetic, metabolic, or neurologic disorder (e.g., Fragile X syndrome or Down syndrome).
- On average, 41 percent of children with ASD also have an intellectual disability.
- Approximately 40 percent of children with ASD are nonverbal.
- The median age for an ASD diagnosis is between 4.5 to 5.5 years of age, with 51–91 percent of these children exhibiting traits prior to age 3.

## What Does Autism Look Like?

Although we realize that your child has only one of five possible ASD diagnoses, we encourage you to read each of the following sections. There are two reasons for this. First, many of the symptoms may be identical across disorders. For example, the only difference between a diagnosis of autism and PDD-NOS is the number of symptoms present. We provide more in-depth descriptions of these symptoms in the Autism section, and these descriptions should prove useful to families of children with PDD-NOS as well.

Second, more people are providing ASD diagnoses today than in the past. This is a good thing! An early diagnosis can help parents obtain proper treatment as early as possible in their child's development. More qualified diagnosticians result in more children accessing services at the youngest possible ages. However, despite their credentials, not all professionals are equally experienced in making complex diagnostic decisions.

After learning more about each of the five ASDs, you may have new questions about your child's specific diagnosis. If this is the case, you will want to discuss your child's diagnosis with your diagnostician. It's possible that you can provide new information that would result in a re-evaluation of your child's symptoms. On the other hand, after further discussion, your diagnostician may provide you more information that clarifies the reasons for your child's original diagnosis. Either way, the more information you have, the better prepared you will be to understand and address your child's unique challenges in the world.

## Autistic Disorder

The symptoms exhibited by individuals diagnosed with Autistic Disorder, or autism, vary greatly depending on age, intellectual abilities, the severity of language impairments, and coping/adaptive skills. A child is diagnosed with autism when he or she meets at least six of the 12 criteria outlined in the DSM-IV-TR (APA, 2000). These include:

- The child meets at least two criteria in the area of social interaction.
- The child meets at least one criteria in the area of communication.

- The child meets at least one criteria in the area of behavior. "Behavior" is used here to describe repetitive behavior or fixated interests.
- The child showed these symptoms before the age of 3.
- Note: A diagnosis should not be given if the individual exhibits symptoms more consistent with one of the other ASDs.
- Note: A diagnosis should not be given if the symptoms are not better explained by a different disorder such as Attention Deficit Hyperactivity Disorder (ADHD), Mental Retardation, Bipolar Disorder, etc.

Let us now consider the symptoms associated with autism. It's important to note that there can be a great deal of variability in each of the symptoms. In terms of communication, language develops slowly in these children, or not at all. Gestures, a common form of communication, may also be affected. A child with autism may not use gestures at all, or gestures may be limited and atypical. In some cases, parents report that children have lost some of their communication skills.

### Examples of symptoms of Autistic Disorder exhibited by some children with autism in the communication domain include:

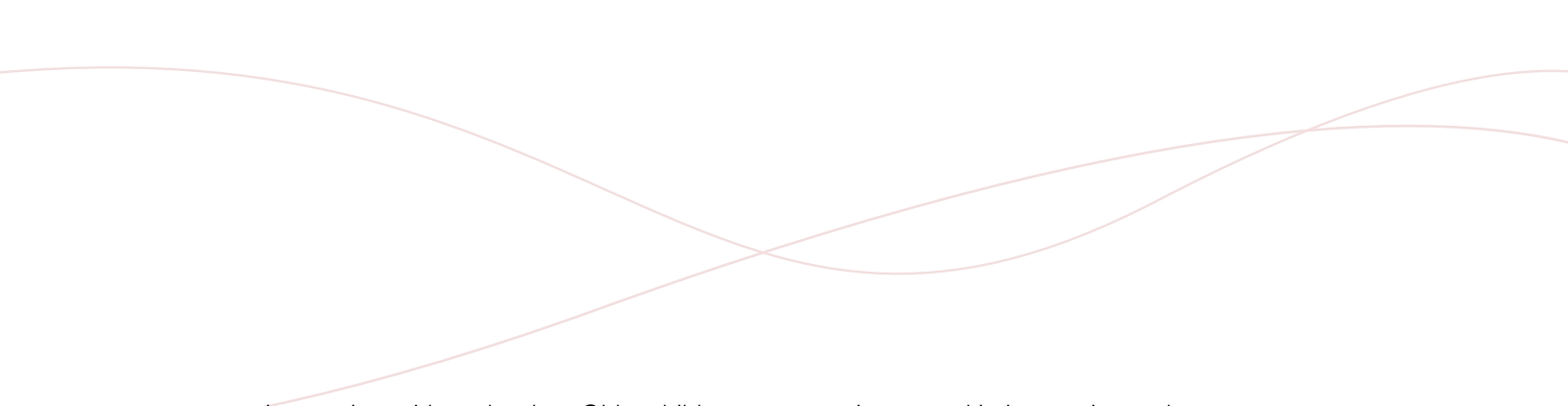
- The child has a delay in language abilities.
- The child uses language in unusual ways, such as repetition of previously heard phrases and/or repetition of entire dialogues of characters from a television program.
- The child has difficulty beginning or ending a conversation with peers and adults.
- The child is better able to converse on preferred topics, and may have little interest or ability to sustain a conversation on non-preferred topics.
- The child has difficulty responding to questions. This can be especially challenging when he is asked open-ended questions that involve “Who,” “Why,” “What,” or other “wh” questions. These questions are more complicated than they seem! They require comprehension of the question, the ability to form a response, and the capacity to communicate it in an appropriate manner.
- The child has significant difficulties with play skills. This could mean that she is not good at make-believe play or cannot imitate others in social play in the same way other children her age do.

People are generally better informed about the symptoms of autism than they were in years past; they know that many children with autism often have communication challenges. As a result, some people believe that any child who experiences challenges in communication therefore has autism. But this is not the case. Children who are able to communicate with others around them—despite a delay in language—are not included in this category. For example, a child who makes up his own communication system to use with his immediate family because he can’t speak, but has a desire to communicate his wants and needs, would not be a likely candidate for an autism diagnosis.

Just as the symptoms of communication can vary greatly, so too can the symptoms of social interaction. Children (and adults) with ASD may show little interest in making friends. They might initiate social interactions with others primarily to have their immediate needs met (such as getting a preferred toy, or something to eat). They may not be likely to share their accomplishments and experiences with others.

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

- The child may have poor eye contact. The severity or form this takes can vary greatly. Some children with autism almost never make direct eye contact with others, and some make eye contact with adults and not peers. Others don't seem to have difficulty with initiating eye contact, but have greater difficulty maintaining eye contact during social interactions. (Note: All people look away some of the time when they are interacting with others.)
- A child's facial expressions and other body language are often impaired. Some children don't show many facial expressions; this can make it difficult to interpret their mood, preferences, etc. Other children will exhibit facial expressions and other types of body language, but their actual behavior does not always match their nonverbal behavior. For example, some children will laugh or smile while hurting themselves, or while kicking or biting out of anger or frustration.
- Many children with autism have difficulty with more subtle, nonverbal ways of communicating. Most people "talk" with their hands, make subtle movements with their eyes and head to indicate the conversation should continue or end, and demonstrate other slight nonverbal gestures as a way of communicating. Children on the spectrum may not know how to use gestures (or other nonverbal aspects of communication) effectively, or at all. In fact, children with autism may have difficulty understanding other people's nonverbal cues. This can lead to awkward interactions and misunderstanding another person's intent. Unfortunately, difficulty with nonverbal aspects of communication may be particularly challenging with school-aged peers, who are often less tolerant of socially inappropriate behaviors than adults and have fewer strategies for managing difficult social interactions with a poor social partner.
- Many children with autism are not good at identifying precisely how they feel. As a result, they are unable to communicate to others that they are happy, sad, angry, frustrated, etc. This may lead to problems in social interactions with others.
- A child with autism may have difficulty initiating and maintaining friendships with peers. Parents often describe their child with autism as "getting along" with much younger children. This is often because of delayed development in play skills. Younger children often like to play side-by-side, but don't spend a lot of time



interacting with each other. Older children are more interested in interactive and creative forms of play. Children on the autism spectrum may prefer to play alone, or may want to play with others but have difficulty joining group activities.

- These children often do not spontaneously seek out other people to “share” something important they are experiencing. They may not see the value in pointing out things they like, or may not share their accomplishments. Even when they’re experiencing something wonderful, they won’t necessarily want to—or know how to—share the activity with others, or share their feelings about the experience. In the same way, they may not seek praise for accomplishments.
- The child may have difficulty with the social “give and take” between individuals. Professionals often refer to this as “social or emotional reciprocity.” Some examples of how these challenges may affect social interactions include the following:
  - It may be difficult for younger children to share and take turns with toys or other preferred items. When this isn’t addressed early on, it can impact an older child’s ability to form and maintain friendships.
  - Adolescents or adults may have trouble showing or expressing concern when someone is upset, or trying to offer comfort to that person. This does not necessarily mean a person on the autism spectrum doesn’t notice when others are upset, or doesn’t want to support them. However, they might have difficulty understanding why someone is crying or distressed or may not be aware that their empathetic efforts might ease a difficult situation for someone else. They may simply be uncertain how to alter their behavior to better meet the needs of others.

As with communication and social interaction symptoms, the symptoms of “behaviors” may vary dramatically. We use the term “behaviors” to describe the repetitive behaviors or fixated interests of a child with autism. These behaviors may involve repetitive motor movements, such as flicking of fingers in front of the eyes or rocking back and forth, or using objects in a repetitive way. On the other hand, children with autism may be consumed with a single item, idea, or person. They may also have difficulty when you make changes to their schedules or their environment. This may be particularly evident during times of transition such as getting home from school, going into or leaving the grocery store, or having a favorite television show interrupted by a speech from the president.

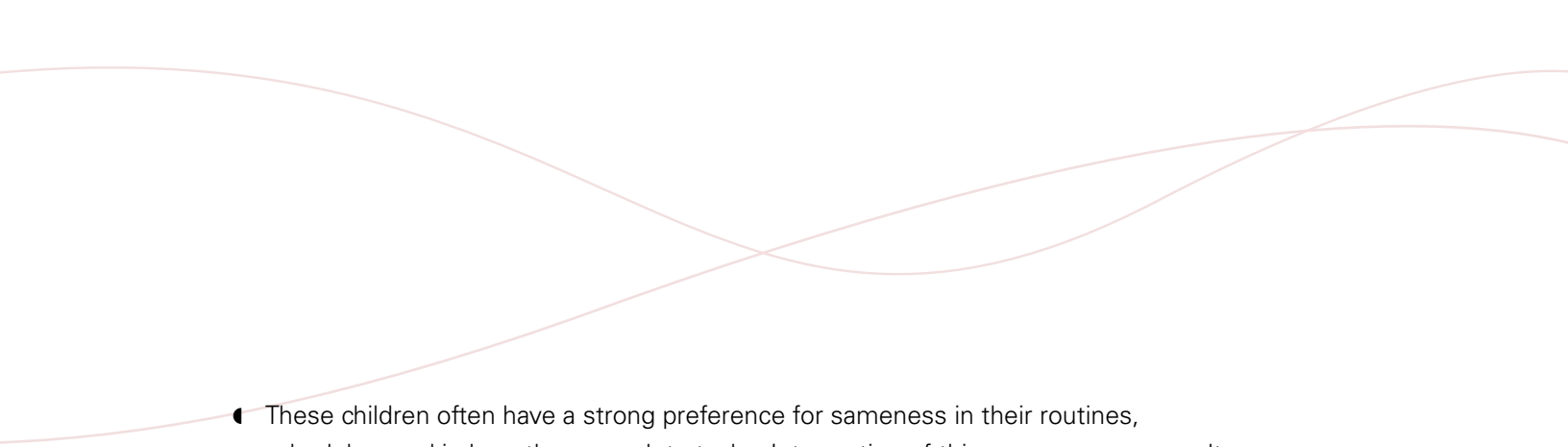
### Examples of symptoms of Autistic Disorder in the behavioral domain include:

- The child may have a very strong interest in or preference for a particular topic or activity; this interest is unusual either in its focus or in the intensity with which the child fixates on that topic or activity. For example, someone with autism may memorize the specifics of different models of cars in a consumer publication, or all the different types of vacuum cleaners. This child (or adult) will often use these subjects as a way to communicate with others. For example, he might ask you about cars you've owned and then share detailed information about those cars. He may also have the ability to remember significant amounts of information in great detail (although this is not a common trait). In contrast, the same person may have difficulty remembering how to complete very simple activities of daily living, or memorizing basic mathematics facts. Whether the strong interest involves memorizing train schedules or dates in history, gravitating to numbers, letters, or colors in their play, or fixating on videos such as Thomas the Tank Engine, people on the autism spectrum often have more difficulty successfully navigating their way around the social world as a result of their extreme preferences.

- It's helpful for parents to prepare their child far in advance for an expected change in routine. Although you obviously can't address unexpected changes like rain that would postpone a trip outdoors, or snow that could result in cancellations, there are many ways to minimize anxiety or stress.
- Structure seems to help many children with autism to manage their environment. It's often much more difficult for parents to provide the same structure at home that a child may have at school. This is often due to other children who need care, job requirements, cooking or cleaning responsibilities, and a parent's legitimate need for personal relaxation. Fortunately, some families have access to in-home services that provide helpers who can assist in structuring a child's evening and weekend hours. Remember that it may be difficult to provide structure during holidays or other extended breaks from school when in-home services are not available. Special planning and preparation can make a big difference.





- 
- These children often have a strong preference for sameness in their routines, schedules, and in how they complete tasks. Interruption of this sameness can result in responses from minor irritation to significant behavioral outbursts that include aggression and self-injury.
  - One of the most well-known features of autism is the presence of unusual body movements. Some examples include hand flapping, body rocking, spinning, toe walking, finger flicking, etc. Yet not all children with autism will show these behaviors, and not all children who exhibit these behaviors have autism. For example, a child may have a preference for where and how she walks (e.g., not on certain colors, only on one side of a sidewalk or hallway, walking by things in a particular order, or always going a certain way), whether or not she is on the autism spectrum.
  - These children often have sensory challenges. They may either be more or less sensitive to the environment than other people are. These sensitivities can be to how things sound, feel, smell, or look, or even to the temperature. A child might have difficulty with the noise level in a classroom or mall, or be unable to tolerate the feel of certain fabrics or the smell of a particular kind of food. Another child may have a need to control how a person looks. For example, she may prefer her mother's hair in a ponytail, or feel the need to fix the clasp on a necklace whenever it slips to the front because it doesn't look "right." Some children are very sensitive to temperatures and may become agitated when playing outside if they become hot. Alternatively, they may not feel cold and prefer to wear shorts all year long.
  - In addition to difficulties with play that are associated with the social and communication symptoms, children with autism may also engage in unusual or repetitive activities with their toys or other objects. Some common examples are lining up or spinning objects, preferring to watch things fall, and having ritualized routines with their toys. Any interruption in these activities may result in agitation. A child may also focus on unusual aspects of a toy or object. This could involve watching toys move from different angles (such as rolling a car on a table and focusing on the movement of the wheels out of the corner of his eye) or flipping toys or objects at the edge of his field of vision. It could involve bouncing toys in his hands and focusing on their sounds or movements.

## Asperger's Syndrome

The diagnostic criteria for Asperger's Syndrome (or Asperger's Disorder) are very similar to the criteria for a diagnosis of autism with the following exceptions: someone with Asperger's Syndrome does not have a significant delay in language, cognitive abilities, self-help skills, or adaptive behavior. An individual should not be diagnosed with Asperger's Syndrome if he or she had a delay in spoken language during their earliest years of development. But this doesn't mean that individuals with Asperger's Syndrome do not experience difficulties with communication. In fact, people with Asperger's Syndrome often experience difficulty in "social pragmatics." This is not about language production, but rather the way we use language to communicate socially with others (such as telling stories, knowing how to alter the type, quality, and volume of our speech in different settings, knowing how to problem-solve in social-communication situations, etc.).

Because people with Asperger's Syndrome may have more developed language abilities, others often expect they will behave according to social norms or in socially appropriate ways. However, just like their peers with autism, individuals with Asperger's Syndrome have significant difficulties with social interaction. They may have sensory sensitivities, prefer to be alone, and often have very developed specialized interests that are their only topics of conversation. Although these individuals may appear more socially adjusted than their peers with autism, they often don't have the ability to engage in conversation outside their preferred topics, or when they aren't motivated.

Even without delays in cognitive functioning, individuals with Asperger's Syndrome often need assistance and modifications with age-appropriate tasks. They don't usually have difficulty with activities of daily living (e.g., feeding, toileting, bathing, dressing, etc.), but may need coaching when doing activities in the community. This will help ensure they are learning and exhibiting appropriate social skills.

Your child will likely benefit from added structure at school, at home, or in the community.

- At school, your child may need help completing larger assignments (such as book reports or science experiments) or participating in group activities that require him to interact with peers to complete a project. He may also need more time to complete tests, assistance with writing down the answers, and a testing area with reduced distractions, etc. Not all school professionals will realize that your child will benefit from these kinds of modifications. This is particularly true if you have a child who appears to be better at communicating than she actually is. This means you may need to advocate on your child's behalf.
- At home, you might want to structure homework time, modify chores by providing specific instructions, create checklists for your child, etc. We realize it may seem overwhelming to put all sorts of new strategies in place. But if your child needs a lot of structure to be successful, remind yourself how much easier things will be once you provide that structure.
- Community outings are naturally less structured. Using Schedules and Story-based Interventions can be a great way to help your child prepare for these activities.



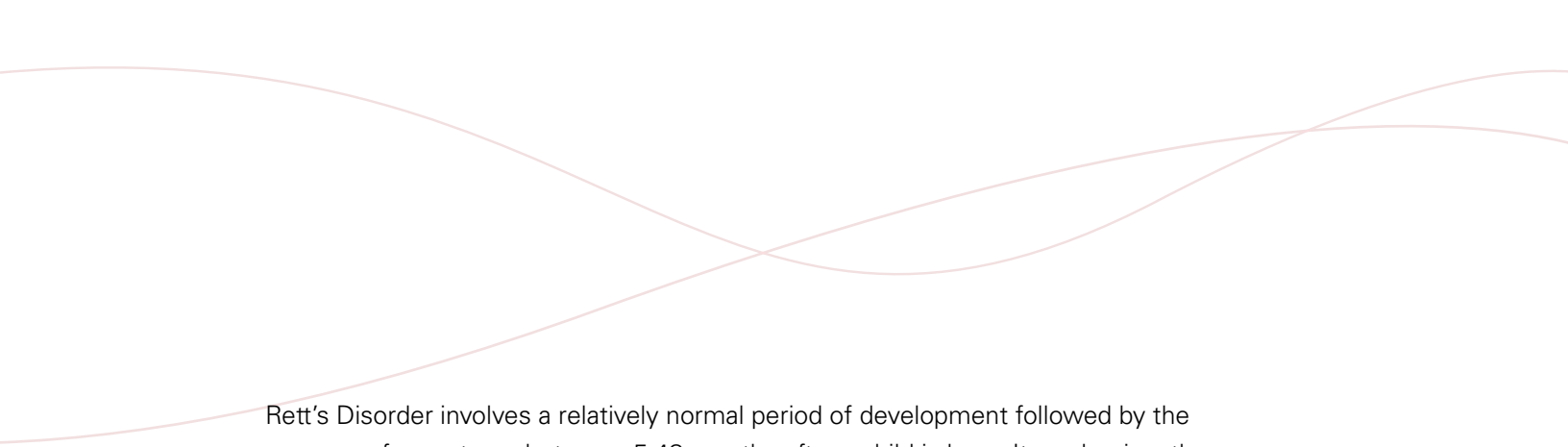
## Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS)

PDD-NOS is a diagnostic category used when a child shows some of the symptoms of autism, but not enough to meet the criteria for autism or Asperger’s Syndrome. A diagnosis of PDD-NOS is given when the child shows fewer than six of the 12 symptoms outlined in the DSM-IV-TR (APA, 2000). This diagnosis is also given to children who begin showing symptoms after age 3.

Many parents are uncertain what a diagnosis of PDD-NOS means. This is not surprising because it is less well-defined than many of the other disorders on the autism spectrum. Some professionals see a diagnosis of PDD-NOS as a “catchall” category that needs further definition and diagnostic criteria. To confuse things further, both parents and professionals sometimes hold misconceptions about PDD-NOS. For example, some people describe PDD-NOS as 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 Disorders (six or more symptoms) can display more mild symptoms, and have fewer deficits overall. Therefore, when formulating a plan 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.

## Rett’s Disorder

Rett’s Disorder is not consistently placed under the umbrella of ASD. Although it is identified as an ASD in the DSM-IV-TR (APA, 2000), it has not always been considered part of the autism spectrum by the CDC. This inconsistency is largely for two reasons. First, a specific gene has been identified that causes Rett’s Disorder, but no single gene has been identified for the other ASDs. Second, the progression of Rett’s Disorder is different than the previously discussed ASDs. You should know that the information on treatments provided in this manual (and in the *Findings and Conclusions* report) did not include a review of the literature on treatment for Rett’s Disorder or Childhood Disintegrative Disorder. However, these treatments may still be applicable to children with these diagnoses.



Rett's Disorder involves a relatively normal period of development followed by the emergence of symptoms between 5-48 months after a child is born. It predominantly affects females and is most often recognized by its behavioral characteristics—hand movements that resemble wringing or washing—and by a decreasing rate of growth for head circumference, eventually leading to a smaller head circumference for children with Rett's Disorder compared to same-aged peers (APA, 2000). Unlike other disorders on the spectrum, a specific gene mutation (on the MeCP2 gene) has been linked to development of the disorder in approximately 80 percent of cases. However, very little is known about the cause of this mutation.

Children with Rett's Disorder may have intellectual disabilities. However, IQ scores may not always accurately measure a child's current skills or ability to learn new materials. This is because problems with motor coordination can interfere with performance on verbal and nonverbal tasks. Unfortunately, the characteristic hand wringing means many children with Rett's Disorder also have very limited use of their hands for functional communication, etc. They also often have difficulty with functional routines and large motor movements such as crawling and walking. These children often have apraxia which affects their ability to perform even basic motor functions; it can interfere with every body movement including being able to move their eyes and producing speech (National Institute of Neurological Disorders and Stroke [NINDS], 2010). People with Rett's Disorder may also experience bruxism (teeth grinding), difficulty chewing food, seizures, and breathing difficulties including hyperventilation, apnea or breath holding, and air swallowing.

## **Childhood Disintegrative Disorder (CDD)**

CDD is also sometimes placed under the umbrella of ASD. The CDC does not currently consider it part of the autism spectrum ([http://www.cdc.gov/ncbddd/actearly/pdf/parents\\_pdfs/autismfactsheet.pdf](http://www.cdc.gov/ncbddd/actearly/pdf/parents_pdfs/autismfactsheet.pdf)). The information on treatments included in this manual did not include a review of the literature on treatment of CDD. However, these treatments may still be applicable to children with these diagnoses.

The causes of CDD are unknown. Some scholars have suggested that it may be a result of problems with neurobiology (i.e., nervous system) of the brain. About half of the children diagnosed with CDD have an abnormal electroencephalogram (EEG). Some children with CDD also have seizures. CDD is sometimes associated with other medical brain disorders, but nothing has been identified that accounts for all symptoms of CDD and all cases. Research in this area is further complicated by how rare the disorder is.

CDD is extremely rare, with boys being affected more than girls. Children who are diagnosed with CDD begin losing skills and exhibiting signs of ASD after an average of 2-4 years of normal development, but typically before age 10. Diagnosticians rely on parental reports of the child's development, records made in baby books, medical records from early visits to the pediatrician, and home videos to confirm normal development prior to the child's loss of skills. Typically at age 3 or 4, children begin regressing in the areas of language, socialization, and

activities of daily living (adaptive skills). Regression or loss occurs in at least two of the following areas: receptive language (their ability to understand); expressive language (their ability to speak); social or self-help skills; play skills with peers; and motor abilities. If the child was previously toilet trained, his bowel and/or bladder control may regress.

Children with CDD may be unable to start conversations with other people, or use nonverbal forms of communication such as smiles, gestures, or nodding. They may lose interest in playing games or engaging in other interactive situations with peers, and may also lose interest in relationships with other people. They may engage in repetitive behaviors (such as body rocking, hand flapping, spinning, or other types of repeated motor movement) or in repetitive vocalizations such as sounds, phrases, or repeating passages from movies, books, or websites. As the regression progresses, the children often begin to look like children diagnosed with ASD (Volkmar et al., 1994).

## Misunderstandings about ASD

There are many myths and misunderstandings about autism, and people with ASD. These are sometimes fueled by inaccurate information on the Internet and images portrayed in the mass media.

One thing we know for sure is that individuals on the autism spectrum face the same challenges, experiences, frustrations, and joys as everyone else does. Another irrefutable fact is that autism is a spectrum with significant diversity. Each person with ASD has a combination of symptoms that makes him or her unique. Furthermore, the same person may experience his or her symptoms of ASD very differently from one situation to the next.

One myth is that ASD is a form of intellectual disability or mental retardation. Another is that everyone with ASD has cognitive or intellectual disabilities. It is true that a large number of individuals with autism or PDD-NOS will be diagnosed with an intellectual disability. The CDC (2009a) reports that 30 to 51 percent of individuals with autism (41 percent on average) have an intellectual disability. However, there are also individuals with ASD who have average to above average intelligence, or who perform well in some areas and poorly in others.

Another myth is that people with ASD can't form relationships because they lack social skills and a desire to interact with others. While difficulty in social interaction is a key factor in the diagnosis of ASD, it doesn't mean that individuals can never form relationships with others, or that they don't desire these relationships. For many people on the spectrum, difficulties in forming relationships center primarily around challenges with understanding language and expressing themselves. Just as with any other characteristic, each person will have varying levels of interest, ability, and anxiety when it comes to forming and maintaining relationships. Also, these relationships may appear different than those typically experienced by neurotypicals (i.e., people who are not on the autism spectrum).

### Parent-to-Parent



Years ago, few people knew about ASD, and treatment was very limited. Unfortunately, parents—particularly mothers—were often accused of causing their children’s symptoms. They were labeled “refrigerator moms” who failed to respond to the needs of their children. It was much more difficult for these parents to network and get support from each other. Friends and family members who weren’t familiar with autism often walked away from relationships with these families because they didn’t know what to do.

Due to extensive coverage in the media, many more people know about ASD than in the past. But this coverage doesn’t always convey the complexities of autism. That means that you’re still likely to encounter professionals, friends, and communities with an inaccurate or incomplete understanding of your child’s disorder or the impact it has on your family.

Don’t be afraid to become an advocate for your child and an educator for your friends and your community. Many people simply require more information, or need to understand your experiences in order to become a source of support for you and other families who have loved ones with ASD.



## ASD Across the Lifespan

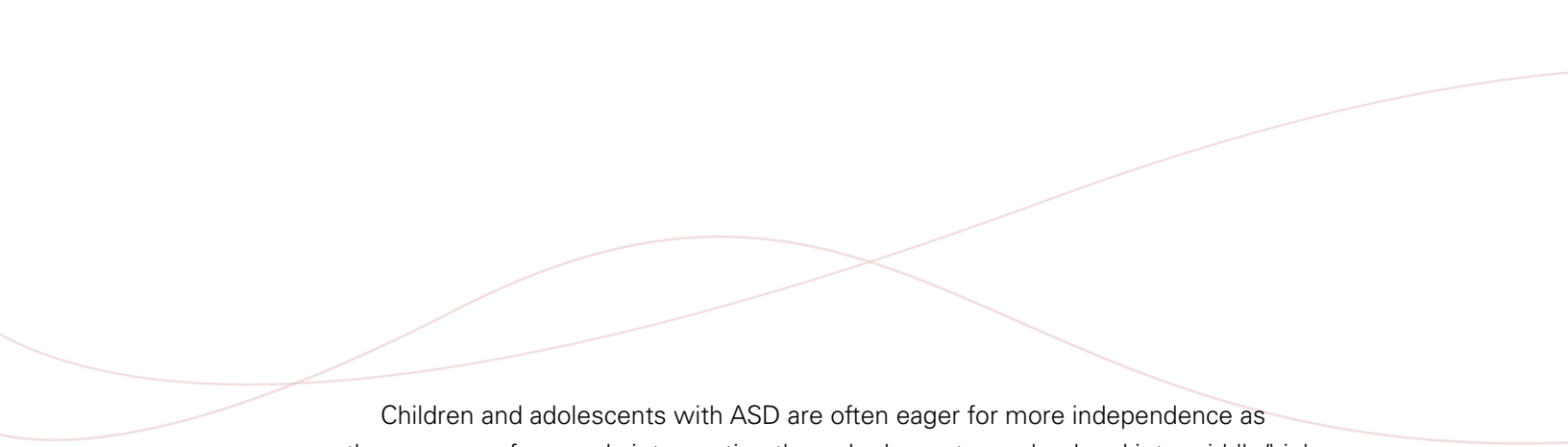
Like everyone else, people with ASD will change over the course of their lifetimes. Because early intervention has shown to produce the best outcomes for very young children, there has been a push to identify children at a very early age who may later develop symptoms of ASD. A recent study by Ozonoff et al. (2010) found that children begin to show losses in social and communication skills after the first six months of life. Many of the children in their sample who displayed these losses were later diagnosed with ASD.

### The study also showed the following:

- Losses included a reduction in eye contact and social smiling, and lower ratings on a test measuring social responsiveness between 6 and 12 months of age.
- By 12 months, significant differences in social smiling and “gaze to face” were identified.
- By 18 months, there were significant differences in all behaviors measured. This included gaze to face, vocalizations, and verbalizations.

Parents start to identify more obvious symptoms of ASD as children continue to age. When this happens, families typically begin the assessment process. Often, parents report that their child is “not doing something,” or is doing something that seems unusual. A well-trained primary care physician may recognize some early warning signs.

As children with ASD continue to grow and develop, they may require different levels of support (or different goals must be targeted) to be able to successfully navigate their increasingly complex social worlds. A very young child may receive early intervention services for social skills to address basic readiness skills such as staying seated, taking turns, or raising a hand and waiting to be called on. On the other hand, an older child or adolescent may need to focus on pragmatics that affect his or her ability to make and keep friends, talk to the opposite sex, apply for a job, etc.



Children and adolescents with ASD are often eager for more independence as they progress from early intervention through elementary school and into middle/high school. Understandably, this is frequently an area of concern for parents. The good news is that, with improvements in technology, it's possible to increase independence by using devices such as Bluetooth headsets, PDAs, MP3 players, tablets, and videos as replacements for "helping individuals." While the need for support, supervision, and/or prompting may continue into adolescence or adulthood, the way you provide these services may need to change to accommodate more socially appropriate independence and community living.

As the number of individuals with ASD increases, we are seeing the development of more services to support the transition to adulthood. Many colleges are beginning to consider the needs of young people with ASD on their campuses. College students with ASD face many difficulties, including increased levels of stress, difficulty making friends, and a lack of relationships with the opposite sex (Graetz, 2009). Some colleges are partnering with agencies that provide ASD-related services to help these students have a more positive college experience and to ensure proper supports.

Less is known about how symptoms may change as children with ASD become adults with ASD. Table 1 focuses on developmental changes children may experience through adolescence or early adulthood.

## How Are ASDs Diagnosed?

There are no medical tests for diagnosing ASD, but when parents become concerned about their children, they should consult a physician. He or she can rule out various potential medical causes of specific ASD-related symptoms. For example, children with a significant hearing problem can experience severe delays in communication, along with a number of other symptoms typically associated with ASD.

Before a child can be diagnosed with ASD, that child should be assessed by a professional with expertise in evaluating ASD. This might be a psychologist, psychiatrist, pediatric neurologist, or developmental pediatrician who specializes in diagnosing and making treatment recommendations for children with ASD.

**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 school (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>

**Best practice guidelines identify the following six components of a comprehensive diagnostic evaluation:**


1. Parent or caregiver interview
2. Review of relevant medical, psychological, and/or school records
3. Cognitive/developmental assessment
4. Direct play observation
5. Measurement of adaptive functioning
6. Comprehensive medical exam

The diagnostician should use the information obtained in this evaluation and assess the child's symptoms in relation to the criteria established in the DSM-IV-TR (APA, 2000).

## Differential Diagnoses and Comorbid Conditions

While there is much more information available about ASD than ever before, it can still be a complicated and confusing task to obtain a diagnosis for your child. There is information for parents and pediatricians about early warning signs that indicate the need for further diagnosis. However, depending on a family's access to a qualified diagnostician, there may be significant differences in how quickly a child obtains a correct diagnosis. This is further complicated by differential diagnoses and comorbid conditions. To help guide you in this process, this section provides background information about disorders that are similar to ASD (differential diagnoses) and disorders that may occur along with ASD (comorbid conditions).

- **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. All of these



symptoms alter with age. It's not easy to diagnose these children or adolescents because these symptoms may or may not be a result of the ASD. An ASD diagnosis must be differentiated from other disorders that are similar to ASD. When psychologists or psychiatrists make these decisions, it's called a differential diagnosis.

- **Comorbid Diagnoses.** Some disorders may occur simultaneously with ASD. In these cases, it's appropriate for children to be diagnosed with ASD and with an additional disorder. When psychologists or psychiatrists make these decisions, the additional diagnosis is called a comorbid condition. The exact prevalence of comorbid conditions in ASD is currently unknown, but studies have estimated from 11 to 72 percent of individuals with ASD have at least one comorbid psychiatric disorder (Mazefsky, 2009).

To confuse the matter further, some disorders may appear as a differential diagnosis for one child and as a comorbid 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
- Can't 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.

## Frequently Occurring Diagnoses and Conditions

**Depression.** Depression is believed to be a common condition in children with ASD. Unfortunately, no clear research has been conducted to identify the exact prevalence of these disorders (Stewart, Barnard, Pearson, Hasan, & O'Brien, 2006). Individuals with ASD may have more difficulty than the general population in self-identifying depressive symptoms. Therefore, it's important for parents to be familiar with some of the most common symptoms of depression.

Parents of children with depression sometimes describe symptoms such as sad facial expressions, or changes in behavior such as increased crying or irritability. Other symptoms include a loss of interest in activities, sleep disturbances, increases in maladaptive behaviors, decreases in self-care, and incontinence (Stewart et al., 2006). If a child is capable of communicating about her internal experiences, it's always important to identify thoughts or actions associated with suicide.

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

- A young child becomes increasingly irritable when asked to do things, exhibits maladaptive behaviors when prompted to continue working, and is no longer interested in the same preferred topics or items that were previously reinforcing. It's possible that this child may have symptoms of depression in addition to an ASD diagnosis, but you'll need a qualified professional to make this decision.
- Because many children with ASD are unable to communicate their feelings and emotions, it's often up to parents to identify symptoms. Professionals must then be able to review the current symptoms and determine if they are part of the ASD diagnosis, or more characteristic of another disorder.

It's difficult to diagnose these depressive disorders in children with ASD because there are no instruments designed specifically for individuals with symptoms of both ASD and depression. Even if such a test were available, it would only be of limited use to professionals. That's because people on the autism spectrum show such variability in symptoms of ASD and expression of symptoms associated with depressive disorders. To further complicate matters, the symptoms of depression can be masked by the symptoms of ASD. For example, being withdrawn socially may be a result of ASD—but may also be a symptom of depression. This is why professionals require extensive training and experience before they are likely to provide an accurate diagnosis of children with both of these symptoms.

**Anxiety.** Children with ASD may show significant symptoms of anxiety. Here are some important facts about anxiety and ASD:

- Eleven to 84 percent of individuals with ASD may also show symptoms of anxiety (White, Oswald, Ollendick, & Scahill, 2009).
- People with ASD may experience symptoms of anxiety regardless of their cognitive functioning.
- Children with autism are more likely to show problem behaviors related to anxiety than their typically developing peers (White et al., 2009).
- The symptoms of anxiety are similar in children with ASD (from preschool through young adulthood) and their typically developing peers. In both groups, younger children are more likely to have specific phobias, and older children/adolescents are more likely to have obsessive compulsive disorder and social phobias (Farrugia & Hudson, 2006).
- Because of social difficulties and a potential increased awareness that they're "different," many children with ASD have a difficult time with the transition from childhood to adolescence. This could lead to more problems with anxiety, depression, and possibly hostility towards others (Tantam, 2003).

An assessment for anxiety relies heavily on what parents report, but self-reporting is used when a child is able to complete a rating scale or participate in an interview. A child with ASD who displays symptoms of anxiety should be monitored carefully, and should receive treatment when the anxiety further impairs his or her ability to function.

**Attention Deficit Hyperactivity Disorder (ADHD).** ADHD is a disorder that involves the following characteristics:

- impairment in a person's ability to focus
- inability to pay attention to schoolwork or other tasks
- existence of hyperactive or impulsive behaviors (for example, difficulty remaining seated, talking to other students, making noises at inappropriate times, and fidgeting or playing with objects)

Because children with ASD exhibit similar symptoms, diagnosing ADHD can be difficult. When determining whether a child should be diagnosed with ASD or ADHD (differential diagnosis), or whether a child with ASD should have an additional diagnosis of ADHD (comorbid diagnosis), professionals need to consider many factors. For example, are the child's symptoms of inattention or hyperactivity extreme, given the situation? Children with ASD often appear

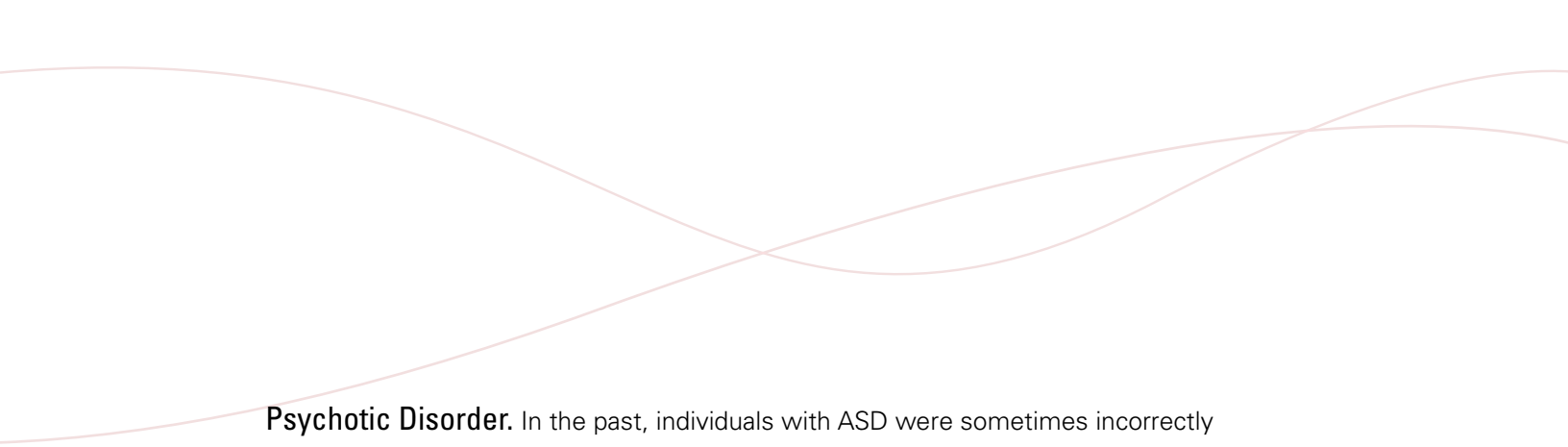
inattentive or hyperactive because the teaching environment isn't appropriate for them. The materials may be too difficult, sounds or sights may be distracting, or the person teaching them might not have the necessary expertise. Whether you are on or off the autism spectrum, inattention and hyperactivity are normal reactions to these kinds of situations! In cases like these, the child with ASD may appear distractible or hyperactive, but does not actually have ADHD.

**Obsessive-Compulsive Disorder (OCD).** OCD is a disorder that involves obsessive thoughts about a particular subject, activity, or object. A person with OCD engages in compulsive behaviors to eliminate the anxiety caused by the obsessive thoughts. Some common examples of these behaviors are hand-washing or other hygiene activities. For example, a child may wash her hands to prevent contamination or contact with germs. There is often a fear that failing to wash hands will result in illness.

**When trying to differentiate between symptoms of OCD and ASD in children, there are some important facts to consider:**

- Children with OCD have more cleaning, checking, and counting behaviors, while children with ASD are more likely to have hoarding, ordering, and self-injurious behaviors (McDougle, Kresch, Goodman, & Naylor, 1995).
- In both OCD and ASD, repeatedly performing behaviors or rituals may help reduce anxiety. For someone with OCD, the anxiety may be related to what will happen if he can't engage in the behavior (for example, he may become ill or someone will be hurt). For someone with ASD, engaging in these same behaviors may be comforting, calming, or just interesting.
- Children with ASD are not always able to accurately self-report whether or not feelings of distress accompany the obsessive-compulsive behaviors. This is a key component in the diagnosis of OCD. It's often this distress that can help differentiate between a child engaged in self-stimulatory or stereotypic (repetitive) behaviors, and a child engaging in ritualized behaviors to relieve anxiety or distress from obsessive thoughts.





**Psychotic Disorder.** In the past, individuals with ASD were sometimes incorrectly diagnosed with a psychotic disorder. As more information and better assessment methods have become available, there have been far fewer misdiagnoses. Unfortunately, some children and adolescents still do receive an incorrect diagnosis of psychotic disorder when an ASD diagnosis would be more appropriate. When a psychotic disorder is suspected, it's important to consult a professional experienced in working with psychotic disorders and ASD, and who also has expertise with differential diagnosis.

**Here are some of the difficulties with making this differential diagnosis:**

- Children with ASD may engage in behaviors that appear strange or psychotic in nature. For example, a child may replay scenes and/or monologues from preferred television programs over and over. He may insist that he is the character in the program, or have difficulty communicating how he can tell the difference between fantasy and reality. He may get upset and engage in inappropriate behaviors such as yelling or aggression if you question him about his beliefs. This response is more likely tied to one of the primary characteristics of ASD—fixated interests and a desire for sameness. But the focus on fantasy characters and an insistence that these beliefs (which are not grounded in reality) are accurate often result in a diagnosis of a psychotic disorder by diagnosticians less familiar with ASD.
- Children with ASD may also report hearing voices. Although this could be a psychotic symptom, this should not be assumed. A child with ASD may be referring to hearing his own thoughts, hearing things people have said to him in the past, or hearing the voice of someone who is in the next room.

Children with ASD have been known to talk to themselves or mumble under their breath. This behavior may reduce anxiety or may be a way to comfort themselves in unfamiliar surroundings or anxiety-producing situations.

**Bipolar Disorder.** Children with ASD also often receive a diagnosis of bipolar disorder (or sometimes they're diagnosed with bipolar disorder in place of an ASD diagnosis). Children with these diagnoses exhibit behavior problems that may look similar but often have very different purposes or causes.

**For example:**

- *A child with ASD* often exhibits problem behaviors due to variables in the environment, such as:
  - ▶ He may not want to do difficult work or may not like interacting with a particular person.
  - ▶ She may want immediate access to something she really likes even though it is not available at the moment.
  - ▶ He may want attention from a preferred adult who is busy.
  - ▶ She may want to feel better. She may be avoiding something that makes her uncomfortable, or engaging in behaviors that make her feel calmer or physically more comfortable.
- *A child with bipolar disorder* can't control when his underlying mood will "cycle" or change (such as when he'll be more moody or easy-going). His behaviors are often related to mood and generally not triggered in isolation by events that occur in the environment. However, his mood may make certain environmental events more or less likely to upset him.

**Oppositional Defiant Disorder (ODD).** Children are sometimes diagnosed with ODD instead of ASD. This is most likely to happen when a child has advanced communication skills that seem to make an ASD diagnosis less likely. For example, a child with ASD may appear "defiant" when she refuses to complete a second math worksheet in one week. She is, in fact, acting defiantly, but it may be because she doesn't understand why she would do something (work on a math worksheet) she has already successfully completed in the past.

## Impact of ASD on the Family

Given the volume of information presented in this chapter, it seems appropriate at this point to discuss the impact that an ASD diagnosis has on a family. One important point to remember is that when any member of a family receives a diagnosis of a disability, it's going to significantly impact the entire family. Some family members may find new energy to do whatever they can to help, while others may become extremely stressed and shut down.

In the last 10 years, some researchers have begun to focus on the challenges that parents face when raising a child with ASD, and how they manage the stress. Much of the research related to the impact of an ASD diagnosis focuses solely on mothers; very little has focused on fathers. Parents generally agree on the strategies they adopt to cope with their child's diagnosis. However, mothers report receiving more support from friends and family than fathers (Altiere & von Kluge, 2009).

Stressors can be present regardless of the severity of a child's symptoms. And, not surprisingly, parents of children with high functioning ASD have higher levels of stress than parents of children without a diagnosis of ASD. All of this means that treatment should not focus exclusively on the child with ASD. In addition to treating the child, parents may also need to learn effective strategies for coping with their own distress (Rao & Beidel, 2009).

### **What follows are some of the major findings of Easter Seals' "Living with Autism" study published in 2008:**

- Parents worry about their child's ability to be independent.
- ASD impacts financial stability because of treatment cost and planning for a child after the parents pass on.
- ASD impacts employment status for parents due to taking time off for appointments, etc.
- ASD impacts a family's quality of life because they are more likely to eat at home, not go out to do much in the community, and spend more time on activities of daily living. Also, they often receive little support from extended family members.

- Parents worry about the quality of life for their child as he becomes an adult and what will happen to him after they die.
- Parents are concerned about the health of their child with ASD; it's often difficult to find doctors and health insurance.

An autism diagnosis certainly impacts parents, but it also significantly impacts siblings. Several factors may determine how much of an effect a diagnosis has on siblings. These factors include age, temperament, personality, birth order, gender, parental attitudes and modeling, and available supports and resources. Research has shown high levels of internalizing behaviors—that is, mood or anxiety difficulties—in both the children diagnosed with high functioning ASD and their siblings (Rao & Beidel, 2009).

**The Indiana Resource Center for Autism suggests siblings need the following supports (Wheeler, 2006):**

- Communication from parents that is developmentally appropriate, factual, and ongoing. They must know that communication within the family is encouraged.
- Attention from parents that is not related to their brother or sister with ASD. They may need time to engage in “normal” family activities.
- Information about how to interact with their brother or sister in ways that are similar to other sibling pairs.
- Choices about how involved they should be in the care and treatment of their brother or sister with ASD.
- To feel safe and know that they will be protected from behaviors their sibling with ASD might exhibit.
- Appropriate time and support to deal with their own feelings about their brother or sister’s diagnosis.
- Interactions with other siblings of children with ASD to share their experiences. Just as parents need help, siblings need guidance on how to respond to questions about their brother or sister’s disability.

## Recommended Readings}

Attwood, T. (1998). *Asperger's syndrome: A guide for parents and professionals*. London, England: Jessica Kingsley.

Baker, B. B., & Brightman, A. J. (2004). *Steps to independence: Teaching everyday skills to children with special needs*. Baltimore, MD: Paul H. Brookes.

Baker, J. (2008). *No more meltdowns: Positive strategies for managing and preventing out-of-control behaviors*. Arlington, TX: Future Horizons.

Grandin, T., & Scariano, M. M. (1986). *Emergence: Labeled autistic*. Novato, CA: Arena Press.

Harris, S. L., & Glasberg, B. A. (2003). *Siblings of children with autism: A guide for families*. Bethesda, MD: Woodbine House.

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Altieri, M. J., & von Kluge, S. (2009). Family functioning and coping behaviors in parents of children with autism. *Journal of Child and Family Studies, 18*, 83-92.

American Psychiatric Association (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., TR). Washington, DC: Author.

Centers for Disease Control and Prevention (2009a, December 18). *Data and statistics: New autism data*. Retrieved from, <http://www.cdc.gov/ncbddd/autism/data.html>

Centers for Disease Control and Prevention (2009b, December 18). *Facts about autism spectrum disorders*. Retrieved from, <http://www.cdc.gov/ncbddd/autism/facts.html>

Farrugia, S., & Hudson, J. (2006). Anxiety in adolescents with Asperger syndrome: Negative thoughts, behavioral problems, and life interference. *Focus on Autism and Other Developmental Disabilities, 21*, 25-35.

Graetz, J. (2009, October). *The college experience for individuals with Asperger syndrome*. Paper presented at the meeting of the Organization for Autism Research, Arlington, VA.

Mazefsky, C. A. (2009, October). *Psychiatric comorbidity in children and adolescents with high-functioning autism and Asperger syndrome*. Paper presented at the meeting of the Organization for Autism Research, Arlington, VA.

## References}

- McDougle, C., Kresch, L., Goodman, W. K., & Naylor, S. T. (1995). A case-controlled study of repetitive thoughts and behavior in adults with autism and obsessive-compulsive disorder. *American Journal of Psychiatry*, *152*(3), 772-7.
- National Institute of Neurological Disorders and Stroke (2010, March 8). *Rett's syndrome fact sheet*. Retrieved from, [http://www.ninds.nih.gov/disorders/rett/detail\\_rett.htm](http://www.ninds.nih.gov/disorders/rett/detail_rett.htm)
- Ozonoff, S., Iosif, A. M., Baguio, F., Cook, I. C., Moore-Hill, M., Hutman, T, ... Young, G. S. (2010). A prospective study of the emergence of early behavioral signs of autism. *Journal of the American Academy of Child & Adolescent Psychiatry*, *49*(3), 256-266.
- Rao, P. A., & Beidel, D. C. (2009). The impact of children with high-functioning autism on parental stress, sibling adjustment, and family functioning. *Behavior Modification*, *33*, 437-451.
- Stewart, M. E., Barnard, L., Pearson, J., Hasan, R., & O'Brien, G. (2006). Presentation of depression in autism and Asperger syndrome: A review. *Autism*, *10*(1), 103-116.
- Tantam, D. (2003). The challenge of adolescents and adults with Asperger syndrome. *Child and Adolescent Psychiatric Clinics of North America*, *12*, 143-163.
- Volkmar, F. R., Klin, A., Siegel, B., Szatmar, P., Lord, C., Campbell, M, ... Towbin, K. (1994). Field trial for autism in DSM-IV. *American Journal of Psychiatry*, *151*(9), 1361-1367.
- White, S. W., Oswald, D., Ollendick, T., & Scahill, L. (2009). Anxiety in children and adolescents with autism spectrum disorders. *Clinical Psychology Review*, *29*, 216-229.

# 2 Research Findings on Autism Treatment

Our understanding of Autism Spectrum Disorders (ASDs) 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 know which of these treatments has 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 on the autism spectrum.
- The lifetime costs associated with ASD are high (\$3.2 million per individual; Ganz, 2007). We can reduce these costs by choosing treatments that effectively increase important life skills and decrease problem behaviors.
- It is not reasonable to expect yourself to become an “expert” in all available treatments. It may feel more manageable if you focus your attention and resources on those treatments that research has shown to be effective.

## National Autism Center

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 treatments for children and adolescents with ASD. The results of this effort are available in the *Findings and Conclusions* report of the National Standards Project that we have included in the Appendix of this manual. We recommend that all parents 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. We have formatted the information about these treatments in easy-to-use tables. You are welcome to make copies of these handouts and distribute them to professionals, family members, or friends who want to learn more about these treatments.

Once you have decided which of these treatments will be the best option(s) for your child and family, we recommend that you make certain your team of professionals has the capacity to implement these interventions with a high degree of accuracy (see Chapter 5).



## 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

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Please note that not all strategies described elsewhere in this manual have support in the research literature. We developed examples throughout this manual based on interventions that are often put in place. Not all of these have solid research support. However, all of the Established Treatments identified in this chapter have solid research support.

## Antecedent Package

<b>Brief Description</b>	Antecedent interventions include a group of treatment strategies that involve modifying the environment <i>before</i> a problem (or “target”) behavior occurs. By concentrating on how we can alter the environment prior to a problem occurring, we can better support an individual with an Autism Spectrum Disorder (ASD).
<b>Basic Facts</b>	<p>Antecedent interventions have been shown to produce favorable outcomes for children and adolescents:</p> <ul style="list-style-type: none"> <li>• Aged 3-18 years</li> <li>• Diagnosed with autism</li> <li>• Who need to improve communication skills; interpersonal skills; learning readiness; personal responsibility; play skills; self-regulation; problem behaviors; and sensory and emotional regulation</li> </ul>
<b>Detailed Description</b>	<p>Most often, Antecedent Package interventions involve observing the child in the setting where problem behaviors occur, then determining which of many possible environmental changes would result in improved performance. This type of analysis is often completed by a qualified behavior specialist (such as a board certified behavior analyst, or behavioral psychologist). These individuals should be experienced in identifying situational events that lead to the target behavior of concern (e.g., off-task behavior, self-injury, problems keeping hands and feet to self, etc.).</p> <p>Using antecedent strategies involves changing environmental factors to increase the chances a child will be successful. These antecedent changes may involve individuals who are present, materials (toys, videos, etc.), tasks, and other motivating variables. Antecedent changes should be considered alone or in conjunction with other research-supported treatments. Antecedent modifications are often made in combination with treatments in the category of Behavioral Package, another “Established Treatment.”</p> <p>Experienced specialists can provide invaluable information, feedback, and support in the use of antecedent strategies with your child.</p> <p>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.</p>
<b>Example</b>	Cathy is a child in third grade with a diagnosis of Asperger’s Syndrome. She was referred to the behavior specialist at school due to problems with “talking out” around 2 p.m. The behavior specialist 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 the teacher 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 the teacher that it is important to give the snack <i>before</i> the problem behavior starts to occur — otherwise Cathy may learn to talk out more in order to get a snack.

### Recommended Readings}

Luiselli, J. K. (2006). *Antecedent assessment & intervention: Supporting children & adults with developmental disabilities in community settings*. Baltimore, MD: Paul H. Brookes.

Note: This is a technical book that should be in your service provider’s library.

<b>Brief Description</b>	Treatments included in the Behavioral Package category are based on behavioral principles. These treatments begin with an evaluation of what happens in the environment before and after a behavior being targeted. Then, using the data they collect, behavior specialists modify the environment accordingly. At a minimum, Behavioral Package strategies alter the <i>consequences</i> that are provided for appropriate and/or inappropriate behavior.
<b>Basic Facts</b>	Behavioral Package treatments have been shown to produce favorable outcomes for individuals: <ul style="list-style-type: none"> <li>• Aged 0-21 years</li> <li>• Diagnosed with autism and PDD-NOS</li> <li>• Who need to improve academic, communication, interpersonal, and play skills; learning readiness; personal responsibility; self-regulation; problem behaviors; restricted, repetitive, nonfunctional patterns of behavior, interest or activity; and sensory and emotional regulation</li> </ul>
<b>Detailed Description</b>	<p>There are four fundamental consequences that explain most behavior:</p> <ol style="list-style-type: none"> <li>1. <i>Positive Reinforcement</i>—adding a consequence for a target behavior that leads to an <i>increase</i> in that behavior. Reinforcers are delivered <i>after</i> the behavior occurs. For example, Jane says, “cookie” and her mom gives her a cookie. In the future, when Jane wants a cookie, she is 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.</li> <li>2. <i>Negative Reinforcement</i>—removing an unpleasant consequence after a behavior occurs. This leads to a greater likelihood the behavior will occur again in the future. For example, Jane hates broccoli and she screams and cries 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 because it has successfully led to the removal of broccoli in the past.</li> <li>3. <i>Positive Punishment</i>—adding a consequence for a target behavior that <i>decreases</i> the likelihood that the behavior will occur in the future. Let’s say Jane wants a cookie. Jane screams and cries, and her mother ignores this behavior. Her mother does not give in, and Jane does not get a cookie. There is likely to be less crying and screaming in the future when Jane wants a cookie (especially if Jane’s mother consistently responds this way).</li> <li>4. <i>Negative Punishment</i>—removing a pleasant consequence after a behavior occurs. This decreases the likelihood the behavior will occur again in the future. Jane loves cookies and her dog. She decides to experience both at the same time. But her dog eats her cookie! Jane is less likely to play with her dog in the future when she wants to eat cookies.</li> </ol> <p>In addition to understanding these four consequences that influence all human beings, behavior specialists should be able to identify the function of the behavior. That is, they should be able to determine why the behavior is occurring. Reinforcement, punishment, and the function of the behavior serve as the foundation for the strategies included in this package.</p> <p>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 facing; 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.</p>
<b>Example</b>	Johnny loves bubbles. His speech-language pathologist wants him to learn to request bubbles. She holds up the bubble wand and says the word “bubble.” Johnny says “bu.” She knows that this is great progress for him, so she blows the bubbles. Johnny is more likely to imitate the word “bubble” in the future—in fact, he may begin by requesting “bu” on his own. The speech-language pathologist will gradually work on helping him say the entire word “bubble.”

### Recommended Readings}

- Fitzer, A., & Sturme, P. (2009). *Language and autism: Applied behavior analysis, evidence, and practice*. Austin, TX: PRO-ED.
- Fouse, B., & Wheeler, M. (1997). *A treasure chest of behavioral strategies for individuals with autism*. Arlington, TX: Future Horizons.

## Comprehensive Behavioral Treatment for Young Children (CBTYC)

<b>Brief Description</b>	Comprehensive Behavioral Treatment for Young Children (CBTYC) programs involve intensive early behavioral interventions that target a range of essential skills which define or are associated with ASD (e.g., communication, social, and pre-academic/academic skills, etc.). These treatments are often described as ABA (or Applied Behavior Analysis program), EIBI (or Early Intensive Behavioral Intervention program), or behavioral inclusive programs.
<b>Basic Facts</b>	<p>CBTYC has been shown to be effective with children:</p> <ul style="list-style-type: none"> <li>• Aged 0-9 years</li> <li>• Diagnosed with autism and PDD-NOS</li> <li>• Who need to improve communication, interpersonal, play, and motor skills; cognitive functioning and personal responsibility; and problem behaviors and general symptoms associated with ASD</li> </ul>
<b>Detailed Description</b>	<p>Research has suggested that CBTYC is more effective than eclectic programs and traditional preschool or special education programs. Although programs consisting of CBTYC vary somewhat across treatment centers, each treatment program typically shares defining features including:</p> <ul style="list-style-type: none"> <li>• Intensive service delivery (typically 25-40 hours per week for 2-3 years) based on the principles of ABA</li> <li>• Data-based decision making that targets the defining symptoms of ASD</li> <li>• Using ABA strategies (e.g., discrete trial teaching, incidental teaching, errorless learning, behavioral momentum, and shaping) in a rich child-to-teacher ratio (often 1:1)</li> <li>• Individualized instruction in various settings (e.g., home, community, inclusive, and self-contained classrooms)</li> <li>• Guidance through treatment manuals</li> </ul> <p>CBTYC programs typically combine many behavioral treatments that focus on: Antecedent Package; Behavioral Package; Joint Attention Intervention; Modeling; Naturalistic Teaching Strategies; Peer Training Package; Schedules; and Self-management (see other Established Treatments for individual descriptions).</p>
<b>Example</b>	<p>Due to the complexity of CBTYC, it is difficult to develop an example that reflects all aspects of treatment. Instruction varies depending on the child's communication, cognitive, social, and adaptive skills, as well as his or her problem behaviors that interfere with skill acquisition and success across environments. A brief description of the possible progression through a CBTYC program is provided below.</p> <p>Billy first enters a CBTYC program at age 3 and begins receiving services for 40 hours per week across home, school, and community settings. He spends a large part of the day in discrete trial instruction learning how to ask for food in a socially acceptable way, share his toys, handle his frustration, and follow directions. This discrete trial instruction happens during snack time and lunch, in the play area, in individualized teaching locations, at home, in the grocery store, and any other setting in which trained parents, educators, or therapists can provide the instruction.</p> <p>After one year of treatment, Billy has acquired many new skills. He now spends a large portion of his treatment time using his newly developed skills with novel situations, materials, and people he encounters. For example, under the intensive supervision of his service delivery professional, Billy interacts with his peers in small social groups where he focuses on initiating interactions, asking others to hold toys, and taking turns while playing games.</p>

### Recommended Readings}

Lovaas, O. I. (2002). *Teaching individuals with developmental delays: Basic intervention techniques*. Austin, TX: Pro-Ed.

Maurice, C., Green, G., & Luce, S. (Eds.) (1996). *Behavioral intervention for young children with autism: A manual for parents and professionals*. Austin, TX: Pro-Ed.

## Joint Attention Intervention

<p><b>Brief Description</b></p>	<p>Joint attention refers to the behavior of two individuals focusing simultaneously on an object or activity <i>and</i> each other. The sharing of an activity is a fundamental skill in communication and social behavior, but it is not a skill that many individuals with ASD automatically develop.</p>
<p><b>Basic Facts</b></p>	<p>Joint attention interventions have been shown to be effective for children:</p> <ul style="list-style-type: none"> <li>• Aged 0-5 years</li> <li>• Diagnosed with autism and PDD-NOS</li> <li>• Who need to improve communication and interpersonal skills</li> </ul>
<p><b>Detailed Description</b></p>	<p>Joint attention is typically taught using a combination of strategies drawn from other Established Treatments identified through the National Standards Project. Joint attention interventions often involve:</p> <ul style="list-style-type: none"> <li>• Discrete trial teaching, which is a component of the Behavioral Package</li> <li>• Choice and prompting, which are components of the Antecedent Package</li> <li>• Modeling</li> <li>• The use of direct response-reinforcer relationship, which is a component of the Naturalistic Teaching Strategies</li> </ul> <p>(See other Established Treatments for individual descriptions.)</p> <p>When focusing on joint attention it is important to:</p> <ul style="list-style-type: none"> <li>• Set a clear goal: Do you want to initiate an interaction or respond to a bid from others?</li> <li>• Identify items the child prefers.</li> <li>• Determine the best settings for teaching the child. Ideally, joint attention skills will be developed in multiple settings where the child naturally spends his or her time (e.g., living room at home; free play area at school; in the park).</li> </ul> <p>There are several forms of joint attention including:</p> <ul style="list-style-type: none"> <li>• Following another person's eye gaze (i.e., the parent looks at some object or event and the child follows the parent's shift in eye gaze)</li> <li>• Showing an object to another person, or responding when someone else shows you an object</li> <li>• Pointing to an object, or responding when someone else points to an object</li> <li>• Watching an activity together and then looking to see each other's response to the event that is being observed</li> </ul>
<p><b>Example</b></p>	<p>Thomas does not respond to others when they attempt to direct his attention to items. Thomas' mother, Mrs. Brown, decides she wants to teach her son to respond by looking at an object when she points to it. Because she wants to motivate Thomas, she begins by identifying something she knows he will want to look at. She has observed Thomas several times showing interest in toys that light up, so she selects a number of these toys.</p> <p>Mrs. Brown starts teaching her son by placing one of the toys that light up on the living room floor. She then places her hand close to Thomas' face, and points at the light-up toy. When Thomas sees her finger, she guides him to look at the toy. She then activates the toy and guides him to look back at her. She knows that he needs to learn both to look at the object and then to look back at her so they can share the experience.</p> <p>She repeats this process multiple times. Eventually, when she points to the light-up toy, Thomas looks at the toy and to his mother with no guidance. Mrs. Brown will use this process with other objects to make sure that Thomas learns to look whenever she points to objects — not just when she points to objects that light up!</p> <p>Mrs. Brown also brings Thomas' 8-year-old sister into the activity. They learn to take turns pointing to objects and shifting their attention from the object to each other. In this way, Thomas learns to respond not only to his mother's pointing, but to other people's pointing as well.</p>

### Recommended Readings}

Linton, S. B. (2010). *Lesson ideas and activities for young children with autism and related special needs: Lessons for joint attention, imitation, play, social skills & more from autismclassroom.com*. CreateSpace.

## Modeling

<b>Brief Description</b>	<p>One of the most effective ways to teach someone what to do is to show him or her how to do it. The goal of modeling is to correctly demonstrate a target behavior to the person learning the new skill, so that person can then imitate the model. Children can learn a great deal from observing the behavior of parents, siblings, peers, and teachers, but they often need to be taught what behaviors should be imitated.</p>
<b>Basic Facts</b>	<p>Modeling has been shown to produce favorable outcomes for children and adolescents:</p> <ul style="list-style-type: none"> <li>• Aged 3-18 years</li> <li>• Diagnosed with autism, Asperger’s Syndrome, and PDD-NOS</li> <li>• Who need to improve communication, interpersonal, and play skills; cognitive functioning; personal responsibility; problem behaviors; and sensory and emotional regulation</li> </ul>
<b>Detailed Description</b>	<p>There are two types of modeling — live and video modeling.</p> <p>Live modeling occurs when a person models or demonstrates the target behavior in the presence of the child with ASD. When providing live modeling:</p> <ul style="list-style-type: none"> <li>• Make sure someone who can successfully model the target behavior is always available in the proper setting. The ideal setting involves any situation in which you would naturally demonstrate this skill or behavior.</li> <li>• Make sure you model the steps consistently (i.e., in the same manner during every session).</li> </ul> <p>Video modeling occurs when you pre-record the person who is modeling or demonstrating the target behavior. Keep the following points in mind:</p> <ul style="list-style-type: none"> <li>• Anyone who can correctly and independently perform the task can serve as a model — this includes the person with ASD. (Note that self-modeling may require significant editing.)</li> <li>• Make sure you shoot the video so your child can see the target behavior from the perspective of the person performing the behavior.</li> <li>• Make sure your child is paying attention to and is interested in the video.</li> <li>• Point out the important steps/features to your child during the video.</li> </ul> <p>Be sure to make the best quality video possible. Remember, after the initial time invested in making the video, it is an easy-to-use teaching tool, and is cost- and time-effective (e.g., the same video clip can be used by multiple individuals any time).</p>
<b>Example</b>	<p>Mrs. Henderson has tried using video modeling with her son Steve in the past. Steve is a 16-year-old with Asperger’s Syndrome and his mother wants him to become more independent. For example, she wants him to learn to make his lunch before he goes to school.</p> <p>Steve seems to have a hard time using this skill in real life unless everything in the kitchen appears exactly the way it does in the video. Mrs. Henderson has three other children — the kitchen <i>never</i> looks like it did in the video!</p> <p>Mrs. Henderson decides to try live modeling with Steve. His 17-year-old brother serves as the model one day and she serves as the model the next. Because there is more variation in live modeling, it may take a bit longer for Steve to understand how to prepare his lunch. But he does eventually respond, and he can make his lunch even when the kitchen looks a bit different from day to day.</p>
<p><b>Recommended Readings}</b></p> <p>Buggey, T. (2009). <i>Seeing is believing: Video self-modeling for people with autism and other developmental disabilities</i>. Bethesda, MD: Woodbine House.</p>	

## Naturalistic Teaching Strategies

<p><b>Brief Description</b></p>	<p>Individuals with ASD face challenges not only in learning new skills, but also in using their skills across different settings, with different people, and using different materials. They also need to know that they can take action in their homes, schools, and communities that will produce desirable outcomes. For these reasons, Naturalistic Teaching Strategies (NTS) primarily involve child-directed interactions to teach real-life skills in natural environments.</p>
<p><b>Basic Facts</b></p>	<p>NTS have been shown to produce favorable outcomes for children:</p> <ul style="list-style-type: none"> <li>• Aged 0-9 years</li> <li>• Diagnosed with autism and PDD-NOS</li> <li>• Who need to improve communication, interpersonal, and play skills</li> </ul>
<p><b>Detailed Description</b></p>	<p>When using NTS, consider the following guidelines:</p> <ul style="list-style-type: none"> <li>• Observe your child to find out what motivates her, and then structure teaching interactions around those interests.</li> <li>• Use materials your child is likely to encounter on a daily basis. For example, if you want to teach her to identify items that fall into the category “things you play with,” you might use dolls, blocks, and cars that are available at home and at school.</li> <li>• Teach skills in a variety of situations and settings (such as the home and community) while using a variety of materials (e.g., teach numbers by using different items such as pieces of candy or silverware).</li> <li>• Provide consequences that are naturally found in the environment and have a direct relationship to the activity you are completing. For example, food might be a natural and direct reinforcer at lunch and toys might be a natural and direct reinforcer during “play time.”</li> <li>• Provide loosely structured teaching sessions that vary based on the child’s interests for that day. For example, you may need to shift your plans from teaching your child to request different size objects using her princess dolls to requesting different size objects using puzzle pieces if she shows a greater interest in puzzles that day.</li> </ul> <p>Different names have been given to the treatment strategies included in the NTS category. These include: focused stimulation, incidental teaching, milieu teaching, embedded teaching, responsive education, and prelinguistic milieu teaching.</p>
<p><b>Example</b></p>	<p>Shawntee shows an intense interest in cars. Her dad, Mr. Carver, knows that she typically plays with her toy cars in her living room. He knows that she needs to learn to correctly identify her colors. He decides to work with her on color identification skills by using her toy cars. However, when he is ready to start, Shawntee shows an interest in blocks instead of the cars. Mr. Carver changes his strategy and works on the concept of colors, but follows his daughter’s interest in the blocks.</p> <p>When they enter the living room, he shows Shawntee that he has put all of the blocks in a clear bag. She shows her interest by reaching for the bag of blocks. He says “Let’s work on our colors,” and then pulls one of the blocks out of the bag. He knows she will need a prompt, so he tells her the name of the color. When Shawntee repeats the color, her father hands her the colored block. He has worked with behavior specialists who have shown him how to gradually fade (or reduce) the number of prompts he provides, and she is correctly identifying colors in no time.</p> <p>Mr. Carter loves to show Shawntee how proud he is of her, so he praises her often and gives her a hug for working so hard. Later, they work on color identification when they color together.</p>

### Recommended Readings}

Charlop-Christy, M. H. (2008). *How to do incidental teaching*. Austin, TX: PRO-ED.

## Peer Training Package

<p><b>Brief Description</b></p>	<p>For children, success in life depends very much on the ability to interact effectively with other children, or with siblings. However, some children with ASD avoid peers because their behavior may appear unpredictable or frightening. Peers may also not know how to create a successful relationship with a child with ASD. Peer Training Packages facilitate skill growth for children with ASD by training peers on how to initiate and respond during social interactions with a child on the spectrum.</p>
<p><b>Basic Facts</b></p>	<p>Peer Training Packages have been shown to produce favorable outcomes for children and adolescents:</p> <ul style="list-style-type: none"> <li>• Aged 3-14 years</li> <li>• Diagnosed with autism and PDD-NOS</li> <li>• Who need to improve communication, interpersonal, and play skills as well as decrease repetitive behaviors or fixated interests</li> </ul>
<p><b>Detailed Description</b></p>	<p>Some children on the spectrum frequently try to interact with peers, but may do so in unexpected or socially inappropriate ways. There are many factors to consider when designing a Peer Training Package including:</p> <ul style="list-style-type: none"> <li>• The age and skill level of the children (with and without ASD) should be similar. You should choose peers who are socially skilled, compliant, regularly available, willing to participate, and able to imitate a model.</li> <li>• The activities you include in the session should address the interests and preferences of both groups to ensure high motivation.</li> <li>• Teach the peers how to get your child's attention, facilitate sharing, provide help and affection, model appropriate play skills, and help organize play activities.</li> <li>• After training, have the peers interact with your child in a structured play setting.</li> <li>• The group instructor should use prompts and feedback to facilitate your child's interactions.</li> <li>• Be sure to train in multiple settings and with multiple peers to increase the likelihood that all the children use their skills frequently.</li> </ul> <p>Different names of peer training programs include: Project LEAP, peer networks, circle of friends, buddy skills package, Integrated Play Groups, peer initiation training, and peer-mediated social interaction training.</p>
<p><b>Example</b></p>	<p>Andrew is an 8-year-old boy who has not shown much interest in his peers. He does like to watch his classmates when they are playing basketball, though. However, when it is recess, he sits on the edge of the playground and rocks back and forth while staring at his peers. His teacher, Ms. Kien, notices this and decides to consult with the behavior specialist to design a Peer Training Package.</p> <p>Ms. Kien chooses four of Andrew's peers who are compliant and have well-developed social skills. She teaches the four peers how to approach Andrew and assist him in joining in their basketball game.</p> <p>Ms. Kien also works with Andrew to explain to him how he can respond to his classmates' requests to join their games. She teaches Andrew what to say when he is approached, what he should do when he joins the game, and how he can appropriately leave the game if he gets tired of playing.</p> <p>Finally, the time has come and Ms. Kien has Andrew's peers ask him to play basketball. She closely supervises their interactions and offers the least intrusive prompts necessary to ensure Andrew participates successfully.</p> <p>Ms. Kien was so pleased with the outcomes that she plans to extend this process to other situations. She knows she can use these strategies with skills like playing other games on the playground, transitioning from one activity to the next, and joining other kids at the lunch table.</p>
<p><b>Recommended Readings}</b></p> <p>Cater, E. W., Cushing, L. S., &amp; Kennedy, C. H. (2008) <i>Peer support strategies for improving all students' social lives and learning</i>. Baltimore, MD: Paul H. Brooks.</p> <p>Reid, D. H., &amp; Parsons, M. B. (2002). <i>Facilitating play dates for children with autism and typically developing peers in natural settings: A training manual</i>. Morganton, NC: Habilitative Management Consultants.</p>	



## Pivotal Response Treatment (PRT)

<b>Brief Description</b>	The goal of Pivotal Response Treatment (PRT) is to target pivotal areas that may have a watershed effect on the development of many other skills. This method focuses on creating situations that will encourage learning, and teaching skills in the natural environment, and helping children learn to initiate interactions with others.
<b>Basic Facts</b>	<p>PRT has been shown to be effective for children:</p> <ul style="list-style-type: none"> <li>• Aged 3-9 years</li> <li>• Diagnosed with autism</li> <li>• Who need to improve communication, interpersonal, and play skills</li> </ul>
<b>Detailed Description</b>	<p>Like Naturalistic Teaching Strategies, PRT aims to teach children to respond to various teaching opportunities within their own natural environment, and to increase independence from prompting. There are many pivotal areas targeted in PRT. For example, motivation, self-initiation, self-management, and responding to multiple cues are typically addressed.</p> <ul style="list-style-type: none"> <li>• <i>Motivation</i> can be enhanced by increasing choice, making learning materials meaningful by building a direct relationship between the target behavior and the reinforcer, incorporating both new and mastered tasks into the day, and reinforcing reasonable attempts (none of us do new tasks perfectly!).</li> <li>• <i>Self-initiation</i> involves teaching children to take action in the world so they can be more independent.</li> <li>• <i>Self-management</i> involves teaching children to regulate their own behavior by tracking their progress and accessing reinforcers for their successes.</li> <li>• <i>Responding to multiple cues</i> involves teaching children to respond to the diverse statements of others, or to different kinds of materials.</li> </ul>
<b>Example</b>	<p>Ms. Tanaka has noticed that her son Hideki has difficulty asking questions about novel items that interest him. She decides she is going to teach her son to ask questions like, "What is that?" She knows that Hideki has a particular interest in books about trains, so she purchases a couple of pop-up books on this topic. She wants to create an environment that motivates him to learn.</p> <p>Hideki's mother sits near him and looks inside the bag that contains the books. She verbally prompts Hideki to say, "What's that?" She responds, "It's a book about trains." She then pulls out the book, opens it, and allows him to look at the trains. They look through the book together and comment on the trains. She has also been helping him learn to make comments to others about things that are interesting to him.</p> <p>They finish the book and set it aside. Ms. Tanaka looks in her bag again and verbally prompts her son by saying, "What's that?" She follows the same procedure, and uses the book to share his interest and work on making comments. She has one more book left. After she looks in the bag, she looks at her son expectantly. After two seconds Hideki says, "What's that?" Hideki's mother is ecstatic! She presents her son with the book and looks through it with him while providing lots of attention.</p>

### Recommended Readings}

- Koegel, R. L., Schreffirnan, L., Good, A., Cerniglia, L., Murphy, C., & Koegel, L. K. (1998). *How to teach pivotal behaviors to children with autism: A training manual*. Santa Barbara, CA: University of California.
- Koegel, R. L., & Koegel, L. K. (2006). *Pivotal response treatments for autism: Communication, social, and academic development*. Baltimore, MD: Paul H. Brookes.

## Schedules

<b>Brief Description</b>	Schedules can be used for children with ASD to increase their independence and allow them to plan for upcoming activities. A schedule simply identifies the activities that must be completed during a given time period and the order in which these activities should be completed.
<b>Basic Facts</b>	<p>Schedules have been shown to be effective for children and adolescents:</p> <ul style="list-style-type: none"> <li>• Aged 3-14 years</li> <li>• Diagnosed with ASD</li> <li>• Who need to improve self-regulation skills</li> </ul>
<b>Detailed Description</b>	<p>Children with ASD may better handle transitions when they can predict what will happen next. This can be accomplished through the use of schedules. Schedules can be used anywhere—at home, in classrooms, during doctor’s visits, or on community outings. Schedules can be used for any activity—including leisure, social interaction, self-care, and housekeeping tasks.</p> <p>Schedules:</p> <ul style="list-style-type: none"> <li>• Can be used once per day, multiple times per day, or once per week</li> <li>• Are often used to help teach “first, then” concepts—such as, first complete your chores, then you can watch television</li> <li>• Should be followed by access to preferred activities. You can gradually increase the number of activities required before giving your child access to preferred activities.</li> <li>• Be presented in multiple formats. You can use pictures (real photos or Boardmaker®), written or typed schedules, 3-D objects, or personal digital assistance programs.</li> </ul> <p>The use of schedules may be as simple as:</p> <ul style="list-style-type: none"> <li>• Placing the pictures/texts on the board at the time of the activity</li> <li>• Pointing to the activity immediately prior to beginning each step or activity</li> <li>• Taking the picture off the board when the step or activity is completed</li> <li>• Placing the picture in a “done” container such as a bin, box, or pile</li> </ul>
<b>Example</b>	<p>Mrs. Hentz’s daughter, Sara, has difficulty remembering how to brush her teeth at night. Mrs. Hentz creates a visual schedule to increase her daughter’s independence with this task. Mrs. Hentz breaks down the task into several steps:</p> <ol style="list-style-type: none"> <li>1. Get the toothbrush and toothpaste</li> <li>2. Wet the toothbrush</li> <li>3. Put some toothpaste on the toothbrush</li> <li>4. Brush your teeth up and down and in circles</li> <li>5. Spit out the toothpaste</li> <li>6. Rinse out your mouth with water</li> <li>7. Rinse the toothbrush off</li> </ol> <p>These steps are depicted in pictures she has taken of Sara performing each step.</p> <p>Right before bedtime, when it is time for Sara to brush her teeth, Mrs. Hentz places the pictures within her daughter’s eyesight right beside the sink. Prior to beginning the task, Sara’s mother reviews the steps with her. She points to each step and asks, “What do we do now?” to assist her daughter in learning the necessary behaviors. As Sara begins to develop an understanding of how to complete each step of the task, Mrs. Hentz reduces the number of prompts she gives her daughter, and praises her for her attempts!</p>
<p><b>Recommended Readings}</b></p> <p>McClannahan, L. E., &amp; Krantz, P. J. (2010). <i>Activity schedules for children with autism: Teaching independent behavior</i> (2nd ed.). Bethesda, MD: Woodbine House.</p>	

<p><b>Brief Description</b></p>	<p>Independence is greatly valued in our society because it increases the likelihood of success in any situation and setting. Self-management strategies have been widely used to promote independence with tasks in which adult supervision is not needed, accepted, or expected. This process involves teaching individuals with ASD to evaluate and record their performance while they are completing an activity. It also involves teaching them to gain access to reinforcers for a job well done.</p>
<p><b>Basic Facts</b></p>	<p>Self-management has been shown to be an effective intervention for children and adolescents:</p> <ul style="list-style-type: none"> <li>• Aged 3-18 years</li> <li>• Diagnosed with ASD</li> <li>• Who need to improve academic skills, interpersonal skills, and self-regulation</li> </ul>
<p><b>Detailed Description</b></p>	<p>Self-management strategies focus on teaching individuals to be aware of and regulate their own behavior so they will require little or no assistance from adults. Before starting a self-management intervention:</p> <ul style="list-style-type: none"> <li>• Make certain your child can perform each component of the task. Initially, you may need to use other strategies like live or video modeling to teach the basic skills.</li> <li>• We all “work” for reinforcers—like a paycheck from your boss and a smile from your child! Before you begin, make sure you have identified reinforcers that will be meaningful for your child.</li> </ul> <p>After completing a step in the activity, your child should evaluate his own efforts to determine if he performed the step correctly. The evaluation process should consist of:</p> <ul style="list-style-type: none"> <li>• Clear criteria so the individual knows when he has succeeded and when he has fallen short of the mark</li> <li>• A systematic method for evaluating performance (e.g., checklists, wrist counters, or Velcro smiley faces that move from the incomplete column to the completed column of a task list)</li> <li>• Adults who can provide neutral feedback about the accuracy of the recording. Prompts may be necessary so your child can learn to correctly self-record his behavior.</li> <li>• Adults who can teach your child to seek access to reinforcers when he has met the pre-established criteria</li> <li>• Initially focusing on rewarding accuracy in <i>recording</i> and not accuracies in <i>performance</i></li> <li>• A plan to systematically fade or reduce the number of cues given by adults during self-management</li> </ul> <p>Benefits of self-management include:</p> <ul style="list-style-type: none"> <li>• Building awareness of your behavior</li> <li>• Accountability for carrying out a task</li> <li>• Direct and immediate self-feedback when recording your own data</li> <li>• Multi-tasking (i.e., managing your own behavior and recording it)</li> <li>• Decreasing social stigma that occurs when an adult’s assistance with simple and personal tasks is required</li> </ul>
<p><b>Example</b></p>	<p>Mr. Tipson’s daughter, Ashley, is a 17-year-old girl with PDD-NOS who likes to go shopping at the grocery store. When she is at the store she often forgets what items to get, grabs items that she does not need, and begins to show problem behavior, like yelling, when her father tells her to put an item back. Mr. Tipson decides to work with Ashley’s behavior specialist to develop a self-management program for his daughter.</p>

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## Self-management

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### Example

Mr. Tipson and the behavior specialist create six criteria they believe are essential to increasing Ashley's independence and preventing problem behavior. They also agree that she is capable of evaluating her performance if she is taught how to do so. They create a form that lists the five criteria they have identified. Next to each item, Ashley will circle the word "yes" if she completed the step and "no" if she did not successfully complete the step. The six criteria are:

1. Only put items in the cart that are on the grocery list
2. Cross off items after finding them
3. Use a "normal" tone of voice
4. Say hello to the cashier
5. Hand the cashier the correct amount of money
6. Wait for the change

Mr. Tipson walks slightly behind Ashley as she makes her way through the grocery store. She has a phone and a Bluetooth earpiece. He prompts his daughter by phone to look at her checklist to ensure she is completing each step accurately. After each step, he gives Ashley feedback about her behavior and her recording. When they leave the store, Mr. Tipson provides Ashley her reward for meeting three out of the five criteria. Once she reaches this goal on several consecutive outings, he will change the criterion to four out of five. He will follow this procedure until she can independently complete each step.

### Recommended Readings}

Koegel, L. K., Koegel, R. L., & Parks, D. R. (1992). *How to teach self-management to people with severe disabilities: A training manual*. Santa Barbara, CA: University of California.

<p><b>Brief Description</b></p>	<p>Story-based interventions identify a target behavior and involve a written description of the situations under which specific behaviors are expected to occur. Most stories aim to increase perspective-taking skills and are written from an “I” or “some people” perspective. The most well-known story-based intervention is Social Stories™.</p>
<p><b>Basic Facts</b></p>	<p>Story-based interventions have been shown to be effective for children and adolescents:</p> <ul style="list-style-type: none"> <li>• Aged 6–14 years</li> <li>• Diagnosed with autism and Asperger’s Syndrome</li> <li>• Who need to improve interpersonal skills; communication skills; social behavior; choice and play skills; understanding emotions; mealtime skills; self-regulation; and problem behavior</li> </ul>
<p><b>Detailed Description</b></p>	<p>Story-based interventions are a simple way to teach individuals with ASD to manage challenging situations in a wide variety of settings. When using a story-based intervention, use written descriptions for:</p> <ul style="list-style-type: none"> <li>• The target behavior</li> <li>• The situations in which the behavior should occur</li> <li>• The likely outcome of performing the behavior. This often includes a description of another person’s perspective.</li> </ul> <p>Although the information included in the story will vary based on your child’s cognitive and developmental level, some typical features include:</p> <ul style="list-style-type: none"> <li>• Information about the “who/what/when/where/why” of the target behavior</li> <li>• Being written from an “I” or “some people” perspective with the goal of increasing perspective-taking skills</li> <li>• Discussion or comprehension questions to make certain the child understands the main points</li> <li>• Pictures to enhance comprehension of the skills</li> </ul> <p>Story-based interventions are often used with individuals who have acquired reading and comprehension skills, but may also be used with individuals with strong listening comprehension skills.</p>
<p><b>Example</b> <i>Note: This example includes behavioral components in addition to the social story.</i></p>	<p>When Mr. Santiago tries to talk on the telephone at home, his son Alejandro has trouble waiting. Alejandro tries repeatedly to get his father’s attention by climbing on him, bringing him activities, and eventually screaming and crying. Mr. Santiago wants to teach his son how to behave when someone is on the telephone.</p> <p>Alejandro’s father develops a story that is written from his son’s perspective, and addresses the following questions:</p> <ul style="list-style-type: none"> <li>• What is he supposed to do? The answer: select a highly preferred activity such as playing with his army men or reading a book.</li> <li>• When is he supposed to demonstrate this behavior? The answer: When his father is on the phone.</li> <li>• What would likely happen if he correctly performed the behavior? The answer: He will probably be able to get extra attention when his father gets off the phone.</li> </ul> <p>The time has come for Mr. Santiago to practice the story with his son. Mr. Santiago reviews the story with Alejandro and asks him comprehension questions along the way to be sure he understands it (e.g., “What should you do when the phone rings?”). He role-plays the situation a couple of times with his son to be sure he understands the procedures.</p> <p>Alejandro’s father then asks a friend to call so that he can have a brief (one minute) conversation on the phone. As soon as the phone rings, Mr. Santiago hands Alejandro the story and then picks up the phone. Alejandro begins looking at the book and then decides to pick one of the activities from it.</p> <p>Mr. Santiago quickly gets off the phone and praises Alejandro for playing with his army men. He then plays with his son for the next five minutes. He knows this is only the beginning. Mr. Santiago will gradually increase the expectation that Alejandro behave appropriately while he is on the phone. He started with one minute, but he wants to work his way up to 10 minutes.</p>

**Recommended Readings}**

Gray, C. (2010). *The new social story book* (10<sup>th</sup> ed.). Arlington, TX: Future Horizons.

## Medication Management

The National Autism Center provided its methodology to medical experts so that a review could be conducted on biomedical treatments. Using this methodology combined with those of other evidence-based practice guidelines, Huffman, Sutcliffe, Tanner, & Feldman (2011) identified the level of scientific evidence supporting pharmaceutical as well as complementary and alternative medication (CAM).

Biomedical treatments were classified as “effective” if there was enough evidence to show they produced favorable outcomes in multiple studies. They were described as having marginal evidence if preliminary research identified possible benefit, but additional well-controlled research must be completed before the treatment’s effectiveness can be clearly stated.

In Table 1, “Medication Management: Pharmacologic and CAM Treatments,” we have identified the evidence supporting a number of biomedical interventions. In addition, we describe the symptoms, common side effects, and other information that may influence a parent’s decision to consider these options. Please note that some biomedical treatments may have been identified as “effective” for some purposes, but have only “marginal evidence” or be ineffective for other symptoms.

**Table 1}** Medication Management: Pharmacologic and CAM Treatments

Effective Treatment	Symptoms Addressed	Most Frequently Occurring Side Effects
<b>Risperidone</b>	Core symptoms (generally), maladaptive behavior, hyperactivity, irritability	Weight gain and sedation
	<i>It is the only medication approved by the FDA for the treatment of children and young adults with ASD. Note: Has marginal evidence of improving sleep disturbance</i>	
<b>Methylphenidate</b>	Inattention and hyperactivity (but response rate may be lower in children with ASD)	Significant agitation
	<i>Note: (1) Methylphenidate is known to be ineffective with restricted/repetitive behavior and irritability; (2) Methylphenidate has marginal evidence of improving behavioral symptoms and maladaptive behavior.</i>	
Medication with Marginal Evidence	Symptoms Possibly Addressed	Most Frequently Occurring Side Effects
<b>NRI anti-depressants</b>	Core symptoms, hyperactivity	Dry mouth, insomnia, nausea, headaches, stomach upset
<b>SSRI anti-depressants (especially fluoxetine and escitalopram)</b>	Restricted, repetitive nonfunctional behavior	Nausea, diarrhea, headaches, agitation
<b>Antihistamines</b>	Core symptoms	Drowsiness, dizziness, headache, loss of appetite, stomach upset, vision changes, irritability, dry mouth and dry nose
<b>Atypical antipsychotics (beyond risperidone)</b>	Core symptoms, behavioral symptoms and maladaptive behavior, hyperactivity	These side effects are medication specific.
<b>Automatic cognition enhancers</b>	Core symptoms, social interactions	None
<b>Certain proteins/amino acids</b>	Social interactions	None
<b>Naltrexone</b>	Behavioral symptoms and maladaptive behavior	Anxiety, appetite loss, chills, constipation, delayed ejaculation, diarrhea, dizziness, drowsiness, feeling down, headache, increased energy, increased thirst, irritability, joint and muscle pain, low energy, nausea, nervousness, sleeplessness, stomach pain/cramps, vomiting
	<i>Note: Naltrexone is known to be ineffective in the treatment of communication, social interaction, or restricted, repetitive, nonfunctional patterns of behavior.</i>	
<b>Psychostimulants such as methylphenidate</b>	Behavioral symptoms and maladaptive behavior	Significant agitation
<b>Secretin</b>	Hyperactivity	Difficulty breathing, shortness of breath, dizziness or lightheadedness, rash or itching, slow or irregular heart rate or palpitations, stomach upset, headache, diarrhea, sweating
	<i>Note: Secretin is known to be ineffective in the treatment of core symptoms, stereotypic behavior, and GI disturbance.</i>	
<b>Anti-epileptics (particularly levetiracetam and topiramate)</b>	Hyperactivity	Dizziness, drowsiness, and mental slowing; other side effects like weight gain, metabolic acidosis, nephrolithiasis, angle closure glaucoma, skin rash, hepatotoxicity, colitis, movement and behavioral disorders



## Final Considerations

You can choose from many interventions for your child. Although a great deal more research is necessary to determine whether or not 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 field. Importantly, several interventions were also influenced by fields such as special education and developmental psychology. In addition, biomedical treatments have been identified that address some of the challenging symptoms that are often associated with ASD. As new research is conducted, parents will have more research-supported options at their disposal.

Selecting among these 11 Established Treatments or the effective biomedical interventions may still pose challenges for you. This is one of the reasons professional judgment (Chapter 3) and family input (Chapter 4) are essential. Our goal in the upcoming chapters is to clarify the roles of professional judgment and family input in the delivery of evidence-based practice in the setting in which your child receives services (e.g., home, school, community). We hope you are on your way to securing evidence-based practice for your child with ASD!



## References}

Hoffman, L. C., Sutcliffe, T. L., Tanner, I. S., & Feldman, H. M. (2011). Management of symptoms in children with autism spectrum disorders: A comprehensive review of pharmacologic and complementary-alternative medicine treatments. *Journal of Developmental and Behavioral Pediatrics*, 32(1), 56-68.



# 3 Why are Professional Judgment and Data Collection Essential?

Without a doubt, you are the most important expert in your child's world. You can provide a detailed account of your child's life, strengths, the challenges he currently faces, and the obstacles he has overcome. This detailed knowledge will be important to the professionals you work with, and they will use this information to identify the most appropriate treatment for your child.

Your expertise is one of the reasons it's important for you to collaborate effectively with the other experts on your child's team. Each of you brings an important perspective to the conversation. They should appreciate your unique expertise, and you can greatly benefit from their professional judgment.

## Professional Judgment

Let's say you are working with a professional named Dr. Ramone, and she is well-versed in the *Established Treatments* identified by the National Standards Project (NSP). You both agree that it is important to improve the social skills of your 4-year-old son, Spencer. Dr. Ramone tells you she has had great success using modeling—one of the Established Treatments in the NSP—to teach social skills. But before she recommends modeling, she has a number of questions that will help determine the course of treatment (or whether it's the most appropriate course of treatment).

She asks, "Can Spencer imitate adults or other children?" "What kinds of things can he imitate?" "Does he like to watch television or spend time on computer games?" This last question is unexpected. What does



Many parents express concern about their child’s development to the child’s pediatrician, teacher, or other provider. Make sure your concerns are heard and understood. Your voice is an important factor in the diagnostic process and overall treatment plan.

watching television or playing computer games have to do with modeling? You know that Spencer can imitate adults and peers, and that he can imitate all kinds of activities, even complex skills like playing with other children. But he is not remotely interested in television or computer games. After you tell her this, Dr. Ramone recommends “live modeling” instead of “video modeling” because Spencer is more likely to pay attention to another person than he is to a television or computer screen with a video model. (Live modeling is when a child imitates a person who is demonstrating the successful performance of a task in real life. Video modeling is when a child imitates a person who has been videotaped successfully performing the task.) In this case, your expertise and Dr. Ramone’s professional judgment have led to the selection of a good treatment for Spencer.

Although it’s critical for parents to educate themselves about the many treatments available for a child with ASD,

you should also take full advantage of the knowledge and experience of professionals. Why is professional judgment so important? Because selecting and implementing treatments is a complex process! There are an unbelievable number of treatment options available to professionals working with children with ASD. Even if a professional only considers treatments that have produced favorable outcomes in research, you will still need to select from among the field of 11 identified by the NSP. In this case, professional judgment will play a central role.

Professional judgment is certainly more than just relying on a “gut instinct” to guide the development and implementation of a treatment program. It involves {a} integrating information about your child’s unique history, {b} an awareness of research findings that go beyond the *Findings and Conclusions* report, and {c} the need to make data-based treatment decisions. See Table 1 for more in-depth information about each of these factors.

It's clear that professional judgment can and should play an important role in treatment selection. And professional judgment should always be influenced 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. We don't want to overwhelm you with information about data collection. Instead, we want to share information that will help you be more comfortable discussing data with your child's professionals/practitioners. After all, treatment selection is only the first step in a dynamic process. Everyone on your child's team should be prepared to consider alternate treatment choices if the data show that a treatment is not helping your child progress.

**Table 1}** Factors Affecting Professional Judgment

<b>Child's History</b>	It is important for a professional to consider your child's developmental history, including social skills, communication, and play skills. As a parent, you can provide detailed information about when your child reached critical developmental milestones, experiences with other caregivers, and interactions with family members. A practitioner should consider all of these factors before suggesting a treatment for your child.
<b>Research Findings</b>	Professionals working with your child should be knowledgeable about relevant research. There are many scientifically sound studies that have contributed to our knowledge of ASD. (You can learn about research-supported treatments in Chapter 2 of this manual and in the Appendix). However, professionals may also need to be aware of research that goes beyond the scope of the NSP. For example, the NSP did not include research concerning adults, or individuals with multiple diagnoses in addition to an ASD. Yet the results of these studies may assist professionals in designing a more effective treatment for your child.
<b>Using Data</b>	We cannot emphasize enough the importance of using data to make decisions about your child's treatment. Your child's practitioners should be using their professional judgment based on the behavioral data gathered before, during, and after treatment.



The idea of collecting data may seem overwhelming. But it becomes easier over time, and there are ways to build it into your family's daily activities. Like every aspect of your child's treatment plan, knowing how to record data is very important. Not all professionals/practitioners have received sufficient training on data collection. This means that you may need to explain to other professionals on the treatment team how to correctly record data or ask them to receive training elsewhere. That way, everyone can see which treatments have helped your child build important skills or decrease problem behaviors. Data also tell you whether or not these improvements are sustained over time and if your child can demonstrate a skill in new situations and/or with different people—which is critical for people on the autism spectrum.

## Data Collection

Data collection is an essential part of any successful program for your child. It's relevant whenever a treatment is designed to increase skills or to decrease challenging behavior. Why is data collection so critical? Because collecting data before, during, and after treatment helps professionals and parents assess whether the child is making progress. Without clear data showing that a treatment leads to improvements, you may waste months or years on a treatment that isn't working for your child.

We all tend to rely on anecdotal evidence (what we happen to notice, what our "gut" tells us, etc.). Unfortunately, it is often unreliable! Therefore, we should only use anecdotal evidence alongside empirical evidence. Consider one behavioral treatment—a token system—as an example. Token systems are commonly used in home and school settings. The concept behind a token system (also known as a "token economy") is very similar to earning money and exchanging it for something you want or need.

The general idea is that a child receives a token (e.g., sticker, penny, poker chip, etc.) when he behaves appropriately or successfully for a given amount of time.

The goal is to increase appropriate behavior and/or decrease problem behavior. Once the child has earned a predetermined number of tokens, he turns in the tokens for a toy, the opportunity to play a game, watch a video, or participate in a really fun activity with a parent. With input from you, a practitioner would determine how many tokens are needed before an exchange is made.

Consider the case of Vanna, an 8-year-old with Asperger's Syndrome. After discussing their options with Vanna's psychologist, her parents put a token system in place at home. They have decided to focus on the following behaviors: {a} keeping your hands to yourself, {b} keeping your feet to yourself, and {c} stopping use of the computer when told to do so by a parent.

Vanna's father forgot to record her performance on the weekend of the baseball playoffs, while Vanna's mother was away. When her mother comes home, she asks, "How did Vanna do this weekend?" Because Vanna's father doesn't collect data regularly, his response might be influenced by a number of factors. If he thought Vanna had a good weekend, he might say, "Vanna was really good—the token system is really working." On the other hand, if he felt that Vanna had a

particularly bad weekend, he might have a more negative response: "It doesn't seem like the token system has affected Vanna's behavior much at all." We all jump to conclusions like these from time to time.

### **But consider the downside of this type of anecdotal evidence:**

- Vanna's father is more likely to remember what happened in the past few hours than how she has responded since the token system was introduced.
- Human beings tend to look for confirmatory evidence. If her father believes the token system will be effective, he is more likely to pay attention when Vanna is doing better. If, however, he thinks Vanna is *not* likely to respond to the token system, he is likely to pay attention when she breaks the rules.
- Vanna's dad was busy "multi-tasking" that weekend. It was probably difficult to concentrate on the playoffs and Vanna's behavior at the same time. It's possible he was more likely to notice things that went wrong instead of things that went right. On the other hand, he might have been so busy watching the baseball game that he missed the boxing match Vanna had with her brother!

Data collection is important because it provides you with a strong foundation on which to draw conclusions and make decisions about the effectiveness of your child's treatment. Before you can use data effectively, however, you will need a solid understanding of data collection procedures.

Parents should have reasonable expectations of the professionals who work with their child. As a parent, one of the things you *should* expect from these professionals is data collection. This is where some education about data collection procedures comes into play. Here are a few topics you should be prepared to discuss with the professionals who are developing treatments for your child. Each point will be discussed in further detail throughout this chapter.

#### Discussion topics regarding treatment and data:

- **Identifying Treatment Goal**

**Consider:** What is the goal, and exactly what behavior needs to be targeted?

- **Measuring Behavior**

**Consider:** How will you measure changes in the behavior you want to decrease or the skill you want to increase?

- **Monitoring Behavior**

**Consider:** How much data is needed, and will I be able to see a difference in the behavior or skill?

- **Analyzing Effectiveness**

**Consider:** How will I know if a treatment is working?



This chapter will probably include many unfamiliar terms or strategies for collecting or analyzing data. Most people need to review this information multiple times before it starts to make sense. Try not to be discouraged if this happens to you!



## Identifying Goals

What goals do you have for your child? You may have many future goals that span forward in time five, eight, or 10 years. When it comes to transitioning to adulthood, you may need to think this far in advance. But it's always important to set and focus on goals you would like your child to accomplish in the next six months to a year.

### Before setting these goals, consider the following:

- Goals should be developmentally appropriate. Parents, teachers, and other people in a child's life sometimes unintentionally set children up for failure by choosing goals that are not realistic. A good goal should be attainable within a year and should be based on the successes a child has already experienced. It should also be developmentally appropriate and necessary. For example, if your child can label 200 pictures of objects but can't request one of those items without being asked, "What do you want?" there is a problem. Developmentally, children are supposed to be able to use basic requesting skills in real life situations. If your child has not yet developed this skill, you should wait to begin working on the next 200 labels until basic requesting skills have improved.

As the parent of a child with special needs, you may not always know when certain skills should develop, or in what order. For example, learning number identification and one-to-one correspondence must be taught before basic math skills. They don't cover that in parenting handbooks! Be sure to discuss developmental timelines with the professionals who serve your child. Pediatricians should be an excellent resource regarding overall development; speech-language pathologists can help when it comes to communication; and educators are often a perfect resource when you need to understand what academic skills need to be targeted. Don't be afraid to ask professionals for more information.



### Parent-to-Parent



It's important for you and your family to communicate clearly about the goals you want to set. For example, is dinnertime overly stressful? Does your child have feeding issues that prohibit you from eating together as a family? Is he unable to sit at the table with the rest of the family because of lack of attending skills? If the behaviors that you identify could significantly change your daily routine in a positive way, you are much more likely to follow through with the treatment plan. Also, being successful in these real life situations is very socially meaningful for your child.

- Goals should be based on helping your child develop socially meaningful skills. Some behaviors might be irritating to adults who share the life of a person with ASD, but don't impede a child's progress or quality of life. At home, for example, your child may tap his fingers on his legs repeatedly. He may do this while you're watching television together, and you may find the habit distracting. But at the same time, he is spending time with you and other family members in an appropriate way. Your child is actually succeeding in this family activity. Even though the behavior is irritating, it should not necessarily be targeted for change.
- Goals should be developed in collaboration with the professionals on your child's team. For instance, you and the members of the team may decide to decrease the number of times your child asks you about upcoming activities. You collect data and determine that she asks approximately 25 questions per day about *each* upcoming event. Then you work with the team to identify a reasonable goal. As you do this, don't be surprised if the team asks you to collect data on one of your *other* children. Children with ASD should be taught to demonstrate behaviors and develop skills similar to those of their peers. It's not reasonable to expect

your child to ask only one question if the average child asks two or three questions in anticipation of an event. After all, kids have a tendency to check in with parents about exciting events (like birthday parties) and not-so-exciting events (like doctor's visits) from time to time.

Understanding the behavior of typically developing children is important because we sometimes hold our children with ASD to a different behavioral standard than their peers. Some parents or families set expectations too low and others may set expectations too high. Ask yourself if a typically developing child would do the same thing on the playground or at the dinner table. Would this behavior draw attention or be perceived as inappropriate? Expectations for our children with ASD should never be so low that they do not develop skills that will allow them to reach their potential and participate in community activities. But children with ASD should also not be singled out for unreasonably high expectations — *all* kids occasionally make bad choices, and many of these choices do not require extensive examination.



## Defining Target Behaviors

Any behavior you are attempting to change is typically referred to as the “target” behavior. You must develop a clear definition of the target behavior in order for your child to be successful. 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 presence of three blocks, the child will stack one block on top of another when asked.” Any person reading this definition should be able to identify the presence of the target behavior (i.e., the child stacks three blocks when instructed, “Build with these blocks”) or the absence of the target behavior (i.e., the child pushes blocks around the table when told, “Build with these blocks”).

In this case, the target behavior is very specific, observable, and can be easily measured. Defining a target behavior sounds easy, but it is actually difficult. Most people write vague behavioral definitions without realizing it. For example, “The child will

play appropriately with the blocks when given the direction to do so.” Do we all agree about what “playing appropriately” means? If the child hits the two blocks together, is that playing appropriately? If she is 6 months old, the answer is “yes.” If she is 5 years old, the answer is “no.” Without knowing this information about child development, two observers might come to very different conclusions about “playing appropriately.”

It’s also important to specify the context in which a behavior is expected to occur. There are behaviors that are very appropriate at the park but not remotely appropriate on a shopping trip to the mall. Definitions of target behavior should include a clear description of the context.

Let’s return to our example of “playing appropriately” to consider how this applies to treatment for children on the autism spectrum. By specifying that the child is expected to stack three blocks when instructed, “Build with these blocks,” it is now possible to determine whether or not the child responded correctly. Specifically, stacking three blocks is a correct response. However,

lining blocks in a row or putting them in a bucket is an incorrect response.

## Measuring Behavior

The following information should be taken as a basic primer of data collection procedures. Most of the professionals serving your child should know much more about data collection than what we provide here. This should be enough to help you feel more comfortable addressing the issue of data collection with the other experts on your child’s team.

There are many different ways to collect behavioral data. Some of the most commonly used data collection procedures include frequency, time sampling, duration data, and latency data. We provide information about each of these procedures in the tables on the next several pages. These tables include a definition, important points to consider, advantages and disadvantages, and examples of behaviors that might be targeted using the data collection procedure. For some of these procedures, we also include sample data collection forms.

## Frequency Data

<b>Definition</b>	<p>This involves counting the number of times a behavior has occurred in a given period of time. You make a tally mark on a data sheet each time a target behavior occurs. At the end of the observation period, you count the number of tally marks. This represents a frequency count.</p> <p>See Figure 1 on page 68 for an example of a frequency recording data sheet.</p>
<b>Important Points</b>	<p>Frequency data collection is typically used when a behavior has a distinct beginning and end.</p> <p>Be sure to collect data for the same length of time and under similar conditions.</p> <p>It is not necessary to continually collect frequency data in order to come up with valuable information. It is a “snapshot” approach that provides reliable data.</p>
<b>Advantages and Disadvantages</b>	<p>There are advantages and disadvantages to collecting frequency data. Recording frequency data is relatively easy. Unfortunately, it may not always best represent the child’s challenging behavior. For instance, you may record one tally mark if the child throws a tantrum for 60 minutes, 30 minutes, or five minutes. If you use a frequency count for a behavior such as tantruming and then implement a treatment, it is harder to see improvement, even when improvements are made. The tantrum could decrease in length from 60 minutes to five minutes, but because a tally mark records the occurrence of behavior (and not its duration), it looks like nothing has changed! You would certainly recognize a change in the behavior, but you need the duration data collection procedure to capture it as well.</p>
<b>Examples of Target Behaviors</b>	<ul style="list-style-type: none"><li>• Aggressive behavior such as hitting, kicking, slapping, or pinching</li><li>• Self-injurious behavior such as head-hitting</li><li>• Playing with toys, such as number of puzzles or mazes completed during a specified play time</li><li>• Academic work such as number of books read or math problems completed during a specified work time</li><li>• Daily living skills such as number of times the child independently used the toilet or number of bites taken during a meal</li></ul>

**Figure 1}** Frequency Recording Data Sheet

<b>Student:</b> <u>Jose</u>		<b>Date:</b> <u>10/2</u>	
<p>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.</p> <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>	

## Time Sampling

<b>Definition</b>	<p>Time sampling methods vary, but essentially require you to:</p> <ol style="list-style-type: none"><li>1. Identify the length of time you will do an observation.</li><li>2. Break down the observation period into smaller intervals.</li><li>3. Record whether or not the behavior occurred during the interval.</li></ol> <p>See Figure 2 on page 70 for an example of an interval recording data sheet.</p>
<b>Important Points</b>	<p>This data collection method is used most often when a target behavior occurs at a relatively high rate or does not have a distinct beginning and end. There are three different kinds of time sampling procedures that can be used:</p> <p><b>Partial interval.</b> The observer records the presence of the target behavior by marking a “+” in the designated box if the behavior occurs at <i>any</i> point during the interval. The observer records a “—” in the designated box if the behavior does not occur during the interval.</p> <p><b>Whole interval.</b> The observer records the presence of the target behavior if the behavior occurs during the <i>entire</i> interval. The observer records the absence of the target behavior if the behavior does not occur throughout the entire interval.</p> <p><b>Momentary time sampling.</b> The observer records the presence of the target behavior if the behavior occurs at the <i>end</i> of a specified interval. This means the target behavior is recorded <i>only</i> if it is present at the exact moment the interval ends. Even if the behavior occurs at other times during the interval, if it does not occur at the exact moment the interval ends, it is not counted.</p>
<b>Advantages and Disadvantages</b>	<p>Time sampling methods are useful when the behavior seems to occur throughout the day. Some forms of time sampling—such as momentary time sampling—easily allow the person recording data to do other things at the same time. In order to complete a time sampling measure, you will need a timer with an interval counter or voice recording marking specified intervals.</p> <p>But time sampling can be frustrating if it doesn’t accurately capture the severity of a problem, or how much improvement is made. For example, a child may behave well for 9½ minutes, and then scream just as the clock hits 10 minutes. In the past, the child spent the full 10 minutes screaming—so this current session seems like quite an improvement. But the data from both occasions simply showed that “screaming occurred” in that interval.</p>
<b>Examples of Target Behaviors</b>	<ul style="list-style-type: none"><li>• Stereotypic behaviors such as flapping one’s hands or rocking back and forth</li><li>• Social behaviors and play behaviors</li></ul>

**Figure 2}** Interval Recording Data Sheet

**Student:** Stacey **Date:** 4/9

**Self-stimulatory Behavior** is defined as any occurrence of Stacey rocking her upper body in a back and forth motion while seated in her chair.

Record self-stimulatory behavior during three 5-minute observations each school day.

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.

<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: _____					

*\*Note: the percentage of intervals is calculated in steps. First, calculate the numerator by adding all of the pluses together. In this case, it is 13. Then, calculate the denominator by identifying the total number of intervals during which your child was observed. In this case, it is 30 (13 + 17). By dividing 13 by 30, then multiplying by 100, we determine that self-stimulatory behavior occurred during 43% of the intervals.*



## Duration

<b>Definition</b>	A measure of duration means that you record how long the behavior lasts. You simply mark when the behavior “starts” and when it “stops.”
<b>Important Points</b>	Be sure to develop a very clear definition so it would be obvious to any observers when the behavior starts and stops.
<b>Advantages and Disadvantages</b>	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 are collecting data can be challenging.
<b>Examples of Target Behaviors</b>	<ul style="list-style-type: none"> <li>• Tantruming or crying</li> <li>• Aggressive or destructive episodes. This may include a combination of different behaviors that occur at the same time. For example, maybe a child hits, kicks, screams, and bites repeatedly for long periods of time.</li> <li>• Completing household chores or homework</li> </ul>

## Latency

<b>Definition</b>	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 when a target behavior occurs. You simply mark the time when an instruction is delivered and the time when the behavior actually starts.
<b>Important Points</b>	In order for most people to be successful, they need to be able to quickly respond to demands in their environment. Many children (including those on the autism spectrum) do not jump to complete an activity the moment they receive an instruction. The goal is to have your child respond to instructions from adults in the same time frame that a typically developing child would respond.
<b>Advantages and Disadvantages</b>	For children who have difficulty responding to directions or requests, a latency measure is a great way to track the effectiveness of a treatment program. However, it may be difficult at times to determine when to stop the timer when taking a measurement of latency.
<b>Examples of Target Behaviors</b>	<ul style="list-style-type: none"> <li>• Following directions</li> <li>• Responding to a peer</li> </ul>

## Additional Data Collection Considerations

The data collection procedures we have reviewed so far are extremely versatile. You can use the same data collection methods (i.e., frequency, time sampling, duration, and latency) for increasing or decreasing target behaviors. There are some additional data collection procedures that are sometimes overlooked, and we describe them below.

“Permanent products” are tangible outcomes associated with specific behaviors. For example, a worksheet, completed art project, or assembled toy (like a Mr. Potato Head) are all permanent products. Permanent products are ideal for the classroom setting because a good deal of academic work lends itself to these measures.

Self-monitoring systems require the child to record the occurrence of his own target behaviors. Many adults self-monitor behaviors such as time spent exercising, food consumed, or money spent. This data collection method can be applied whenever the goal is to increase or decrease a target behavior. A child may learn to monitor if she has completed all the steps required to clean her room, or if she has taken the steps necessary to build a social network that supports her. These



Did you know there are applications for your smartphone or tablet designed to help you with data collection?

self-monitoring systems are often used in conjunction with Self-management, one of the Established Treatments. Self-monitoring can occur in any setting.

## Final Data Collection Considerations

Be sure you understand the “Who, What, When, and Where” of the data collection procedure. Getting answers to the following simple questions will provide you with much-needed information as you get started on your child’s treatment.

**At a minimum, ask the practitioner:**

- **WHO** will be collecting the data?
  - **Considerations:** Be sure to inform team members of their responsibilities.
  - **Practitioner’s guidance:** The practitioner should provide training to all team members collecting data.
- **WHAT** do you need to collect the data?
  - **Considerations:** Some data collection procedures require specific materials (e.g., a stopwatch).
  - **Practitioner’s guidance:** The practitioner should provide data sheets and inform you if you need other materials.
- **WHEN** will the data be collected?
  - **Considerations:** Data collection may be required throughout the day, or only for a few minutes a day.
  - **Practitioner’s guidance:** The practitioner will inform you of times and days when data collection will occur. He or she will need to ask you a series of questions before making this recommendation. You should rarely have to collect data throughout the day.
- **WHERE** will the data be collected?
  - **Considerations:** You may be collecting data in specified environments.
  - **Practitioner’s Guidance:** The practitioner will list all environments where data collection should occur (e.g., home, playground, school, etc.). He or she should make this recommendation based on your input about when behaviors are most likely to occur and what is manageable for your family.



## Monitoring Behavior

Data collection is important! But it's only useful if it serves the purpose of helping us to understand factors that produce the best outcomes. In order to successfully monitor a child's progress, the data need to be organized in a meaningful way. To monitor progress, both baseline and treatment data must be collected.

### Using Data to Establish Baselines

We recommend that data be collected *before* a treatment is implemented. The data you collect before beginning treatment are called "baseline" data. Without collecting baseline data, it will be impossible to clearly show that the treatment has led to your child's improvement. Baseline data collection need not be tedious or time-consuming once you have a system in place. Your practitioner should guide you through the entire data collection process by providing materials (such as data sheets), training, and support.

A trained practitioner will use professional judgment to determine the best data collection procedure based on your child's behavior or skill that needs improvement. At times, the practitioner may determine there is a need to change the data collection procedure because it is not capturing elements of the target behavior, or because there is a change in the behavior. For example, instead of just throwing himself on the ground, your child now kicks and screams when having a tantrum. It may be necessary to make modifications so that the data accurately capture the right behavior. Don't be afraid to ask your practitioner why changes are necessary. This may help you participate more fully in future decisions regarding your child's treatment.

### Treatment Data

Once you have identified the treatment goal and collected baseline data, it's time to actually implement the treatment. You will have selected the treatment 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 treatment at this time (see Chapter 5).

Can you and other members of your family realistically implement a treatment across all settings? For instance, can you use the recommended treatment at the grocery store, playground, or in the car? If not, the proposed treatment may not be the correct one for you, or you may need more training to know how to use the treatment in these situations. See Chapter 4 for recommendations about making your voice heard.



Data collection during the treatment phase is important to determine whether the treatment is working. Some people like to make that decision based on their *perception* of effectiveness. But if you don't collect data during the treatment phase, it will be hard to know if the treatment is really working. For a child 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? More importantly, you don't want to continue using a treatment that isn't helping your child make progress.

It's essential for your practitioner to compare how your child performs during both baseline and treatment. Without completing these kinds of analyses, practitioners are really just guessing about what to do next. These comparisons should be done frequently (e.g., daily or semi-weekly) so decisions about whether

or not to continue with a treatment are made in a timely manner. The practitioner may decide to continue treatment if improvements are detected when comparing baseline and treatment data. Or the practitioner may decide to revise the current treatment, or implement an entirely new treatment, if it becomes clear things are not improving, or are getting worse!

**You should also expect the practitioner to:**

- Provide you with the rationale for continuing the treatment or making changes.
- Take into account any difficulties you and your family may have implementing the treatment with integrity. Be honest with the practitioner if you are unable to implement the treatment as designed, so changes can be made to make the situation manageable.

### Parent-to-Parent



Your ultimate goal is for your child to use his new skill—or control her behavior—today, tomorrow, and in different situations that are important to your family. Clinicians refer to this as “generalization.” The data collection techniques discussed in this chapter will help you determine if your child is maintaining skills over time and generalizing these skills to new situations. When you develop goals, be sure to include maintenance and generalization components. Then use data to determine if your child is successfully performing the new skill or behavior in all important “real life” situations.

Ongoing data collection will help you determine how changes in your child’s treatment affect the target behavior.

Remember—it’s important to use the same data collection procedure during both baseline and treatment phases.

It’s good to keep in mind that treatments often require revision. Imagine that your physician recommends a new antibiotic when the one you previously used was not effectively battling your infection. You know the initial antibiotic did not work based on data (your temperature won’t go down!). You do not rule out the second antibiotic simply because the first one didn’t work. In the same way, your child’s practitioner should frequently analyze the data and recognize if your child would benefit from a change to the treatment plan.

## Analyzing Treatment Effectiveness

Determining if a treatment is effective begins with graphing data. Once data are graphed, the process of visual analysis allows us to quickly decide if the treatment {1} has led to improvements, {2} has not made any difference or, {3} has made things worse! The last thing anyone wants is to continue all of the effort that goes into providing a treatment if it is not making any difference or is making things worse.

## Graphing Data

As data are collected, your practitioner should graph your child's performance (e.g., frequency of target behavior or a newly acquired skill). Graphing is a useful tool that can help you and your practitioner make timely decisions regarding your child's treatment plan. Looking at tally marks on a data sheet can be informative. But what happens when you need to look across five, 10, or 20 data sheets?

Putting the data into a graph allows you to interpret it more easily. Line graphs are commonly used to track changes in behavior over time. Basic computer software such as Microsoft Excel™ can be used to generate simple but informative graphs. Some people still draw graphs by hand.

On a line graph, each data point represents one data collection session (e.g., one school day, one therapy session, one evening at home, etc.). See Figure 3 on page 78 for a simple example of a graph. A vertical line (i.e., phase line) can be drawn between the baseline and treatment phases to indicate the introduction of the treatment. All data points in the same phase are connected by a line, but data points are not connected across phases (e.g., moving from the baseline phase to the treatment phase).

Phase lines can be inserted at any point on the graph to show where a change in the treatment occurred. For example, if your child started a new medication while you were implementing the treatment, you would use a phase line to indicate when that change took place. The new phase reflects the multi-component aspects of treatment that may be influencing your child's behavior.

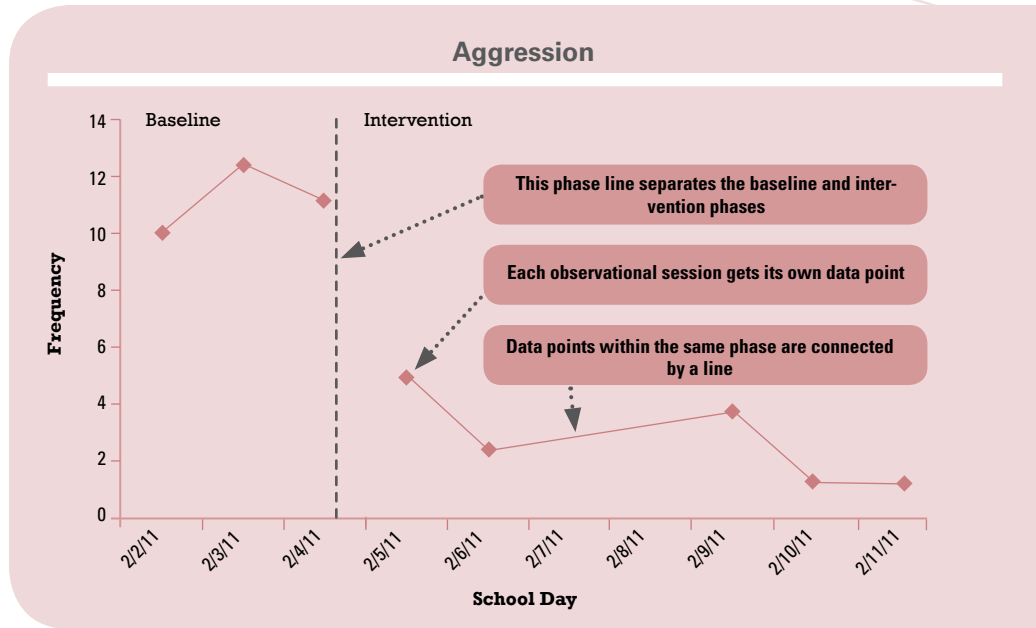
## Visual Analysis of Data

The practitioner should guide you through a visual analysis of the graph so you are comfortable understanding what it says. He or she will 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 treatment is so fast and dramatic that the improvement will just jump out at you.

Unfortunately, that may not always be the case. It becomes easier to interpret graphs if you understand the concepts of "stability" and "trends" in the data.

- Stability simply refers to how consistent the behavior is within a phase.
- Trend refers to the direction of change across data points within a phase.

**Figure 3}** Graphical Representation of Data



Before we begin a full discussion of these concepts, it's important to point out that they will be applied to all data points *within* a given condition (phases are often referred to as conditions; there are both baseline and treatment conditions). For example, you will apply the concepts of stability and trends separately to your baseline and your treatment conditions. This is necessary to see if a change has really occurred in your child's behavior.

Let's apply the concept of stability to Henry, a 15-year-old adolescent with ASD. Henry likes to talk about the solar system. In fact, Henry will make statements about the solar system whether

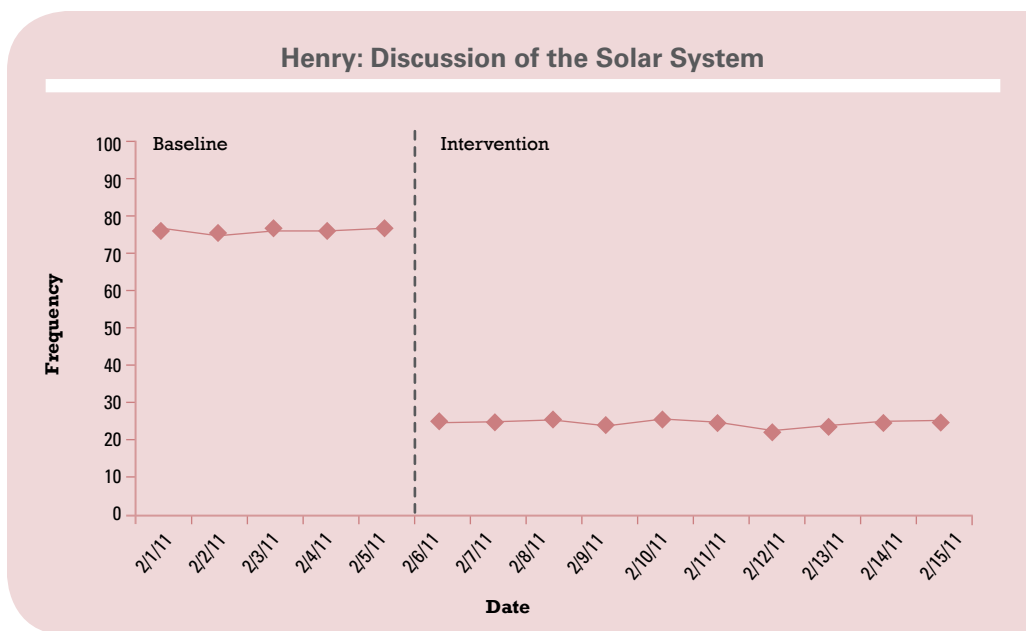
or not others are interested in the topic. Henry's team has implemented a treatment plan (including self-monitoring) to decrease the frequency of Henry inappropriately talking about the solar system. In addition to self-monitoring, Henry is practicing discussing a wide variety of topics with his practitioner and parents.

Figure 4 is a line graph representing the frequency of Henry inappropriately discussing the solar system. Notice that the number, or frequency, of Henry's discussions about the solar system is quite stable in both the baseline and treatment phases. It's easy to see that the treatment was effective because Henry's



behavior is so consistent in both phases. By comparing the baseline and treatment conditions, his parents and practitioners can all see that a big change occurred after the treatment was put in place. The number of times Henry talked about the solar system was reduced, and it remained consistently low after treatment.

**Figure 4}** Graphical Representation of Stability in Data



Now let's take a look at trends in data. There are several ways to show a trend. The easiest way is to visually determine what line best "describes" all of the data. A practitioner can "draw" this trend line using a program like Microsoft Excel™.

Analyzing trends in the data will help determine if behavior change is moving in the desired direction. Ideally, when you implement a treatment to reduce problem behaviors, the desired effect would be a decreasing (or descending) trend relative to baseline. That is, consistently implementing the treatment is leading to a decrease in the problem behavior. In contrast, when implementing a treatment to increase behaviors or skills, the desired effect would be an increasing (or ascending) trend relative to baseline. That is, consistently implementing the treatment is leading to an increase

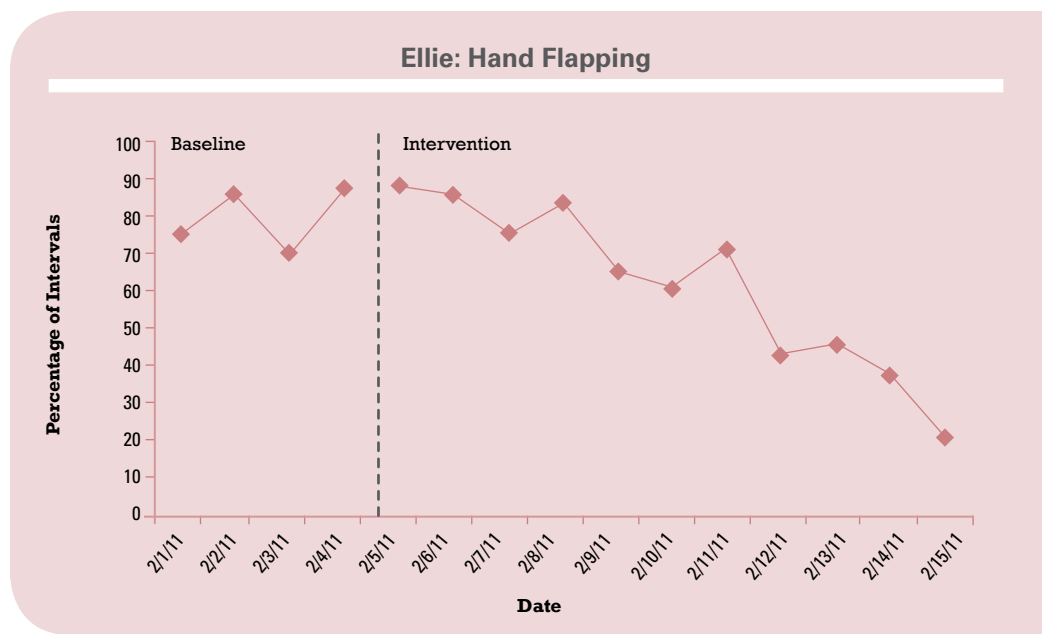
in the behavior or skill. It's important to collect at least three data points per condition. Identification of a trend requires at least three data points and often may require five or more. It can be difficult to identify a trend when the increase or decrease in behavior is gradual.

Let's take a look at an example of a trend in data. Ellie is a 3-year-old girl with ASD. She frequently flaps her hands. Her parents and practitioners are working hard to help Ellie decrease the frequency of hand flapping. The treatment includes giving Ellie many preferred toys to keep her hands busy. It also includes

a reinforcement program designed to increase the amount of time she keeps her "hands down." The practitioner recommends the data be collected using a partial-interval time sampling method. Twice during each evening, Ellie's parents collect data during a 5-minute time sampling.

Figure 5 shows the percentage of intervals during which Ellie flapped her hands. Although the data are not as stable as the data presented for Henry, it's clear that there is a decreasing trend in the treatment phase. This decreasing trend suggests the treatment for hand

**Figure 5}** Graphical Representation of Trend in Data



flapping is effective. The following section should help you understand why a practitioner will want to further investigate the effectiveness of the treatment.

Based on the examples we provided here, it may seem that data analysis is very easy. That's because the changes we have shown from the baseline to the treatment condition are very great. Graphed results are not always this clear. The professionals you work with may need to apply additional data analysis methods such as an evaluation of the percentage of overlapping data points or the magnitude of change. However, what you've learned here should provide you with a foundation in data analysis, and will help you understand how to determine if a treatment is effective. But to really know if a treatment works, more data will need to be collected.

## Is the Treatment Effective?

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

This research design is used by scientists and practitioners. Practitioners like single-subject research design for many reasons, but primarily because it can be applied to one individual. It can also be applied to a small group of people.

Try not to be intimidated by terms like "research design." One of the most commonly used single-subject designs is the reversal design. It is also known as the ABAB design. Clinicians should use this kind of research design to answer questions about your child's response to treatment.

Reversal (ABAB) designs most often involve a baseline phase (A) followed by a treatment phase (B)—and then another baseline phase (A) followed by a treatment phase (B). This type of design demonstrates the relationship between the treatment 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 after stepping on the scale a few times.

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

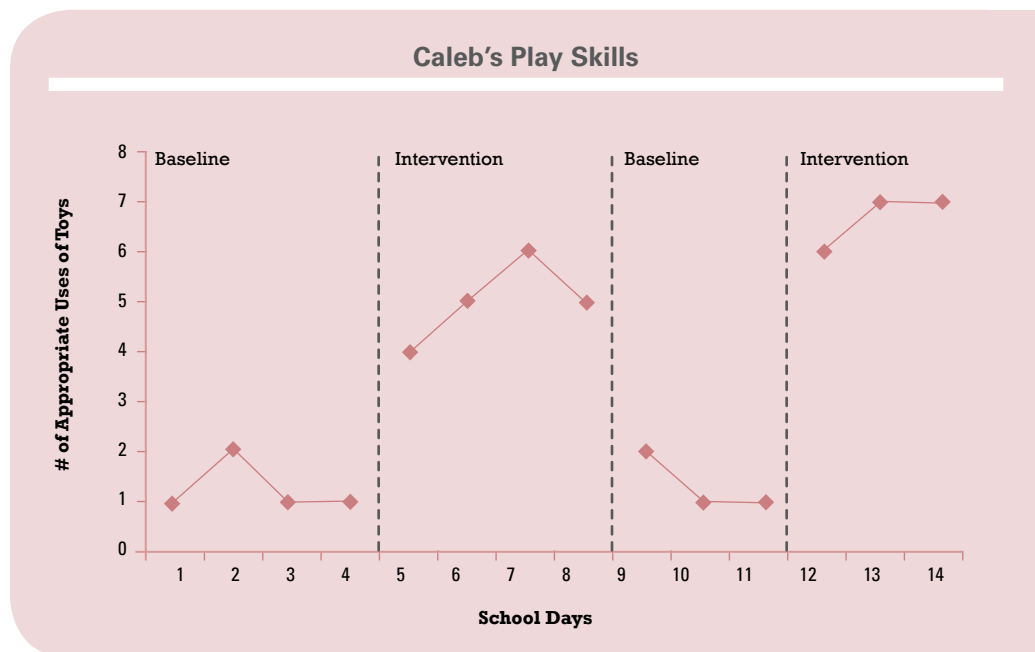
**A (Baseline):** You go off the diet—only to find a few months later that you have gained a few pounds.

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

An example illustrating the use of this research design may be helpful. Caleb, a 4-year-old with ASD, is learning to play. Caleb’s team (i.e., practitioner, teacher, and parents) has decided to use a Story-based Intervention Package that includes a story designed to teach specific behaviors. In Caleb’s case, the stories may focus on play skills, such as asking friends to play or taking turns. Data are collected during one baseline phase and one treatment phase. The practitioner analyzes the data using the line graph and concludes the treatment appears to be effective for Caleb. Some people would rather skip the second baseline and treatment phases and might wonder why they would need to repeat them.

Caleb’s practitioner knows there is a very good reason to go back to baseline and then re-implement the treatment. Often, a number of “environmental variables” change at the same time. Let’s say a new child moves into the neighborhood and befriends Caleb at the same time you begin the Story-based Intervention Package. If both of those events occur at the same time, how do you determine whether the story-based intervention, and not his new friend, is responsible for the behavior

**Figure 6}** Graphical Representation of Caleb’s Play Skills Based on Reversal Design



change? By using an ABAB design, you can see a clear relationship between the treatment (in this case the Story-based Intervention Package) and the behavior.

With Caleb, the data suggested an improvement in play skills during the first story-based intervention phase. Although the team would like to see those play skills continue to improve, the team decides to take a few days to re-introduce a baseline phase. This is one way to determine whether the treatment is really effective. After graphing the data (see Figure 6), it becomes apparent that removing the treatment has resulted in a substantial decrease in Caleb's play skills. The team quickly re-introduces the treatment and his play skills just as quickly begin to improve again.

The team is now confident the story-based intervention is effective. You may think, "But we already thought the treatment was effective. Was it really necessary to remove the treatment?" We would argue that it *was* necessary. The data could have just as easily shown that the treatment was not the reason Caleb's play skills improved. Perhaps the new neighbor 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 gather materials and review the stories is not the best use of everyone's time!

The process of finding effective treatment for your child may seem overwhelming! And, sometimes, things may get worse before they get better. Although this process **WILL** be frustrating at times, the end result—helping your child succeed—will be exciting, rewarding, and tremendously worthwhile.



## Final Considerations on Professional Judgment and Data

Professional judgment is critical when questions arise and decisions need to be made.

**For example:**

- How long should we continue in baseline and treatment phases?
- Is your team able to accurately implement the treatment?
- What environmental variables are influencing the stability of the data?
- Based on visual analysis, is this treatment effective?

In a perfect world, a child's behavior would respond to all treatments in the desired direction. In reality, professional judgment is essential when things don't go as planned. Problem-solving strategies rely heavily on professional judgment. Problem-solving through a challenging situation is not just about dropping the current treatment for another treatment. It involves solid case conceptualization with a critical eye. This requires good training, an understanding of the science of behavior, a variety of clinical experiences, compassion, and professional judgment.

Be realistic about your child's overall treatment plan. Not everything will work the first time. It may take several weeks or months to collect baseline data, introduce the treatment, then collect more baseline data, and re-implement the treatment. This is an ever-changing process—that is why professional judgment in analyzing and making modifications to the treatment plan is crucial to success.

### Treatment Integrity

Treatment integrity refers to the degree to which you are correctly implementing a treatment. Implementing the prescribed treatment with integrity is critical to your child's success. Consider a weight-loss program with a diet and exercise component. Let's say you follow the program most of the time. Maybe you have a piece of cake or large cheese pizza a couple times a week. When you do not lose weight, can you say that the weight-loss program did not work? No. You are unable to determine if the weight-loss program is ineffective until you implement the diet component based on your dietician's prescription.

Treatment integrity is just as important with your child's treatment plan. If you do not implement the treatment as prescribed by the practitioner, you cannot say with any certainty that it was ineffective. Writing out the treatment plan, reviewing it with all team members, and participating in necessary training are just a few ways to help ensure treatment integrity. If any team member is unable to implement the treatment as prescribed, the team should discuss the barriers that are getting in the way.

Every person involved in a child's treatment plan needs to implement it the same way across multiple settings. This may be difficult for many parents who have jobs, other children, and social obligations. Take the time to allow everyone to discuss the difficulties of implementing your child's treatment. Other team members may have some creative ideas to help improve treatment integrity.



## When the Data Are Disappointing

So, what do you do when a treatment fails to produce the desired behavior change? Although this can be frustrating and discouraging, there are ways to problem-solve and move beyond the setbacks.

**Ask yourself the following questions and use these strategies to help assess the situation:**

### ● Are the definitions clear?

**Strategy:** 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 data—especially if you have multiple data collectors (parents, teacher, paraprofessional, etc.).

### ● Has the team identified relevant variables?

**Strategy:** 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 adding another research-supported treatment on days when the environmental variable (e.g., lack of sleep) occurs will improve the outcomes.

### ● Has the team consulted with all available experts?

**Strategy:** Be sure to draw on the expertise of all available professionals. Perhaps the speech-language pathologist determines that your target behavior is not appropriate given your child's communication delays. Similarly, the psychologist or behavior specialist might help you identify the function (or purpose) of the 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 behavior). The psychologist or behavior specialist could help identify the function(s) of the behavior to develop more effective treatments.

### ● Has the team assessed treatment integrity?

**Strategy:** Ensure the treatment 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.

If you are like most parents I know, it never occurred to you that you would spend time learning about data collection as an adult. Some of you may even prefer to clean your oven or garage instead of focusing on this chapter! But here are some positive things to keep in mind:

- Data collection becomes easier over time. In fact, you're likely to reach a point when you can't believe it was not always a valuable tool at your disposal.
- You will feel more comfortable at meetings with schools and therapists. Once you understand how to collect and interpret data, your input about your child's needs and progress has more validity. You're not just asking for random changes—you have the information (data) explaining *why* you are asking.
- You will know that your child is making progress!
- When your child seems to stop making progress on a skill from time to time, you will be empowered to challenge professionals. I recommend doing this nicely!

Good luck and happy data collection.





# 4

## Family Preferences and Values in the Treatment Process

**As a parent, you are the expert on your child. You know his or her likes and dislikes, strengths and needs, struggles and successes. You have learned — through experience, trial and error, and instinct— what helps your child feel calm, happy, and secure.**

You are also your child’s strongest advocate in the goal of developing the skills he or she needs to live an enjoyable, successful life. As you learned in Chapter 3, you should feel comfortable having a strong voice in decisions concerning your child’s treatment. And the values your family holds can and should influence this process.

The term “family values” takes on a specific meaning in the context of raising a child with ASD. Think of a family’s values as the unique preferences or concerns that individuals with ASD—and/or their family members—bring to the discussion about treatment. Family values should have direct bearing as you select skills and behaviors to target, and as you identify appropriate treatments to help your child reach his or her potential and/or enhance the family experience.

For example, your family may value attending worship services together. If so, your goals for your child’s treatment could include learning to sit or kneel quietly in a church, temple, mosque, or other worship setting for a specified period of time, understanding and following the content of a religious service, or participating in various aspects of the service. Other families may value spending time outdoors together. For them, working on leisure activities such as hiking or playing kickball may become a focus of treatment.

**There are many factors that can influence family values, including:**

- Cultural variables
- Family structure
- Work and career issues
- Financial factors and considerations
- Community factors

## **Cultural Variables**

Family values and preferences are strongly influenced by cultural variables (Connors & Donnellan, 1998). Therefore, treatment goals and strategies for your child should be congruent with your family's cultural values. It's important that your voice is heard when decisions are being made, and that members of your child's treatment team understand your family's cultural preferences.

**Consider the following examples:**

- Many young students with ASD do not make frequent eye contact like their peers do or, when they do, that eye contact is fleeting. Eye contact is often a treatment target because it is a socially important skill for most individuals in the larger culture of the United States. It is often one of the first skills taught in many research-supported treatment programs that focus on improving attending and responding to adult treatment providers. Yet, in some Native American and Asian American cultures, eye contact with adults is considered a sign of disrespect (Lian, 1996; Wilder, Dyches, Obiakor, & Algozzine, 2004).
- Reducing self-stimulation is also a frequent treatment goal for children with ASD. However, these behaviors are largely ignored by Navajo parents of children with disabilities. Navajo parents tend to focus more on the strengths of their children rather than behavioral excesses or deficits.

In each of these cases, the values of the family may play a very important role in the decision to target these behaviors for change. If the child can make progress without targeting eye contact or self-stimulatory behaviors, there is no reason for these behaviors to be altered, especially given the cultural values and preferences of the family.

## Family Structure

The composition of your family may also influence your values and preferences about treatment for your child. For example, your child's grandparents may take an active role in his or her care and well-being. It is not uncommon for parents to feel 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 experiencing distress. Regardless of the support or challenges offered by extended families, it may be helpful for you to seek out resources that support grandparent involvement.

Families raising a child with ASD along with typically developing siblings face a unique set of challenges. Some siblings do not understand why their brother or sister doesn't play with them. Other siblings need to learn strategies for managing the stress when classmates make fun of the child with ASD. Older siblings may need help and guidance as they grapple with the possibility of having to be a lifelong protector for their sibling on the spectrum. As a result, you might seek out resources that provide sibling support. The structure of your family may influence your selection of specific treatment goals for your child on the spectrum or therapy for other family members.

## Other Factors

Other considerations that may influence your family values and preferences include work and career issues, financial factors, and available community resources. For example, your job requirements may impact the amount of time you have available to participate in your child's treatment program. Or, as is the case in some two-parent households, one parent may choose to 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, or may become one of the primary out-of-school "therapists" for their child. Complicating matters still further, it's not unusual for parents to have more than one child with some type of disability or educational need. In this case, the stress is increased as you work to ensure that each of your 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 (such as limited financial resources).

Financial factors may influence a family's ability to purchase prescribed medications, provide transportation to appointments, or buy materials to support a child's skill development at home. Community factors—such as access to trained professionals, support services for individuals with disabilities, and family support services—must also be considered both in terms of the quality of services that are available and the costs to the family. It's important to remember that these services may help the family function more effectively as a unit, and that the financial cost may be vastly outweighed by the gain in general well-being among family members—but this is not necessarily the case.

Military families face a unique set of employment issues. For example, 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.

Given the many factors that may influence your current levels of stress, or your capacity to participate in certain treatments, your values and preferences may change over time. A treatment goal that would seem essential under different circumstances may suddenly get moved into an "important in the long run but not today" category. You should voice your concerns if and when your child's needs and/or the needs of the family change. The professionals working with you may also voice their concerns. This dialogue is vitally important to ensure that critical goals are being addressed, and that the strategies used are both feasible and effective.

Providing families with a voice in the educational and treatment process is often called "family-centered care." The family-centered approach recognizes the

Parent-to-Parent



As the parent of a child with an ASD, it's critical that you actively share your perspectives with your child's treatment team. There may be times when you may become more than a participant in the treatment and planning process. In fact, you may become the team leader when selecting and implementing the best strategies for your child.

partnership of parents with treatment professionals in decision making (Murray et al., 2007). It 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).

We know that active family involvement leads to better outcomes.

### **Consider the following:**

- Children have been more successful when parents are involved in the education and treatment of children with and without disabilities in early childhood programs (Levy, Kim, & Olive, 2006; Pérez Carreón, Drake, & Barton, 2005).
- In educational settings, high parental involvement leads to improved academic performance, positive attitudes toward school, higher homework completion rates, fewer placements in special education, academic perseverance, lower dropout rates, and fewer suspensions (Christenson, Hurley, Sheridan, & Fenstermacher, 1997).
- In other treatment settings, high levels of parental involvement lead to improvements in generalization of skills across environments (Crockett, Fleming, Doepke, & Stevens, 2007; Schreibman & Koegel, 2005), development of communication skills (Kern, 2000), and improved treatment gains overall.

Parental involvement in treatment is also important in medical settings. According to Horwitz et al., (2002), health professionals should provide "primary medical care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective." Physicians and other primary care providers should support families by providing education about ASD. They can also work effectively with families by assisting them in implementing interventions, facilitating access to resources, and providing emotional support for the child with ASD as well as his or her family (Carbone, Behl, Azor, & Murphy, 2010).

If your physicians or primary care providers are not providing this level of care, take the time to discuss your concerns with them. Some primary care providers take their cue from parents about how much information they should offer. They worry about overwhelming families. Don't be afraid to address your concerns with your child's healthcare providers if you feel that you need more information or a different level of support. A healthcare provider who was perfect for one of your other children may not be the best match for your child with ASD.

There are clear benefits when parents are actively involved in their child's treatment. But exactly how can parents be involved? The goal of this chapter is to provide you with concrete recommendations in response to this question.



We live in a culture that often tells us not to question the authority of healthcare providers. But keep in mind that some healthcare providers may not have a great deal of experience or comfort with providing care to a child with ASD or other special needs. It's perfectly acceptable to take the time to identify options, talk to other families, and be honest about your concerns. You might even need to have materials ready to educate the healthcare provider! As you do with all other professionals caring for your child, be respectful, listen carefully, engage in a candid dialogue, and advocate for your child when needed.

## Range of Services

During a sixth-month period, children with autism receive an average of six different types of intervention or medical services, provided by an average of four different agencies and seven different professionals (Kohler, 1999)! As a parent, you are very likely to interact with a variety of professionals on a frequent basis. These individuals should understand your family's preferences and values. And communication between them and you is key.

Many parents come to think of themselves as a manager or team leader. In that role, you may need to encourage, coordinate, and facilitate information across these providers, as well as share your expertise about your child. Of course, not every parent is in a position to take on such a challenging role. You must decide what is best for you and your family. You may have to be the breadwinner, the taxi driver, the housekeeper, or all of the above. In that case, you may decide that it's not in your family's best interest for you to be a manager or team leader at the same time.

As mentioned earlier, many children with ASD require multiple services. Let's consider each type of service separately, and then discuss coordination of care among services.

## Educational Supports

If your child is between the ages of 3 and 21, many of the services he receives are likely to be provided in the school setting. Your child may have an Individualized Family Support Plan (IFSP) or Individualized Education Plan (IEP) that describes the types of services he receives at home or school, as well as specific goals for his educational progress. Your child may receive one or a few specialized services at school, such as learning support and speech/language therapy. Or he may receive many supports, including occupational therapy, physical therapy, autism support services, life skills education, social skills support, counseling services, and others.

Some children may not have an IEP, but may still receive specialized services in the school setting. Other children may have no specialized services or supports at all. Regardless of the level of support that your child receives from the school, your involvement in many aspects of your child's education is very important.

### **We offer the following recommendations for getting involved in your child's school experience:**

- **Educate yourself.** The first step in becoming involved in your child's education is to educate yourself! Start by familiarizing yourself with special education law.
  - ▶ The primary law that pertains to special education in the United States is called the Individuals with Disabilities Education Improvement Act (IDEIA). It spells out rules and regulations that schools must follow when providing special education services. IDEIA contains many terms, such as "least restrictive environment" or "specially designed instruction." The language can be confusing or overwhelming, so it's important to take time to learn what these terms and regulations mean for your child.
  - ▶ Your child's educational team should provide you with materials to explain your rights and your child's rights under educational law. If the school doesn't provide these materials, ask for them. If you don't understand the materials, ask for clarification from the educational team, other professionals, or other parents. You may be in the habit of declining these materials. We encourage you to take and review them every year. Many parents find that, based on their experiences with school professionals over several years, they are in a better position to understand these materials when they revisit them over time.

In Table 1 you will find some commonly used terms related to special education law. We recognize that this is only a small sampling of the information contained in educational law. Perhaps one of your best resources is other parents who have worked with an educational team to design an appropriate educational program for their child. You may also want to visit the following websites: [www.autism-pdd.net/law.html](http://www.autism-pdd.net/law.html) and [www.aboutautismlaw.com](http://www.aboutautismlaw.com).

- **Communicate frequently with your child’s educational team.** You need to establish frequent and clear communication with your child’s educational team. This communication can take a variety of forms, such as a daily communication notebook, observing your child in his classroom, or weekly reports on his progress. As noted in Chapter 3, one of the most important issues to discuss with your child’s team is exactly how his progress is being monitored over time and what types of data are being collected.

Recently, one of the authors of this chapter participated in an IEP meeting for a student with ASD. The student’s teacher, occupational therapist, and speech-language therapist discussed the gains she had made over the past year, and were very pleased with her progress in all areas. Her exasperated mother finally said, “But she can’t even tell me what she wants to eat for dinner!” The team realized immediately that there was an important need affecting the whole family that was not being addressed. By opening up the line of communication, the team was able to identify educational goals to meet the family’s specific needs.

- **Get involved in your child’s education.** Spending time in your child’s school or participating in school activities can provide you with more information about your child’s education. It can also facilitate communication between you and school staff. You can become involved by volunteering in your child’s classroom, participating in parent support groups, joining the Parent Teacher Association, and in many other ways. Ask your child’s teacher, principal, or special education director for ideas about getting involved in school. (We recognize that this is not a feasible choice for all parents.)



**Table 1}** Common Terms in Special Education

<b>Educational Term</b>	<b>Acronym</b>	<b>Definition</b>
Behavioral Intervention Plan	BIP	A plan of positive behavioral interventions in the IEP of a child whose behaviors interfere with his/her learning or that of others.
Consent		Requirement that the parent (1) be fully informed of all information that relates to any action the school wants to take concerning the child; and (2) understands that consent is voluntary and may be revoked at any time. See also “procedural safeguards notice” and “prior written notice.”
Due Process Hearing (or Impartial Due Process Hearing)		Procedure to resolve disputes between parents and schools — an administrative hearing before an impartial hearing officer or administrative law judge. Called a “fair hearing” in some states.
Extended School Year	ESY	Special education and/or related services that are provided beyond the usual school year, at times when school is not usually in session — typically during the summer.
Free Appropriate Public Education	FAPE	Special education and related services that are provided in conformity with an IEP; without charge; and meet standards of the State Education Agency (SEA).
Functional Behavior Assessment	FBA	The process of determining the cause (or “function”) of behavior before developing an intervention.
Family Educational Rights and Privacy Act	FERPA	A statute about confidentiality and access to a student’s education records.
General Curriculum		Curriculum adopted by the Local Educational Agency (LEA) or the State Education Agency (SEA) for all children from preschool through high school.
Individuals with Disabilities Education Improvement Act	IDEA or IDEIA	A law ensuring services to children with disabilities throughout the nation. IDEA governs how states and public agencies provide early intervention, special education, and related services to more than 6.5 million eligible infants, toddlers, children, and youth with disabilities.
Independent Educational Evaluation	IEE	An evaluation conducted by a qualified examiner who is not employed by the public agency responsible for the education of the child in question.
Individualized Education Plan	IEP	A legal document that details what special education services and supports a child will receive, as well as goals and objectives for those services.

{Continued on following page}

**Table 1}** Common Terms in Special Education (cont.)

Educational Term	Acronym	Definition
Individualized Family Service Plan	IFSP	A plan that documents and guides the early intervention process for children with disabilities and their families.
Inclusion		The practice of educating children with special needs in regular education classrooms in neighborhood schools. See also “least restrictive environment.”
Least Restrictive Environment	LRE	A requirement to educate special needs children with children who are not disabled to the maximum extent possible.
Local Education Agency	LEA	Local education agency or school district.
Modifications		Substantial changes in what the student is expected to demonstrate — includes changes in instructional level, content, and performance criteria; may include changes in test form or format; includes alternate assessments.
Prior Written Notice	PWN	Concerns and requests made by the parents must be accepted or rejected. The IEP team must list the reasons for accepting or rejecting the parents’ proposal.
Procedural Safeguards Notice		Requirement that schools provide a full, easily understood explanation of procedural safeguards that describe parents’ rights to an independent educational evaluation, to examine student records, and to request mediation and due process.
Reasonable Accommodations		Adoption of a facility or program that can be accomplished without undue administrative or financial burden.
Related Services		Services that are necessary for a child to benefit from special education, including: speech-language pathology and audiology services, psychological services, physical and occupational therapy, recreation, early identification and assessment, counseling, rehabilitation counseling, orientation and mobility services, school health services, social work services, and parent counseling and training.
Supplementary Aids and Services		Aids, services, and supports that are provided in regular education classes that enable children with disabilities to be educated with non-disabled children to the maximum extent appropriate.
Transition Services		Services designed to facilitate movement from the school to the workplace or to higher education.
*This information is summarized from <a href="http://www.wrightslaw.com">www.wrightslaw.com</a> “Glossary of Special Education Terms”		

## Medical Supports

Children with ASD may have medical concerns that will sometimes be the focus of treatment. For example, seizure disorders are more common in some children with ASD. In addition, many children with ASD take medication prescribed by a psychiatrist, developmental pediatrician, or other physician. This means you'll need to visit health professionals frequently to monitor the effectiveness and/or side effects of the medication, and to share updates or concerns. Your voice is most clearly heard when you bring data to support your conclusions (see Chapter 3). As with educational professionals, it's also important for medical professionals to understand your family preferences and values.

### We offer the following recommendations as you establish relationships with your child's medical providers:

- **Educate yourself.** You will feel more comfortable sharing your thoughts, concerns, and needs if you are armed with information about your child's medical treatment. We include some sample questions to ask your child's physician below. Use the answers to these questions to determine if a medication or treatment prescribed by your physician is congruent with your values and goals for your child.
  - ▶ What does research tell you about this treatment or medication? (See Chapter 2.) How old were the children in the relevant study? Were children with autism included in the study?
  - ▶ What are the possible side effects of this treatment or medication? How will this treatment or medication impact or interact with my child's other treatments or medications? (Note: Be sure your physician knows about all complementary and alternative medical approaches you may be using. Anything that has the potential to have a desirable effect can also have a side effect!)
  - ▶ How will you know if this treatment or medication is effective? How soon can we expect to see improvement?
  - ▶ How long will my child need to take this medication or participate in this treatment? Is there a plan to discontinue this treatment or medication at some point in the future?
  - ▶ What other procedures might be involved with this treatment or medication? For example, will my child need blood tests or other procedures while taking this medication?

### ● **Share your family's preferences and values with your child's physician.**

Medical visits often feel rushed, and you may feel that you don't have time to share important information about your family's preferences and values. Preparing for the doctor's visit ahead of time will help. Make some short notes about your family's values related to:

- ▶ Managing symptoms with medication
- ▶ Goals for your child
- ▶ Activities your child enjoys or finds reinforcing
- ▶ Areas where your family needs support
- ▶ Any other topic you feel is important to share

If your visit does not allow time to discuss your questions and concerns, leave your notes with the physician so he or she can review them at a later time. Make sure the physician knows that you'll be waiting for a follow-up phone call. You may also use more formal documents like those provided in Forms 1–3 to share information about your family preferences and values. If you are completing the *Autism Spectrum Disorders–Parental Participation Questionnaire* (ASD-PPQ), it's likely that only page 3 of Form 2 will be useful for the physician. We include this document in its entirety, however, so you can also use it with school professionals.

## **Behavioral, Mental Health, and Other Supplemental Support Services**

Behavioral and mental health services for your child may be short-term and focused on a specific behavior or mental health problem, such as sleep issues. Or they may be long-term and focused on teaching a variety of skills and strategies. Children with ASD also frequently participate in private speech-language therapy, occupational and physical therapy, or other therapy services.

**As you incorporate these types of services into your child’s treatment plan, consider the following:**

- **Educate yourself.** By now you are probably noticing a pattern in our recommendations! One of the most important things you can do is educate yourself about the type of treatment your child receives. Here are several questions you should ask regarding behavioral and mental health services or supplemental support services:
  - ▶ What treatment model, if any, does your child’s therapist use? What does the research say about the use of this treatment model for children with ASD? (See Chapter 2.)
  - ▶ What is the expected course of treatment? How long will treatment last? How will you know when treatment is finished? How often will your child need to come to therapy?
  - ▶ What are the treatment goals? Your therapist should talk with you about the goals for treatment, and should base these goals on the needs of your child and your family.
  - ▶ How will the services be paid for? It’s important to understand insurance benefits for your child with ASD. While many states are beginning to pass legislation related to payment for services, many insurance plans still do not reimburse families for specialized autism services. You should discuss your therapist’s fees up front, and find out what services will and will not be covered by your insurance plan.
  - ▶ What are the expectations for parents in therapy? Does your therapist involve parents in therapy? Will you attend all, some, or just parts of the sessions? What information will your child’s therapist share with you about his or her interactions with your child?

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Ask questions to be certain that the professional working with your child has appropriate credentials, and that the organization has a proven track record of success. See Chapter 5 for an extensive list of questions.

## 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?

<b>TOPICS</b>	<b>No</b>	<b>Not Sure</b>	<b>Yes</b>
<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.*

### 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.

I am not familiar with this treatment.		<b>Antecedent Package</b>																		
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 <i>not</i> 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.

**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

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.

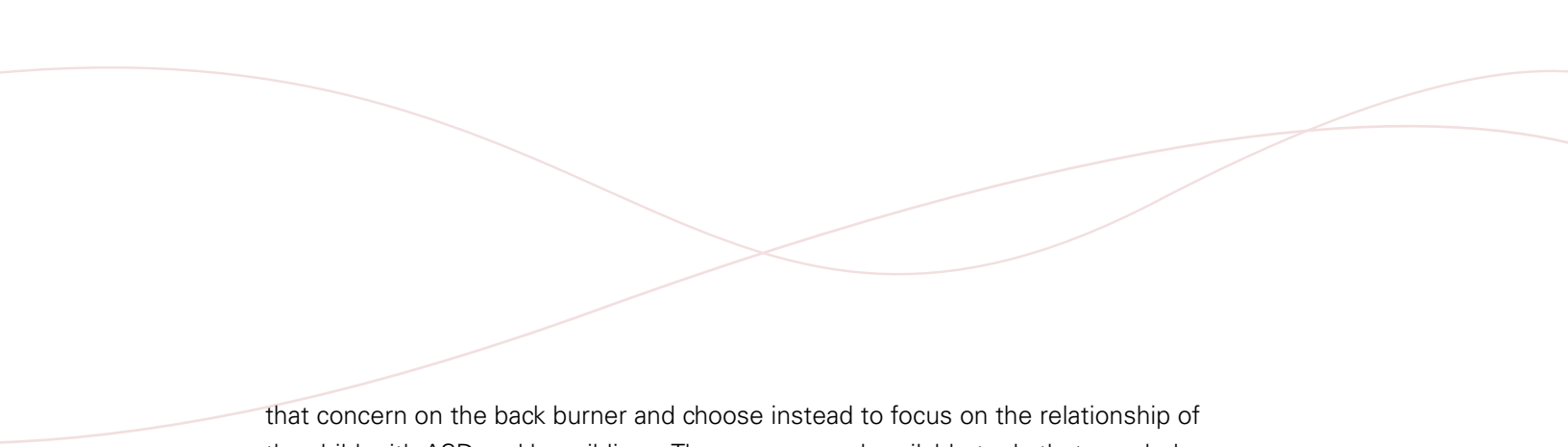
## Coordination of Care Among Service Providers

As the parent of a child with ASD, you are the linking pin among all of the service providers who interact with your son or daughter. You may find yourself telling the behavior specialist that your son Don's occupational therapist (OT) has learned that swinging is a good reinforcer for Don; telling the OT that Don's teacher has concerns about his handwriting; telling the teacher that Don's speech pathologist would like to incorporate more visual strategies into Don's day for communication; and telling the speech pathologist that Don's physician has concerns regarding feeding.

It's an understatement to say it can be difficult to keep up with all the important information that needs to be shared when so many providers are involved in your child's care.

### Some suggestions for care coordination include:

- ❶ **Organize information.** Keep a binder or folder that contains information you want to share among providers. It might include copies of your child's IEP, evaluation reports, information about prescription medications, treatment plans, etc. Take this binder with you to physician visits, educational team meetings, and therapy appointments so you can easily share information among providers. There are also websites that facilitate this kind of coordination (e.g., [www.Parlerai.com](http://www.Parlerai.com)).
- ❷ **Direct communication.** Because coordinating communication between providers can be very time-consuming, it's often helpful to allow providers to speak directly to each other. If you would like for one provider to communicate with another, they must have your permission to do so. Ask to sign a "release of information" that will allow them to share information about your child. You can specify what type of information you would like them to share, and how long you would like providers to have the ability to share information. You may revoke this consent at any time.
- ❸ **Share information.** Be sure to share information about your family's values and preferences. Talk to your child's providers about your family's cultural values, and how they might influence treatment. For example, one family may be concerned with how frequently their child with ASD flaps his hands, but another family may put



that concern on the back burner and choose instead to focus on the relationship of the child with ASD and her siblings. There are several available tools that may help you to identify your treatment priorities, including:

- ▶ *The Family Needs Survey* (Bailey & Simeonsson, 1990), which can provide information related to current family stress (see Form 1 on page 100);
- ▶ *The Child Preference Indicators* (Moss, 2006), which allows a family to share personal knowledge and expertise about their child with providers (available online at <http://www.ou.edu/content/dam/Education/documents/child-preference-indicators.pdf>)
- ▶ *The Autism Spectrum Disorders–Parental Participation Questionnaire*, which provides information regarding parent knowledge of and interest in research-supported treatments for ASD (see Form 2 on page 102).

## Pulling It All Together

Throughout this chapter, we have stressed the importance of self-education about your child's treatment. But sometimes, knowing how to educate yourself about these topics—or even where to start—can be difficult.

**We offer the following suggestions:**

- **Take advantage of your local library.** You will find a list of suggested readings at the end of this chapter, and there are many other books available that provide information related to the treatment of ASD. Look for books from reputable sources. We hope the recommended readings in Chapter 2 help you identify useful literature that is based on appropriate scientific evidence, but is still easy to understand. Your local library can also provide access to academic or scientific search engines that you can use to help you find peer-reviewed articles related to specific treatments.
- **Use the Internet—cautiously.** As is the case with many topics, there is an abundance of information about ASD on the web. Consider the source when you are gathering information via the Internet. Be aware that many websites advocating treatments for ASD were developed with the goal of marketing specific treatments or products directly to you. Some of these websites contain misinformation and will

even state that a treatment is effective despite the fact that no research has ever been conducted on the treatment. See “Recommended Websites” at the end of this chapter for a list of useful websites.

- **Ask other parents.** One of the best resources for information about treatments for ASD is other parents. Consider joining a parent support group so you have frequent contact with other parents of children with ASD. Ask them about their child’s successes with treatments, doctors, and therapists, and share your own experiences. But remember, like any other resources, some parents provide more helpful or accurate information than others.
- **Ask your child’s therapists, educators, and physicians.** Your child’s providers should be a source of support and information for you. They may be able to answer many of your questions, or direct you to other sources for your answers. At times, it may be intimidating to discuss your concerns with your providers, but keep in mind that you have a choice concerning who you work with. You should feel comfortable having open, honest discussions with the providers you choose.
- **Attend parent trainings.** Many universities, mental health centers, schools, and other facilities offer low-cost or free parent training sessions that can provide additional information about many topics. These trainings can answer questions, and can also help you make connections with other parents or providers in the area.



If all of this sounds like a full-time job to you, you’re right! Many parents will forfeit or postpone their careers or modify their future plans to be able to participate in all the meetings and therapy sessions that may be necessary to care for a child with ASD. Not every family can do this, so it can feel even more overwhelming when you have to juggle work outside the home with self-education, meetings, and direct support for your family. Be sure to set reasonable expectations for yourself and realize that a happy, healthy parent can better set the stage for a child’s success than a parent who is too exhausted and overwhelmed.



## Care for Yourself!

Parenting is difficult. Parenting a child with ASD carries unique challenges and stressors. Parents of children with ASD often report significant stress as they manage their child's care. Common activities, such as shopping and dinners out with the family, can be difficult. Although "taking care of yourself" is the last recommendation of this chapter, it's certainly not the least important!

Supporting a person with ASD can place significant strain on a family's physical, financial, and emotional well-being. 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 or interpersonal relationships is challenged, or 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.

It would be easy to focus all of your energies on your child with ASD, but it's in his or her best interest for you to have the resilience that comes from remaining connected with other adults who care about you and your child. These relationships may exist in your household, but might also exist with friends, colleagues, or other people who have a sustained interest in your well-being.

Don't feel guilty if you need to leave your child with a sitter while the rest of your family sees a movie. Sometimes this is best for the entire family! Have your child's team help him develop the skills he needs to go to the movies with the rest of the family, but don't make the rest of the family wait indefinitely while these skills are being developed. In the meantime, you may also want to see if AMC offers Sensory Friendly Films in your community. To learn more about Sensory Friendly Films, visit <http://www.amctheatres.com/SFF/>



As you read this chapter, you may feel there is simply not enough time for all the suggestions we mention here. Keep in mind that you don't need to implement *all* these recommendations, but can choose those which best fit the needs of your family. The goal of presenting a variety of resources is to make you aware of your choices as a parent. It's up to you to determine which of these strategies meet the needs of your child and family.

## Your Child's Values and Preferences

Parental involvement is important, but keep in mind that your child should also have a voice in his educational, medical, and treatment planning and implementation. As long as your child can meaningfully participate in any way, he should be involved in IEP meetings, discussions with therapists and physicians, and selection of additional programs and supports.

Not all individuals on the autism spectrum are capable of actively making decisions about their treatment, but there is a danger in assuming *all* children with ASD are unable to help identify treatment strategies and targets. Many children with ASD may have strong preferences about which interventions they do or don't prefer. Ensuring individuals with ASD can participate in the treatment process by sharing their values and preferences provides them with opportunities for developing social skills, independence, and self-advocacy skills.

You should frequently ask your child about her feelings or thoughts regarding treatment, medication, and other activities. You can use the *Autism Spectrum Disorders—Student Participation Questionnaire* to gather information from older children (or those with strong communication skills) regarding their treatment needs and goals (see Form 3 on page 106). If your child is not able to answer such questions directly, pay attention to her behaviors during treatment; they may provide a clue about her values and preferences.

But remember, therapy is hard. Most of us would prefer *not* to do the hard work that's required to make real progress. Sometimes, children with ASD only know that the current situation is difficult for them. Your child may actually seem happier when using a treatment that does not have sufficient research support. Make sure you

assess not only your child's expressions, but also her progress so you can make the best decisions. There may be times where she prefers not to receive a treatment but, after discussion with the therapist and your evaluation of the data, you determine that the hard work will be worth it for your child in the long run.

## Know Your Rights

At times, you may feel as though your family preferences and values are not being heard. Perhaps you shared your thoughts with your educational team but they were not incorporated into treatment planning; or you provided a therapist with a copy of the Child Preference Indicators (Moss, 2006) but felt it was not considered in the treatment process. Although we hope you don't experience such frustration, there are steps you can take if you believe your family's preferences and values are not being supported.

In educational settings, special education law provides specific guidelines to help resolve disputes regarding a child's educational programming. You should receive a copy of these guidelines from school personnel. In addition, many parents will enlist the support of an educational advocate, particularly when they are uncertain about how best to ask

the school to address specific needs their child may have. An educational advocate should be trained in educational law, and can help to mediate conflicts between parents and school districts. If you have concerns about your child's education, you may contact your state's Department of Special Education to gather more information about how to proceed.

In therapy or medical settings, individual offices or hospitals often have their own policies and procedures for addressing disputes or concerns. You should obtain a copy of these policies when you meet your therapist or doctor. In addition, ask your therapist or doctor to identify who, if anyone, provides support for his or her practice.

Parenting a child with ASD clearly presents a real challenge. By being educated about ASD and your child's rights, you will be best positioned to help your child reach his or her potential. Don't be afraid to ask questions of all of the professionals who serve your child—including your child's teacher, doctor, speech-language pathologist, behavior analyst, or other healthcare providers. But it's also important to remember that your child is part of a family, and parents must take care of themselves if they wish to best support their child on the autism spectrum.

## Recommended}

### Readings

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Anderson, K., & Forman, V. (Eds.). (2010). *Gravity pulls you in: Perspectives on parenting children on the autism spectrum*. Bethesda, MD: Woodbine House.

Ariel, C. N., & Naseef, R. A. (2006). *Voices from the spectrum: Parents, grandparents, siblings, people with autism, and professionals share their wisdom*. London, England: Jessica Kingsley.

Donnell, E. B. (2008). *Dad and autism: How to stay in the game*. Califon, NJ: Altruist.

Harris, S. L. (2003). *Topics in autism. Siblings of children with autism: A guide for families* (2nd ed.). Bethesda, MD: Woodbine House.

Morvay, B. J. (2010a). *My brother is different: A parent's guide to help children cope with an autistic sibling*. Ashland, OH: Bookmasters.

Morvay, B. J. (2010b). *My brother is different: A sibling's guide to coping with autism*. Ashland, OH: Bookmasters.

Nelson, L. (2009). *A mother's song: Helpful tips for raising a child with autism*. Pittsburg, PA: Dorrance.

Satterlee-Ross, D., & Jolly, K. A. (2006). *That's life with autism: Tales and tips for families with autism*. London, England: Jessica Kingsley.

Schopler, E. (1995). *Parent survival manual: A guide to crisis resolution in autism and related developmental disorders*. New York, NY: Plenum Press.

Sherman, D. A. (2007). *Autism: Asserting your child's right to a special education*. Oxford: Churchill.

Thompson, C. (2009). *Grandparenting a child with special needs*. London, England: Jessica Kingsley.

Volkmar, F. R. (2009). *A practical guide to autism: What every parent, family member, and teacher needs to know*. Hoboken, NJ: John Wiley & Sons.

### Websites

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Autism & Asperger's Research Reports  
<http://aarr.stanford.edu>

Autism Consortium  
[www.autismconsortium.org](http://www.autismconsortium.org)

Organization for Autism Research  
[www.researchautism.org](http://www.researchautism.org)

FEAT  
[www.feat.org](http://www.feat.org)

ASPEN  
[www.aspenj.org](http://www.aspenj.org)

MAAP  
[www.maapservices.org](http://www.maapservices.org)

National Autism Center  
[www.nationalautismcenter.org](http://www.nationalautismcenter.org)

Wrightslaw  
[www.wrightslaw.com](http://www.wrightslaw.com)

Autism Speaks  
[www.autismspeaks.org](http://www.autismspeaks.org)

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# 5 Does Your Team Have the Expertise to Help Your Child?

Throughout this manual, we have tried to provide you with the most current and accurate information about research-supported treatment for children and adolescents with Autism Spectrum Disorders (ASDs).

Each of the preceding chapters focused on the factors we identified as critical to the development of evidence-based practice: understanding ASD; the Established Treatments identified by the National Standards Project, as well as biomedical interventions; the importance of professional judgment and data-based decision making; and the need for family input—from both the parents and the individual on the autism spectrum. In this final chapter, we discuss the need for a team of professionals with the necessary skills to *accurately* implement effective interventions for your child.

The simple truth is that it's hard to know who is qualified to work with your child. Many people are now self-described "autism experts." In many cases, these individuals have experience, but it might be with a small number of children who are at a different developmental level, age, or profile than your child.



Don't be afraid to ask! Even when a professional has a great deal of experience, you should still feel perfectly comfortable asking questions. Find out if he or she has experience with children the same age as your child, and/or what their experience is with children who are functioning at a similar cognitive, social, or communicative level.

When you seek services from an organization (as opposed to an individual), things can get even more complicated. Your team members may all come from a single organization, or they may come from diverse settings such as schools, hospitals, and private practice. They are also likely to represent a number of different professional disciplines—such as psychology, pediatrics, speech-language pathology, etc. Each of the organizations and disciplines may have a different culture. Some will hold great respect for certified professionals who are supported as they seek continuing education. Others will find it difficult to find qualified staff; and limited staffing makes it more difficult to dedicate staff time to training.

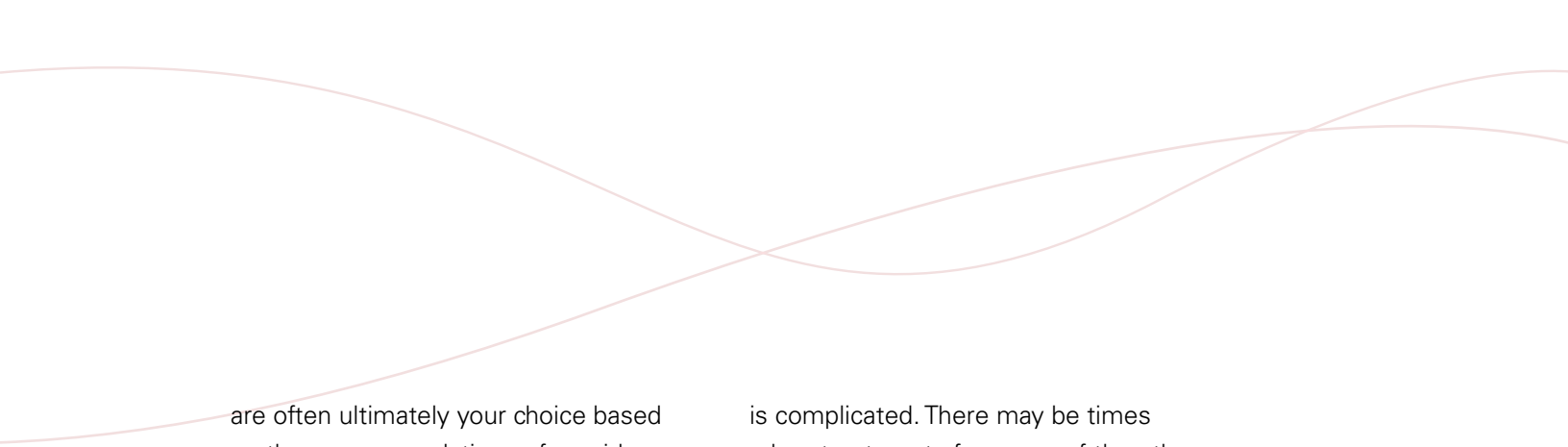
Finding the right team members who, ideally, are employed at great organizations may require a good deal of time and inquiry on your part. So how do you make the best possible choices for your child? In this chapter, we suggest a number of “indicators of excellence” you can use to evaluate schools and treatment programs. (See Table 2 on page 131 for a checklist.) You should also consider many of these same indicators when you work with a single professional.

## Commitment to Evidence-based Practice

You want to make certain that the professional or organization that serves your child has a clear commitment to evidence-based practice. In Chapter 2, you had a chance to review the Established Treatments identified through the National Standards Project, as well as the biomedical treatments that have been shown to be effective.

One way to assess if a school, treatment program, or professional is committed to evidence-based practice is to find out if they are providing at least some of the 11 Established Treatments or biomedical interventions. Although treatment decisions





are often ultimately your choice based on the recommendations of providers, your child should almost certainly spend most of his intervention time receiving treatments that have been shown to be effective.

It's also important to get the right "dosage" (or amount) of treatment for your child. If your child has a fever, you probably read the side of the bottle to determine how much of the medication she should receive. This is because the right dosage is important to ensure your child gets enough medication to reduce the fever but not so much that the medication could harm her.

The issue of dosage applies equally with all treatments for ASD. It's important to provide these treatments with a sufficient level of intensity so that your child can make reasonable progress across a broad range of skills. This will need to be balanced with the demands of the family (see Chapter 4) and your child's quality of life. For example, if running from treatment to treatment means that your child is too exhausted to benefit from his next session, you may need to reconsider dosage!

Although it's true that your child should spend most of her intervention time receiving Established Treatments, we recognize that treatment selection

is complicated. There may be times when treatments from one of the other categories from the National Standards Project (e.g., "Emerging") might be appropriate. These kinds of decisions are often made based on important input from professionals. For example, a speech-language pathologist may recommend an Augmentative and Alternative Communication (AAC) device for your child. You notice it is not one of the Established Treatments. Should you consider it anyway? Yes!

In this case, the speech-language pathologist is making this recommendation based on research involving individuals with communication challenges—not just children with ASD. This research *includes* children with ASD, but also involves individuals with intellectual disabilities or communication disorders. The results of the research are clear: using an AAC device or another alternative communication strategy helps individuals with severe communication challenges to develop speech. If it is the speech-language pathologist's judgment that the AAC device is appropriate for your child, this information is invaluable to decision making.

Professionals should rely not only on their professional judgment, but also on data. Chapter 3 describes some of

the strategies that professionals use for collecting data. You should always feel comfortable emphatically stating, “Show me the data!” Professionals should collect data frequently and be willing to meet with you often to review their data. The data should be used to quickly make changes in treatment if your child is not responding, or if new treatment targets must be selected.

Schools and treatment programs should also have a clear strategy for incorporating your perspective and the opinion of your child into the treatment selection process (see Chapter 4). It is critical for individuals with disabilities to develop skills that will enable them to become their own advocates. However, it’s also important to find an organization that seeks *your* input. This may happen in writing or through formal or informal meetings. Many organizations may be open to this idea but don’t have much experience requesting family input.

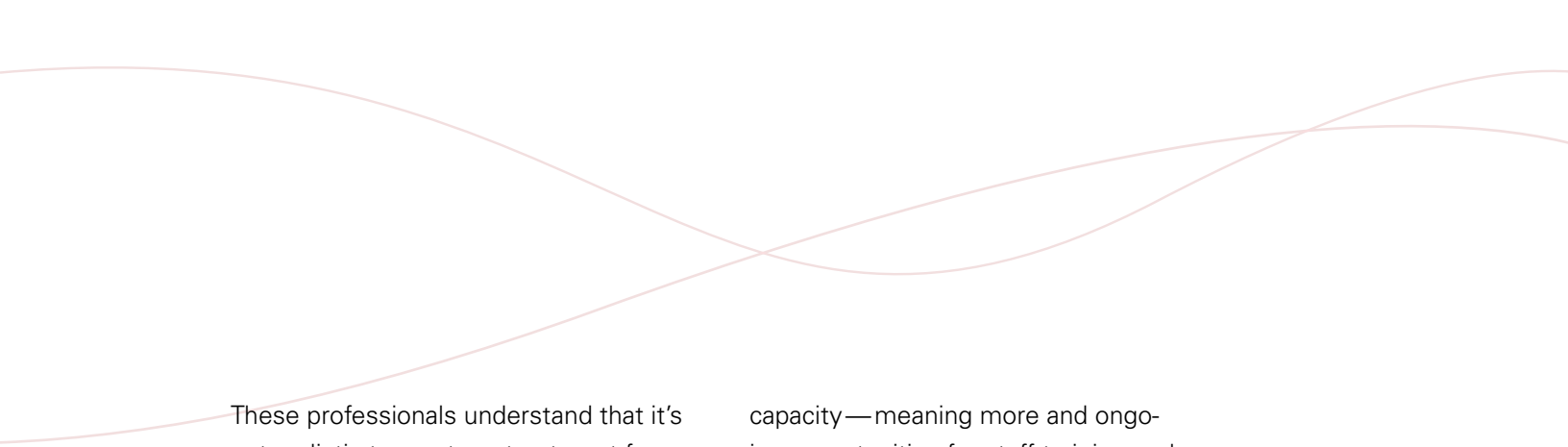
Even if you and your child’s team agree to use one or more of the Established Treatments, your child won’t get access to evidence-based practice if the providers cannot accurately *deliver* the intervention. Unfortunately, some professionals don’t have enough

training and/or ongoing coaching to be able to provide treatments accurately. And, professionals providing educational or behavioral treatments don’t always recognize the need to have a high level of treatment fidelity—that is, to deliver the treatment in the exact way it was provided in research studies.

Compare this to medicine. Imagine if you required dialysis or chemotherapy and the technician was not trained sufficiently. Would you accept that? Of course not! It’s important to find a team of professionals that understands the importance of treatment fidelity.

There are two primary reasons professionals lack sufficient training. First, some professionals don’t know their own limitations. They do not realize that attending a workshop at a professional conference is not sufficient to develop real mastery when it comes to complex treatments for ASD.

Second, many professionals desperately *want* more training, but the organizations they work for don’t have a systematic approach to capacity development. That is, system-wide training, ongoing coaching, and assessment of treatment fidelity do not regularly occur.



These professionals understand that it's not realistic to master a treatment for autism in a one-day workshop. However, they return to an organization that is insufficiently staffed and/or does not have adequate resources at its disposal. These professionals are trying to do their best to help your child, but they are not getting ongoing coaching and are not sufficiently prepared to provide treatments with a high degree of accuracy.

In the final analysis, your child is *not* getting access to a research-supported treatment—despite a professional's good intentions and hard work—if that person does not have adequate training and support. If this is a concern for you, ask for data. Specifically, get enough data to determine if the treatment is being accurately implemented and if your child is making progress. Organizations should be able to provide you with data not only on your child's progress, but also on the treatment provider's accuracy in delivering the intervention. Although this may be uncomfortable for everyone involved, it's the only way to feel confident that your child is getting access to treatments that are effective.

All organizations that seek to serve individuals with special needs should work toward building better

capacity—meaning more and ongoing opportunities for staff training and support, and the ability to provide the treatment accurately. Therefore, it's not necessarily a troublesome sign if the organization serving your child is working toward improved services. If the organization has a plan to build capacity, you have two choices: choose another organization that has a demonstrated history and data showing they can provide the treatment accurately, or wait until the current organization builds capacity. Each choice has its challenges. Changing schools can be difficult for a child on the autism spectrum. Yet a move may be necessary if the school or treatment center doesn't have an aggressive plan to build capacity.

It often takes longer for an organization to build its capacity to accurately deliver treatment services than it does for a single practitioner. If the best decision for your child is to stay with your current organization, consider working collaboratively with the individuals involved in your child's treatment. Learn more about their capacity-building plan and offer to help if you can. And, keep in mind that this will not magically happen overnight.

## Leadership and Vision

Organizations require strong leaders who are committed to supporting individuals with ASD. Leadership can take many forms, and leaders can demonstrate their commitment in various ways, including through a written statement that acknowledges the commitment of the organization.

It's a good sign when administrators also state a commitment to ongoing staff training. But there is some truth to the old saying, "Actions speak louder than words." Have the staff received training in the past? If so, what was the nature of the training? If it was a workshop, was there any ongoing coaching available for staff? Are treatment fidelity data being collected to ensure the treatment is being implemented as intended? The purpose of training is to help professionals develop skills that will then be applied in real-world situations.

Find out if administrators at your child's school or program are committed to the type of training that is required to develop and sustain their staff's capacity to accurately implement treatments. If they need assistance in this area, please encourage them to read the National Autism Center's *Evidence-based Practice and Autism in the Schools*. They can download this document for free at [www.nationalautismcenter.org](http://www.nationalautismcenter.org). Chapter 5, called "Building and Sustaining Capacity to Deliver Treatments that Work," describes the process of systemic capacity building for school systems. These same methods can be applied in treatment programs.



As a parent of a child on the autism spectrum, you have to spend a good deal of your time thinking outside the box. It's okay to ask the leaders in your child's school or treatment center to think outside the box too. Problem solving often requires creativity.

## Experience and Clinical Expertise

The experience of professionals makes a difference! It impacts their ability to accurately implement your child's treatments, and increases the likelihood that they will successfully manage challenges when they arise.

**When evaluating a person's experience, there are a number of factors to consider:**

- **How many years have they worked in the field?** Keep in mind that this number can be deceptive. Some professionals have worked for many years in a specific field—such as education, speech-language therapy, or behavior analysis. But they may have only recently specialized in working with children on the autism spectrum. The number of years of general experience will certainly help them to more quickly develop expertise working with individuals with ASD, but *some* experience working with individuals on the spectrum is essential.
- **How many children with ASD have they served?** There are people who have worked with children with ASD “for years,” but have served only one or two children on the autism spectrum. There is a popular saying in the autism community: “If you have worked with one child on the spectrum, you have worked with *one* child on the spectrum!”
- **What is their history of working with similar children or adolescents with ASD?** The autism spectrum is as diverse as all humanity. You need to know if the professional serving your child has served children of similar ages with comparable developmental and skill levels. Do they have experience working with children who face similar obstacles, and do they have experience overcoming these challenges?
- **What is their knowledge about and experience with effective strategies to increase motivation and address challenging behaviors?** People on the autism spectrum will not reach their full potential if they don't participate in treatment. Therefore, all professionals must know some of the Established Treatments, such as antecedent and behavioral strategies, because these are most associated with improved motivation and reductions in challenging behaviors. Similarly, when an individual with ASD uses a communication method other than speech—such as an AAC device, the picture exchange communication system (PECS), or sign language—the professionals providing other services (e.g., education, occupational therapy, behavior supports, etc.) must be able to effectively communicate with that individual. They may require training to do so.

**Table 1} Professional Certification and Licensure**

Profession	Certification		Licensure (Required)
	Required	Voluntary	
Board Certified Behavior Analysts	Behavior Analyst Certification Board		
Nutritionists and Dietitians	12 states – statutory certification	Commission on Dietician Registration of the American Dieticians Association	35 states – licensure
Occupational Therapists		National Board for Certifying Occupational Therapy	State Licensing Board
Physical Therapists	State Certification		
Physicians	American Board of Medical Specialists or American Osteopathic Association		United States Medical Licensing
Psychologists	American Board of Professional Psychology	National Association of School Psychologists	State Licensing Board
Speech-Language Pathologists		American Speech-Language-Hearing Association	State Licensing Board
Teachers	State Board of Education (in some states)		State Board of Education (in some states)

In addition to experience, it’s important to know the area of clinical expertise of the professionals serving your child. Is the professional licensed or certified in his or her field? If you want to learn more about the qualifications required for professionals working with your child, visit the U.S. Bureau of Labor Statistics website and download the free Occupational Outlook Handbook (<http://www.bls.gov/OCO/>). This document highlights the required training and qualifications for different professionals. In Table 1, we briefly outline certification and/or licensure requirements for many of the professionals who may work with your child.

In many organizations, licensed or certified professionals spend most of their time supervising direct care staff. When this is the case, it’s important that the staff members they supervise have {a} sufficient training and {b} sufficient experience. It is critical that the supervisor oversees the work of relatively few staff so the licensed/certified staff can reasonably review data and guide treatment as needed.

## Parent Participation

Effective educators and therapists will not be afraid to have you participate in your child's treatment process. Don't hesitate to ask if you can do a few observations when the professional is treating your child. It is perfectly reasonable for you to observe your child's performance and the way the treatment is being implemented.

**If the administrators seem reluctant to have you observe, consider the following factors/questions:**

❶ **Has your child historically shown a negative response to treatment when you are present?** Some children throw temper tantrums, become aggressive, or refuse to participate in treatment when their parents are present. If this is the case, it may be important to initially limit your exposure during treatment—but this is not a long-term solution. Make sure a qualified behavior specialist is working with the treatment team. He or she can help your child learn to respond successfully when you are in the room. It may take time, but you should eventually be able to observe treatment sessions. In the meantime, check to see if your child can be videotaped so you can review the sessions at a later date.

❷ **Is your child very distractible?**

Some children can only focus on skill development when no distractions are present. People can be distracting—and that includes parents. Again, it may be important initially to limit your exposure during treatment if this is the case. But the treatment team should then set a goal of improving engagement in treatment. Your presence can be therapeutic in this case if there is a plan to improve your child's ability to pay attention. It may mean that your initial presence will be so fleeting that you do not get to conduct a comprehensive observation. But it's a worthwhile goal, and your child will eventually get there.

Providing effective treatments requires more than just randomly selecting from among the 11 Established Treatments identified through the National Standards Project. Good schools and treatment centers should base their treatments on a thorough evaluation of your child's skills and the challenges he faces.



Remember that you want to build the most collaborative relationship possible with the treatment team.

**It is absolutely reasonable for you to complete observations, but keep the following points in mind:**

- **The treatment is for your child.** You want the professional to be highly focused on your child's treatment—not on your observation. Only you can decide how many observations you will need to complete, and how often you will do so. Just make certain they do not interfere with treatment.
- **Decide in advance exactly what situations would warrant interrupting your child's treatment.** Under most circumstances, you'll want to get the most extensive picture of what is happening during the course of treatment. If you interrupt the session, you will potentially miss the opportunity to observe something relevant. Of course, in the event that the professional is doing something harmful to your child, you will want to take immediate action. With the exception of these kinds of critical circumstances, it's generally best to set up a brief meeting to discuss your thoughts with the professional immediately after your observation.
- **Remember to share positive feedback when professionals provide high quality treatment and really engage your child!** Be sure to keep your eye out for successes, and not just for what didn't go well.

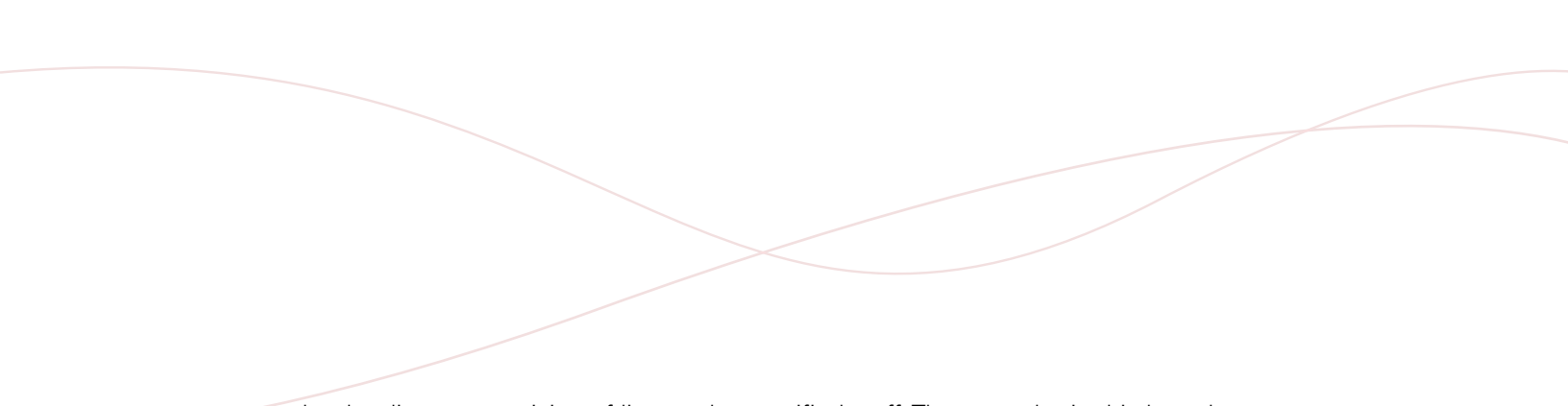
## Emphasis on Training

In the history of helping professions, no one has become an expert in any treatment after taking a one-day workshop! True expertise requires knowledge and the demonstrated capacity to use the skill in real-world situations with diverse individuals.

**There are several factors that should help you determine the level of expertise of the professionals who work with your child:**

- Has the staff completed coursework or training that ensures they have learned the information required to successfully deliver a treatment? Treatment providers must have a working knowledge of the treatment they provide even if they are working





under the direct supervision of licensed or certified staff. They can obtain this knowledge through formal coursework, workshop trainings, or online training (e.g., Autism Training Solutions at [www.autismtrainingsolutions.com](http://www.autismtrainingsolutions.com)).

- What type of experiential trainings have staff members completed? Knowledge is necessary, but knowledge alone doesn't necessarily lead to accurate implementation of treatments. Increasingly, many workshops that are designed to teach staff how to implement treatments include not only information, but also hands-on practice with a new technique. Of course, practice is not the same as providing the treatment in real-world settings where there may be demands from other children, interruptions from staff, challenges in obtaining needed materials, and other barriers. Similarly, formal coursework is often accompanied by a practicum requirement in which the teacher, speech-language pathologist, psychologist, or other professional-in-training applies his or her knowledge in real-world settings or situations. The more closely the practicum reflects the real challenges the professional will face, the better!
- When you examine research on how adults learn, it consistently shows that they require ongoing coaching in real-world situations in order to apply the treatment accurately in those settings. Following workshop training, treatment centers, schools, or professionals should obtain ongoing coaching from experienced professionals.
- Even after coaching, the best systems are set up so that critical decisions made by treatment providers are reviewed by qualified colleagues, administrators, or consultants.

## Quality Assurance and Family Satisfaction

You know that your child deserves access to high quality care. And, as noted in Chapter 4, you play a central role in treatment selection. Schools and treatment programs should have a process in place that allows you to express your concerns when treatments are selected. The professionals providing treatment to your child should discuss your concerns with you so that they fully understand the points you are trying to make. Without this input, there is a chance an inappropriate treatment may be selected for your child.

Your participation should extend beyond initial treatment selection. You should have an ongoing dialogue with the professionals serving your child. There may be new information you can provide that would have a strong bearing on whether or not a treatment should be continued.

Many schools and/or treatment programs recognize that the best way to support a person on the autism spectrum is to make certain that the people who share his or her life are well-informed and can put supports in place at home and in the community. For this reason, you should also find out if the organization or professional providing services to your child also provides supports for you or other members of the family, such as siblings.

Parents of children with ASD are often well-connected through organizations like the Autism Society or other grassroots groups. The families you meet may be able to help you get additional insights into any of the questions we raise in this chapter. A “jury of moms and dads” can tell you about their experiences with an organization or professional. This personal perspective may prove more valuable than information you can acquire directly from the source.

In addition to family input, one of the most essential components of quality assurance is treatment fidelity. As we mentioned previously, treatment centers and schools can demonstrate treatment fidelity when they collect data to show that a treatment is being accurately implemented. There are so many real-world factors that can make it difficult to accurately put a treatment into place—even when you have the most motivated professional in the world! Schools and treatment programs should collect and share treatment fidelity data with families.

Parent-to-Parent



If you are not already connected with other parents of children on the spectrum, consider asking the leaders at your child’s school or treatment center to put you in touch with other parents. Because of confidentiality concerns, they may ask if they can give your name to other parents and have them contact you. Be open to these connections.

## Other Factors

There are a number of additional factors that will set some schools or treatment centers apart from the rest. For example, has the organization, or professionals within the organization, been recognized for good service or distinction? Also, are there leading professionals in the field of autism who advise or have partnerships with the school or the treatment center?

The final factors to consider when selecting schools or treatment centers are described in this section.

**Written policies.** Schools and treatment centers often have written policies about the procedures they may use. For example, does the school or treatment center use restraint procedures on children with ASD? If so, under what conditions? Who performs the restraint and for what period of time? Who reviews the data to ensure that a child does not spend too much time in restraint? It's best to know these policies before they need to be put into practice.

**Honors.** Some organizations, or the professionals working for the organizations, receive formal recognition for their excellence. You should not avoid an organization because it has not yet attained this recognition. However, it's useful to know if the organization has been recognized for the quality of its work.

You might think, "My child will never be like that!" It's easy to think that your child will not require a restraint procedure or any other punishment technique when he is a cute 4-year-old. What happens when he is 14 years old, weighs 210 pounds, and is dealing with the same hormones that drive all teenagers over the edge some of the time? It's best to be prepared, just in case your child demonstrates behaviors that put him or others at risk.



**Affiliations and partnerships.** Many treatment programs or schools have a working relationship with professional organizations. Do they work with universities to train their students to become professionals? Do they collaborate on research to identify effective treatments? Are they involved with other educational, medical, or human services organizations to ensure that the services they provide will be of the highest quality?

**Commitment to research and dissemination.** Decisions about treatment should be based on data. As such, it's helpful to find out if your child's treatment program or school collects data and shares their outcomes at professional conferences. They should only do this with your permission, of course, but sharing data-based outcomes with other professionals reflects an ongoing commitment to improving services for *all* children with ASD. It is even better when these data are shared with other professionals in the form of publications in professional journals and/or peer-reviewed<sup>1</sup> book chapters.

**Professional Advisory Board.** All professionals benefit from additional input from experts. Ideally, your child's treatment program or school has developed a professional advisory board filled with experts representing diverse fields of study (e.g., educators, psychologists, speech-language pathologists, etc.).

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Consider taking a copy of Table 2 with you when you make decisions about organizations serving your child. It may help to briefly review this chapter again before you go.

We hope the information we have given you will be helpful when you are trying to identify good treatment options for your child. Keep in mind that it's possible the professional or organization serving your child meets the criteria on paper, but is simply not a good fit for your child. You may decide that the organization providing services to your child is not flexible enough. If it's a treatment center, recognize that, in the end, the choice is yours.



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<sup>1</sup> Peer review is a term describing the process used by all reputable scientists to publish their research. Peer-reviewed studies have undergone the scrutiny of experts before publication. Studies may be deemed worthy of publication for two reasons. First, the scientific methods used in the study were good enough that they met a minimum criterion for scientific usefulness. Second, studies may not be controlled well enough to determine if a treatment was truly effective, but the results are thought-provoking enough that it might encourage researchers to conduct better or additional research in the area.

**Table 2} Indicators of Excellence Checklist**

Indicator	Questions to Ask	Notes
Commitment to evidence-based practice	<ul style="list-style-type: none"> <li>• Are they using Established Treatments?</li> <li>• Do they have a system to consider:               <ul style="list-style-type: none"> <li>› The judgment of professionals?</li> <li>› Treatment decisions based on data?</li> <li>› Your input and the input of your child (when appropriate)?</li> <li>› Capacity (and treatment fidelity)?</li> </ul> </li> </ul>	
Leadership and vision	<ul style="list-style-type: none"> <li>• Do they have a written commitment to supporting individuals with ASD?</li> <li>• Do administrators state and demonstrate a commitment to ongoing training?</li> </ul>	
Experience and clinical expertise	<ul style="list-style-type: none"> <li>• How many years of experience do the professionals have in the field?</li> <li>• How many children with ASD have they served?</li> <li>• Do they have a history with similar children or adolescents?</li> <li>• Is there cross-disciplinary experience?</li> <li>• Are the staff licensed/certified in their field of expertise (e.g, behavior analysis, education, speech-language pathology, occupational therapy, physical therapy, etc.)?</li> <li>• Do licensed/certified staff have direct contact with children or adolescents and/or do licensed/certified staff supervise a small number of qualified professionals?</li> <li>• Do administrators typically support your request to complete observations in the classroom?</li> </ul>	
Emphasis on training	<ul style="list-style-type: none"> <li>• Has staff completed coursework related to the treatment of ASD?</li> <li>• Has staff obtained training to increase their knowledge?</li> <li>• Has staff completed experiential training?</li> <li>• Is a process in place for ongoing coaching?</li> <li>• Is a system in place for qualified colleagues or supervisors to review clinical decisions?</li> </ul>	

{Continued on following page}

**Table 2}** Indicators of Excellence Checklist (cont.)

Indicator	Questions to Ask	Notes
Quality assurance/Family satisfaction	<ul style="list-style-type: none"> <li>• Is your input requested before a treatment is put in place?</li> <li>• Is there a process in place to provide ongoing input?</li> <li>• Are there family supports available?</li> <li>• Is there evidence of treatment fidelity?</li> <li>• Is there a parent advisory council or committee?</li> <li>• Are there support groups for parents?</li> <li>• Are there parents who are willing to network?</li> </ul>	
Written policies	<ul style="list-style-type: none"> <li>• Does the school or treatment center use restraint procedures on children with ASD? If so, under what conditions?</li> <li>• Who performs the restraint and for what period of time?</li> <li>• Who reviews the data to ensure that a child does not spend too much time in restraint?</li> </ul>	
Honors	<ul style="list-style-type: none"> <li>• Has the school or treatment program or its staff received recognized awards or honors?</li> </ul>	
Affiliations and partnerships	<ul style="list-style-type: none"> <li>• What national and international professional relationships are established with educational, medical, and human services organizations?</li> </ul>	
Commitment to research and dissemination	<ul style="list-style-type: none"> <li>• Have data collected in the treatment program been presented at professional conferences?</li> <li>• Have studies examining treatment effectiveness been published in peer-reviewed journals?</li> <li>• Have organizational leaders written or edited book chapters or books?</li> </ul>	
Professional Advisory Board	<ul style="list-style-type: none"> <li>• Does the treatment program obtain input from experts representing a broad range of professional disciplines?</li> </ul>	

Note: This checklist should help you remember what information to gather when making decisions about schools and treatment programs. Feel free to share it with the professionals with whom you come in contact.



## In Closing

The treatment of ASD is constantly changing. As researchers provide clearer answers about which treatments produce benefit for children, adolescents, and adults on the spectrum, professionals and organizations providing treatment will need to continue to build their capacity. Building capacity to deliver treatments with a high degree of accuracy (treatment fidelity) will always be essential, and we applaud those who are dedicated to this goal.

The good news is that schools, treatment centers, and other organizations around the country are increasingly recognizing the need to provide evidence-based practice. As they do so, your encouragement is critical. We hope the information contained in this manual will make this a mutually beneficial process and, most of all, will help your child and others on the spectrum to reach their potential.





**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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Randolph, Massachusetts 02368

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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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# 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.

---

<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

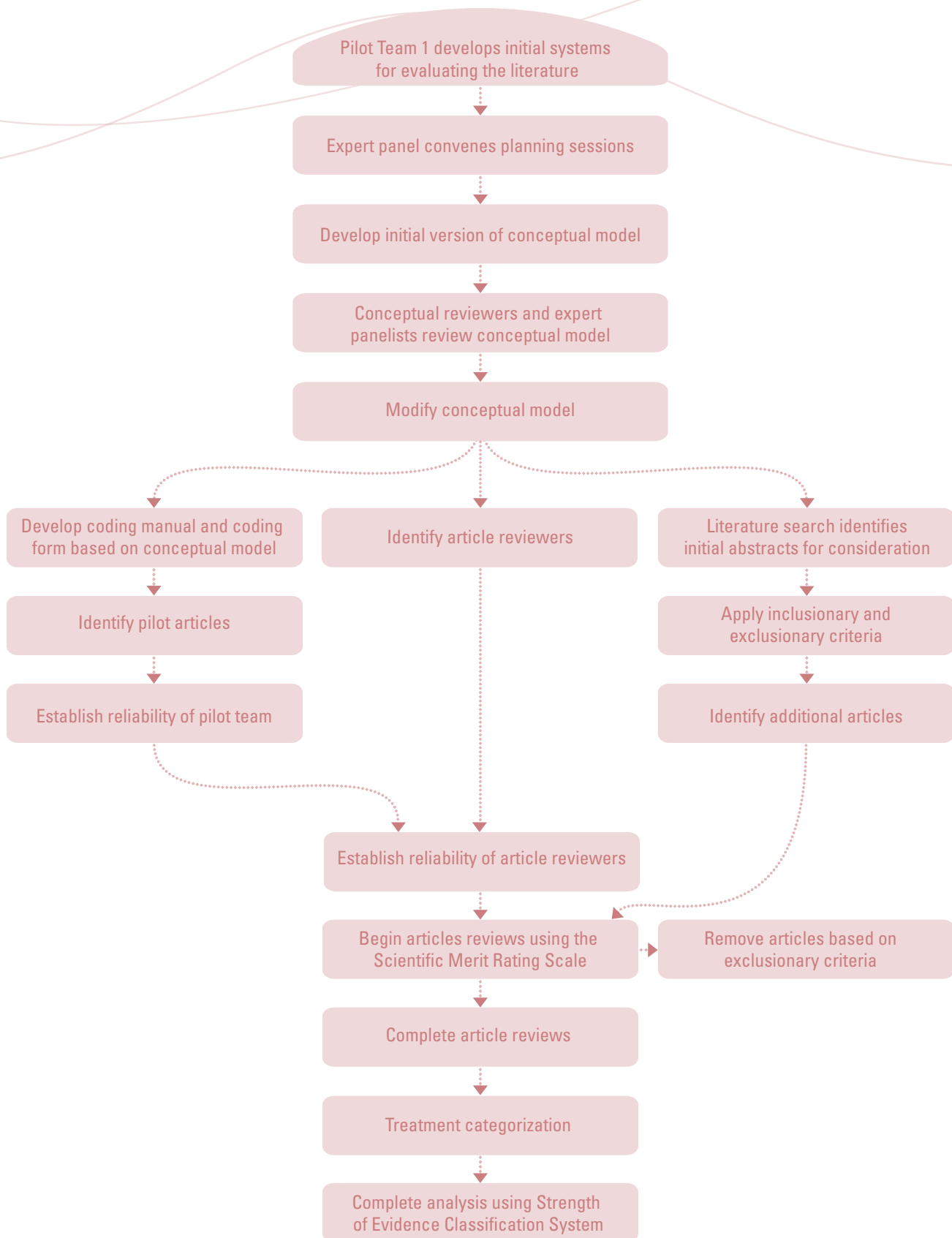
Prior to data collection, we identified the ASD treatment articles that should be included in our review. These treatments were generally designed to address the core features of these neurological disorders. A number of these studies also addressed the associated features of ASD. The studies were conducted 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 pathologists, educators, occupational or physical therapists). Search engines produced

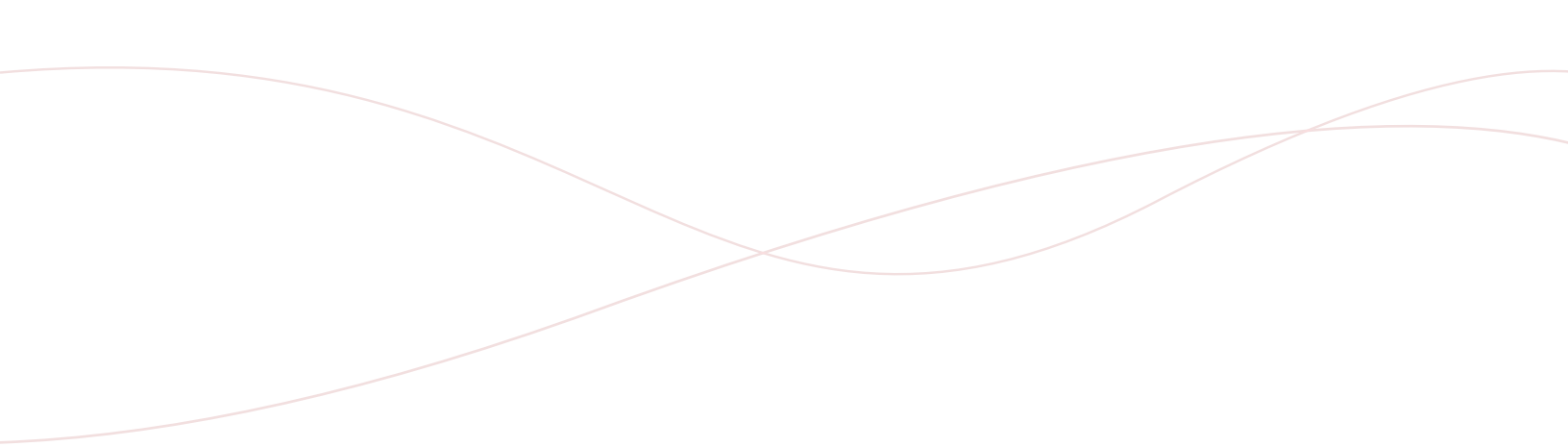
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<sup>2</sup> The pilot team relied on the following sources: Sidman (1960); Johnston & Pennypacker (1993); Kazdin (1982; 1998); New York State Department of Health, Early Intervention Program (1999) and; Task Force on Promotion and Dissemination of 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





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.

---

<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.

---

<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.

---

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.

---

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.

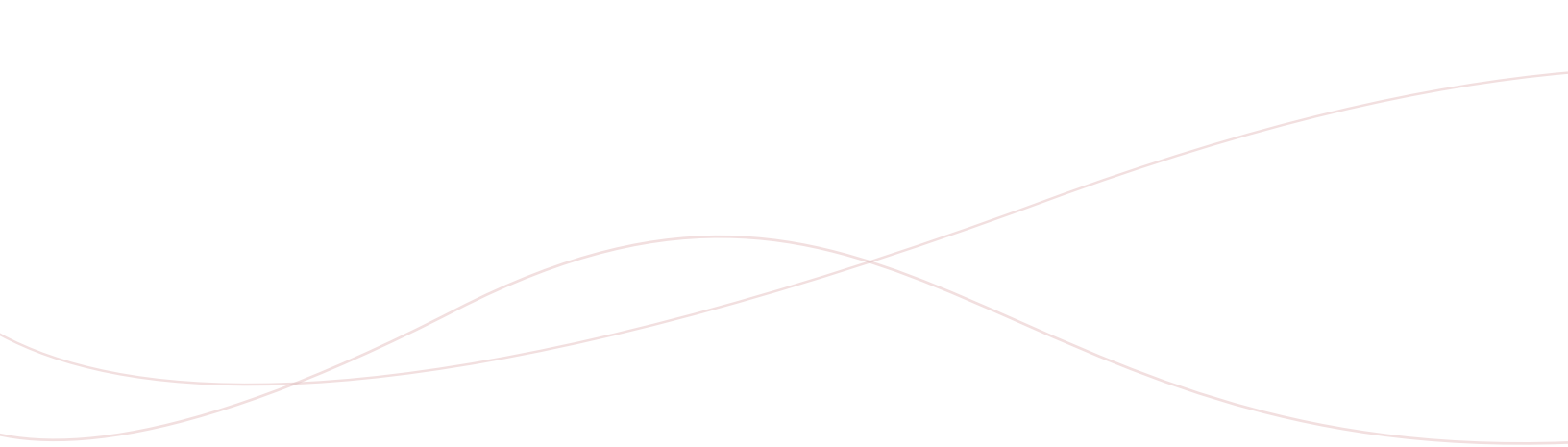
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This treatment is an expansion of Natural Language Paradigm which is also included in this category.

### ● **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

Skills Increased				
Academic	Communication	Higher Cognitive Functions	Interpersonal	Learning Readiness
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
Motor	Personal Responsibility	Placement	Play	Self-Regulation
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

Behaviors Decreased			
Problem Behaviors	Restricted, Repetitive, Nonfunctional Behavior, Interests, or Activities	Sensory/Emotional Regulation	General Symptoms
Antecedent Package Behavioral Package CBTYC Modeling Self-management	Behavioral Package Peer Training	Antecedent Package Behavioral Package Modeling	CBTYC

Ages					
0-2	3-5	6-9	10-14	15-18	19-21
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

Diagnostic Classification			
Autistic Disorder		Asperger's Syndrome	PDD-NOS
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



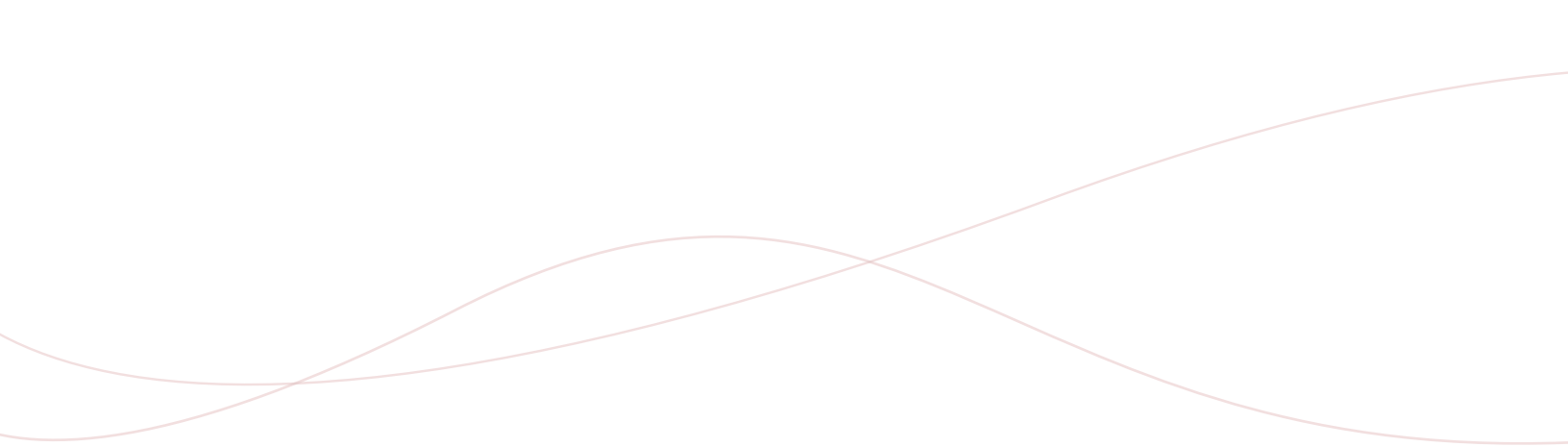
## Emerging Treatments

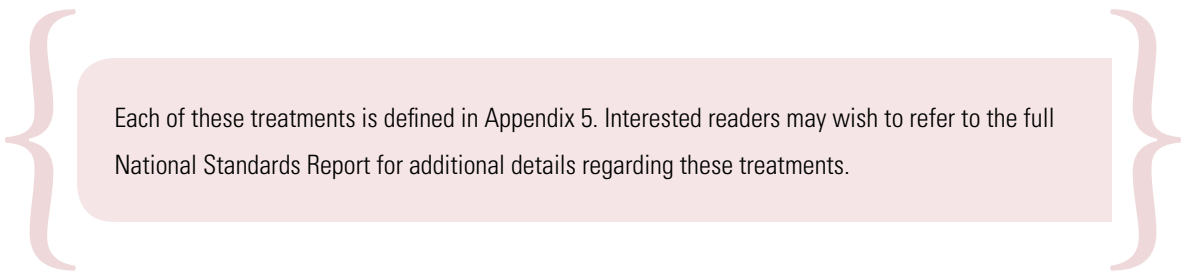
Emerging Treatments are those for which one or more studies suggest the intervention may produce favorable outcomes. However, additional high quality studies that consistently show these treatments to be effective for individuals with ASD are needed before we can be fully confident that the treatments 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}

- 
- 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 comorbid 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.

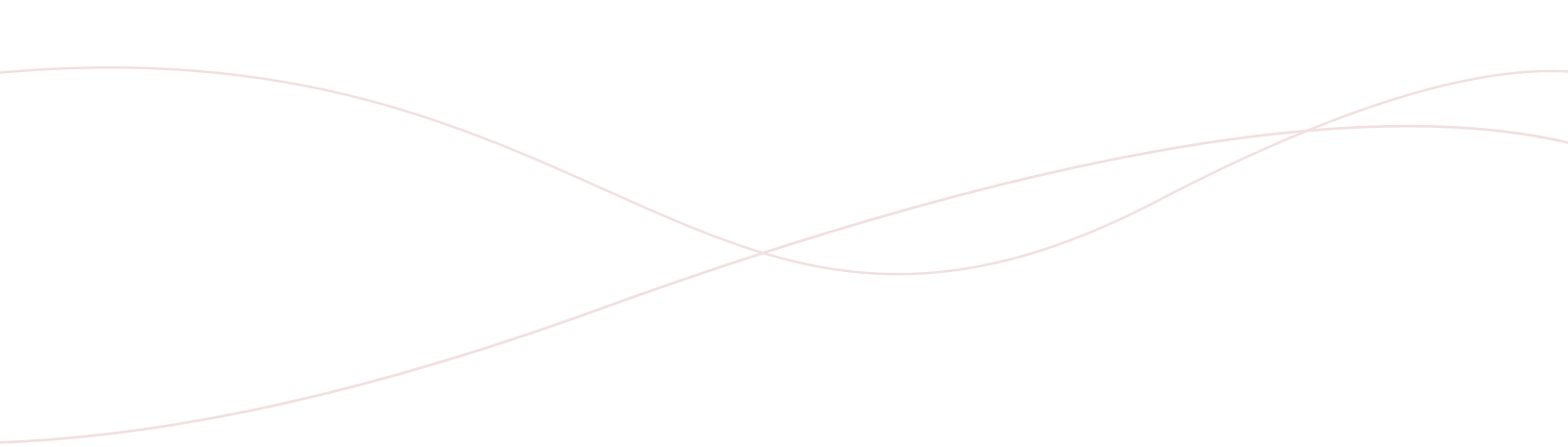
# 4

## 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.

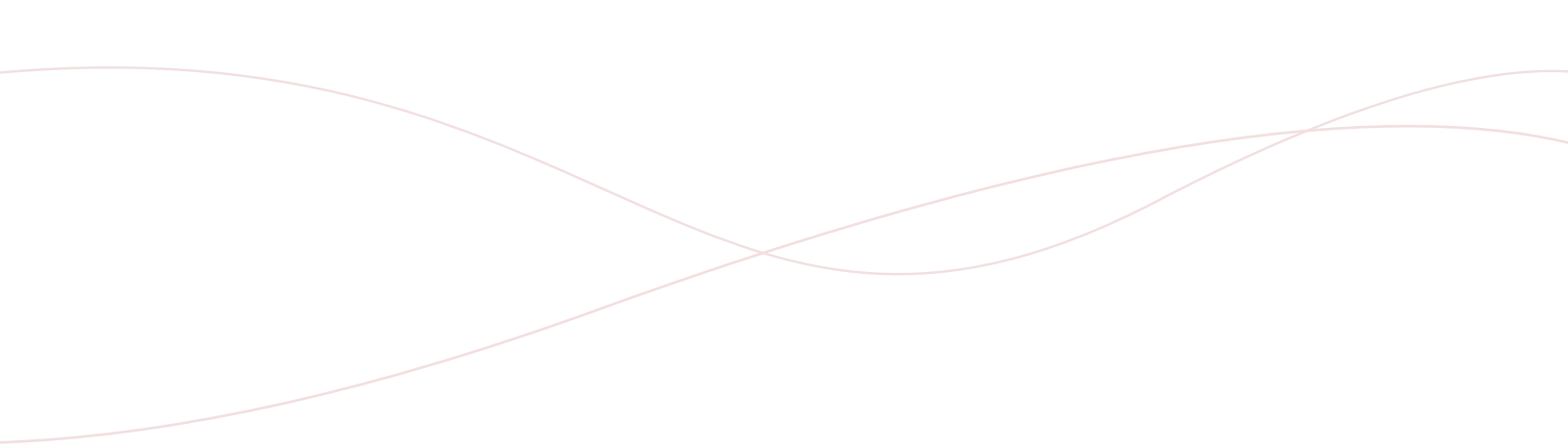
**We have identified the following four factors of evidence-based practice:**

- **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, care providers, 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.

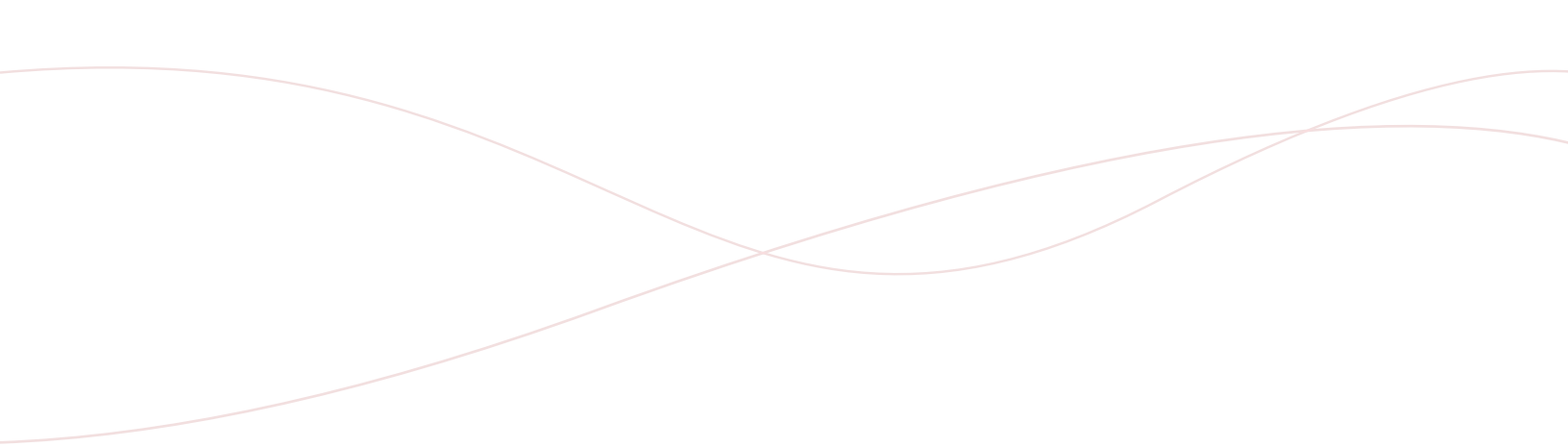
We have identified the following limitations:

- 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.



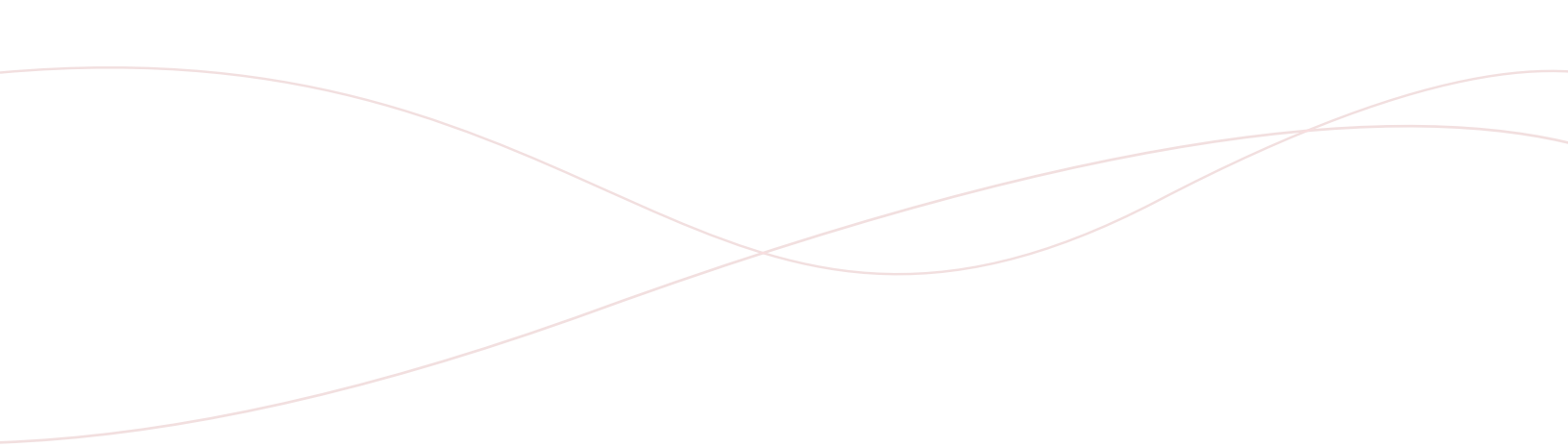
many readers may be interested in more detailed analysis using a smaller unit of analysis, or data using on a different arrangement of treatment categories based on a larger unit of analysis. We look forward to your feedback to guide the next version of the National Standards Project.

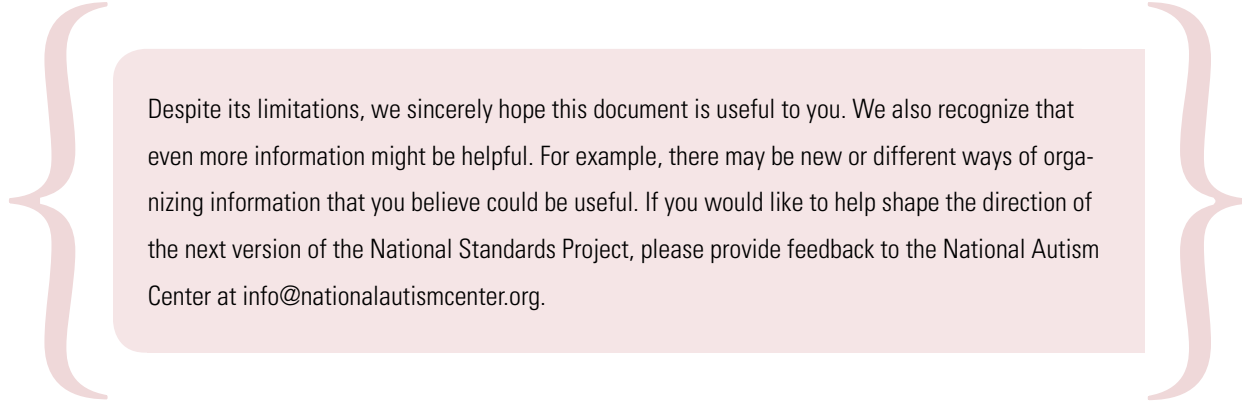
- This review included an examination of most group and single-subject research design studies but did not include every type of study.
  - ▶ For this report, we only looked at research that was designed to answer questions about the measurable effectiveness of an intervention based on quantifiable data. 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.



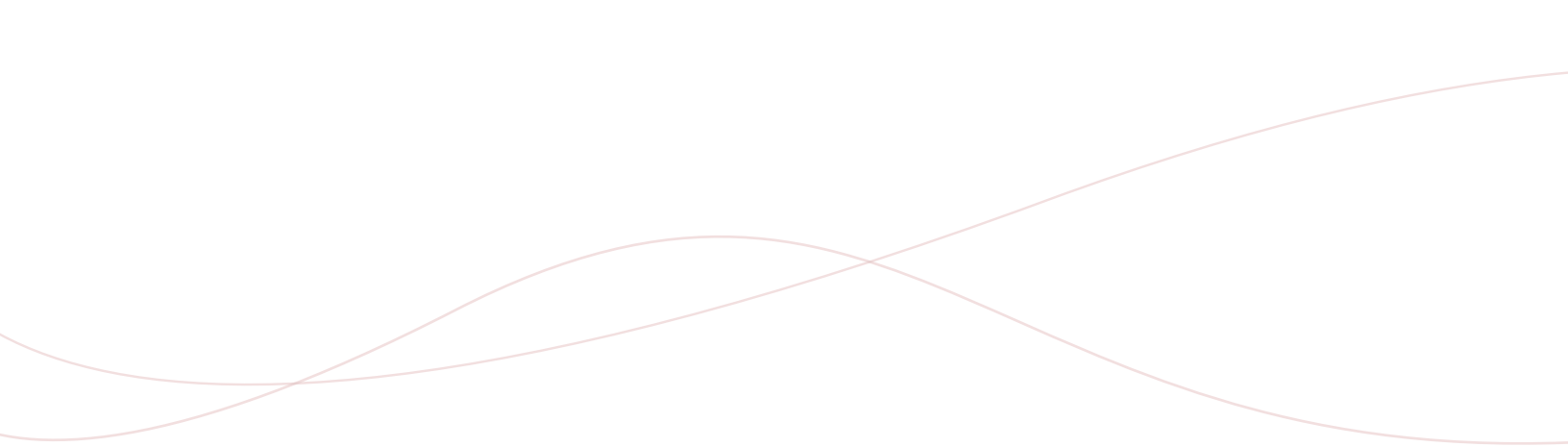
## Future Directions with Methodology

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 comorbid 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

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 5

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			
<p>Number of groups: two or more</p> <p>Design: Matched groups; No significant differences pre-Tx; or better design</p> <p>Participants: n &gt; 10 per group or sufficient power for lower number of participants</p> <p>Data Loss: some data loss possible</p>	<p>A minimum of three comparisons of control and treatment conditions</p> <p>Number of data points per condition: &gt; five</p> <p>Number of participants: &gt; three</p> <p>Data loss: some data loss possible</p>	<p>Type of measurement: Observation-based measurement</p> <p>Protocol: standardized</p> <p>Psychometric properties sufficient</p> <p>Evaluators: blind</p> <p>OR</p> <p>independent</p>	<p>Type of measurement: continuous or discontinuous with no calibration data</p> <p>Reliability: IOA &gt; 80% or kappa &gt; .75</p> <p>Percentage of sessions: Reliability collected in &gt; 25%</p> <p>Type of conditions in which data were collected: all sessions</p>	<p>Implementation accuracy measured at &gt; 80%</p> <p>Implementation accuracy measured in 20% of total session for focused interventions only</p> <p>IOA for treatment fidelity: not reported</p>	<p>Diagnosis provided/ confirmed by independent and blind evaluators for research purposes using at least one psychometrically sufficient instrument</p>	<p>Objective data</p> <p>Maintenance data collected</p> <p>AND</p> <p>Generalization data collected across at least one of the following: setting, stimuli, persons</p>

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*	Test, scale, checklist, etc.	Direct behavioral observation			
<p>Number of groups: two or more</p> <p>Design: Pre-Tx differences controlled statistically or better design</p> <p>Data loss: some data loss possible</p>	<p>A minimum of two comparisons of control and treatment conditions</p> <p>Number of data points per condition: &gt; three</p> <p>Number of participants: &gt; two</p> <p>Data loss: some data loss possible</p>	<p>Type of measurement: Observation-based measurement</p> <p>Protocol: non-standardized or standardized</p> <p>Psychometric properties adequate</p> <p>Evaluators: neither blind nor independent required</p>	<p>Type of measurement: continuous or discontinuous with no calibration data</p> <p>Reliability: IOA <math>\geq</math> 80% or kappa &gt; .4</p> <p>Percentage of sessions: Reliability collected in <math>\geq</math> 20%</p> <p>Type of conditions in which data were collected: all or experimental sessions only</p>	<p>Implementation accuracy measured at <math>\geq</math> 80%</p> <p>Implementation accuracy measured in 20% of partial session for focused interventions only</p> <p>IOA for treatment fidelity: not reported</p>	<p>Diagnosis provided/ confirmed by independent</p> <p>OR</p> <p>blind evaluator for research purposes using at least one psychometrically adequate instrument</p> <p>OR</p> <p>DSM criteria confirmed by a qualified diagnostician or independent and/or blind evaluator</p>	<p>Objective data</p> <p>Maintenance data collected</p> <p>OR</p> <p>Generalization data collected across at least one of the following: setting, stimuli, persons</p>

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			
<p>Number of groups and Design: If two groups, pre-Tx difference not controlled or better research design</p> <p>OR</p> <p>a one group repeated measures pre-test/post-test design</p> <p>Data Loss: significant data loss possible</p>	<p>A minimum of two comparisons of control and treatment conditions</p> <p>Number of data points per Tx condition: &gt; three</p> <p>Number of participants: &gt; two</p> <p>Data loss: significant data loss possible</p>	<p>Type of measurement: Observation-based or subjective</p> <p>Protocol: non-standardized or standardized</p> <p>Psychometric properties modest</p> <p>Evaluators: neither blind nor independent required</p>	<p>Type of measurement: continuous or discontinuous with no calibration data</p> <p>Reliability: IOA &gt; 80% or kappa &gt; .4</p> <p>Percentage of sessions: Not reported</p> <p>Type of conditions in which data were collected: not necessarily reported</p> <p>Operational definitions are extensive or rudimentary</p>	<p>Control condition is operationally defined at an inadequate level or better</p> <p>Experimental (Tx) procedures are operationally defined at a rudimentary level or better</p> <p>Implementation accuracy measured at &gt; 80%</p> <p>Implementation accuracy regarding percentage of total or partial sessions: not reported</p> <p>IOA for treatment fidelity: not reported</p>	<p>Diagnosis with at least one psychometrically modest instrument</p> <p>OR</p> <p>diagnosis provided by a qualified diagnostician or blind and/or independent evaluator with no reference to psychometric properties of instrument</p>	<p>Subjective data</p> <p>Maintenance data collected</p> <p>AND</p> <p>Generalization data collected across at least 1 of the following: setting, stimuli, persons</p>

**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
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<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 {a} results were not replicated but at least two replications were attempted {b} a minimum of five data points were collected in baseline and treatment conditions {c} a minimum of two participants were included {d} a fair or good point of comparison (e.g., steady state) existed</p>	<p><b>Single:</b> A functional relation is established and is replicated at least two times 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 Carryover effects were minimized 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 Carryover effects were minimized A minimum of five data points per condition 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* *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

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#### *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 everyday 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

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#### *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 problem 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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