

100 Day Kit for Newly Diagnosed Families of School Age Children



AUTISM SPEAKS® FAMILY SERVICES

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The Autism Speaks 100 Day Kit is a tool designed to help assist families of children recently diagnosed with autism during the critical period following an autism diagnosis.

The 100 Day Kit for School Age Children was released in 2014 and adapted from the 2010 Asperger Syndrome/High-Functioning Autism Tool Kit after the DSM-5 was published. The kits were created by the Autism Speaks Family Services staff in conjunction with both an advisory committee and the Family Services Committee.

Autism Speaks would like to extend special thanks to the Advisory Committee for the time and effort that they put into reviewing this kit:

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It's time to listen.

**Autism Speaks would like to thank Just Cabinets Furniture & More
for generously funding the printing of the 100 Kit for Newly Diagnosed
Families of School Age Children.**



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About Autism

Why Was My Child Diagnosed with Autism? And What Does It Mean?

Your child has been diagnosed with autism spectrum disorder and you have asked for help. This is an important turning point in a long journey. For some families, it may be the point when, after a long search for answers, you now have a name for something you didn't know what to call, but you knew existed. Perhaps you suspected autism, but held out hope that an evaluation would prove otherwise. Many families report mixed feelings of sadness and relief when their child is diagnosed. You may feel completely overwhelmed. You may also feel relieved to know that the concerns you have had for your child are valid. Whatever it is you feel, know that thousands of parents share this journey. You are not alone. There is reason to hope. There is help. Now that you have the diagnosis, the question is, where do you go from here? The **Autism Speaks 100 Day Kit** was created to help you make the best possible use of the next 100 days in the life of your child. It contains information and advice collected from trusted and respected experts on autism and parents like you.

Why Does My Child Need a Diagnosis of Autism?

Parents are usually the first to notice the early signs of autism. You probably noticed that your child was developing differently from his or her peers. The differences may have existed from birth or may have become more noticeable later. Sometimes, the differences are severe and obvious to everyone. In other cases, they are more subtle and are first recognized by a daycare provider or preschool teacher. Those differences, the symptoms of autism, have led



thousands of parents like you to seek answers that have resulted in a diagnosis of autism. You may wonder: *Why does my child need a diagnosis of autism?* That's a fair question to ask - especially when right now, no one is able to offer you a cure. Autism Speaks is dedicated to funding global biomedical research into the causes, prevention, treatments and a possible cure for autism. Great strides have been made and the current state of progress is a far cry from the time when parents were given no hope for their children. Some of the most brilliant minds of our time have turned their attention toward this disorder.

It is important to remember that your child is the same unique, lovable, wonderful person he or she was before the diagnosis.

There are, however, several reasons why having a diagnosis is important for your child. A thorough and detailed diagnosis provides important information about your child's behavior and development. It can help create a roadmap for treatment by identifying your child's specific strengths and challenges and providing useful information about which needs and

skills should be targeted for effective intervention. A diagnosis is often required to access autism-specific services through your local school district.

How is Autism Diagnosed?

Presently, we don't have a medical test that can diagnose autism. As the symptoms of autism vary, so do the routes to obtaining a diagnosis. You may have raised questions with your pediatrician. Some children are identified as having developmental delays before obtaining a diagnosis of autism and may already receive some **Early Intervention** or **Special Education** services. Unfortunately, parents' concerns are sometimes not taken seriously by their doctor and as a result, a diagnosis is delayed. Autism Speaks and other autism-related organizations are working hard to educate parents and physicians, so that children with autism are identified as early as possible.

Your child may have been diagnosed by a **developmental pediatrician**, a **neurologist**, a **psychiatrist** or a **psychologist**. In some cases, a team of specialists may have evaluated your child and provided recommendations for treatment. The team may have included an **audiologist** to rule out hearing loss, a **speech & language therapist** to determine language skills and needs and an **occupational therapist** to evaluate physical and motor skills. A multi-disciplinary evaluation is important for diagnosing autism and other challenges that often accompany autism, such as delays in motor skills. If your child has not been evaluated by a multi-disciplinary team, you will want to make sure further evaluations are conducted so that you can learn as much as possible about your child's individual strengths and needs.



For more information, visit the Autism Speaks Autism Treatment Network at autismspeaks.org/atn.

Once you have received a formal diagnosis, it is important to make sure that you ask for a comprehensive report that includes the diagnosis in writing, as well as recommendations for treatment. The doctor may not be able to provide this for you at the appointment, as it may take some time to compile, but be sure to follow up and pick up this helpful necessary report as soon as it's available.

What is Autism?

Autism spectrum disorder (ASD) and **autism** are both general terms for a group of complex disorders of brain development. These disorders are characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors. With the May 2013 publication of the fifth edition of the **American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders** (commonly referred to as the DSM-5), all autism disorders were merged into one umbrella diagnosis of ASD. Previously, they were recognized as distinct subtypes, including autistic disorder, **childhood disintegrative disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS)** and **Asperger Syndrome**. The DSM is the main diagnostic reference used by mental health professionals and insurance providers in the United States.

You may also hear the terms Classic Autism or Kanner's Autism (named after the first psychiatrist to describe autism) used to describe the most severe form of the disorder. Under the current DSM-5, the diagnosis of autism requires that at least six developmental and behavioral characteristics are observed, that problems are present before the age of three and that there is no evidence of certain other conditions that are similar.

There are two domains where people with ASD must show persistent deficits:

- 1) challenges with social communication and social interaction**
- 2) restricted and repetitive patterns of behavior**

More specifically, people with ASD must demonstrate (either in the past or in the present) deficits in social-emotional reciprocity, deficits in nonverbal communicative behaviors used for social interaction and deficits in developing, maintaining and understanding relationships. In addition, they must show at least two types of repetitive patterns of behavior, including stereotyped or repetitive motor movements, insistence on sameness or inflexible adherence to routines, highly restricted, fixated interests, hyper or



hyporeactivity to sensory input or unusual interest in sensory aspects of the environment. Symptoms can be currently present or reported in past history. In addition to the diagnosis, each person evaluated will also be described in terms of any known genetic cause (e.g. Fragile X syndrome, Rett syndrome), level of language and intellectual disability and presence of medical conditions such as seizures, anxiety, depression and/or gastrointestinal (GI) problems.

The DSM-5 has an additional category called **Social Communication Disorder (SCD)**. This allows for a diagnosis of disabilities in social communication, without the presence of repetitive behavior. SCD is a new diagnosis and much more research and information is needed. There are currently few guidelines for the treatment of SCD. Until such guidelines become available, treatments that target social-communication, including many autism-specific interventions, should be provided to individuals with SCD.

To read the whole DSM-5 criteria, please visit autismspeaks.org/dsm-5.

How Common is Autism?

Autism statistics from the U.S. Centers for Disease Control and Prevention (CDC) released in March 2014 identify around 1 in 68 American children as on the autism spectrum – a ten-fold increase in prevalence in 40 years. Careful research shows that this increase is only partly explained by improved diagnosis and awareness. Studies also show that autism is four to five times more common among boys than girls. An estimated 1 out of 42 boys and 1 in 189 girls are diagnosed with autism in the United States.

ASD affects over 2 million individuals in the U.S. and tens of millions worldwide. Moreover, government autism statistics suggest that prevalence rates have increased 10% to 17% annually in recent years. There is no established explanation for this continuing increase, although improved diagnosis and environmental influences are two reasons often considered.

What Causes Autism?

Not long ago, the answer to this question would have been “we have no idea.” Research is now delivering the answers. First and foremost, we now know that there is no one cause of autism, just as there is no one type of autism. Over the last five years, scientists have identified a number of rare gene changes or mutations associated with autism. Research has identified more than 100 autism risk genes. In around 15% of cases, a specific genetic cause of a person’s autism can be identified. However, most cases involve a complex and variable combination of genetic risk and environmental factors that influence early brain development.



In other words, in the presence of a genetic predisposition to autism, a number of non-genetic or environmental influences further increase a child’s risk. The clearest evidence of these environmental risk factors involves events before and during birth. They include advanced parental age at time of conception (both mom and dad), maternal illness during pregnancy, extreme prematurity, very low birth weight and certain difficulties during birth, particularly those involving periods of oxygen deprivation to the baby’s brain. Mothers exposed to high levels of pesticides and air pollution may also be at higher risk of having a child with ASD. It is important to keep in mind that these factors, by themselves, do not cause autism. Rather, in combination with genetic risk factors, they appear to modestly increase risk.

A small but growing body of research suggests that autism risk is lower among children whose mothers took prenatal vitamins (containing folic acid) in the months before and after conception.

Increasingly, researchers are looking at the role of the immune system in autism. Autism Speaks is working to increase awareness and investigation of these and other issues where further research has the potential to improve the lives of those who struggle with autism.

While the causes of autism are complex, it is abundantly clear that it is not caused by bad parenting. Dr. Leo Kanner, the psychiatrist who first described autism as a unique condition in 1943, believed that it was caused by cold, unloving mothers. Bruno Bettelheim, a renowned professor of child development, perpetuated this misinterpretation of autism. Their promotion of the idea that unloving mothers caused their children’s autism created a generation of parents who carried the tremendous burden of guilt for their child’s disability. In the 1960s and 70s, Dr. Bernard Rimland, the father of a son with autism who later founded the Autism Society of America and the Autism Research Institute, helped the medical community understand that autism is a biological disorder and is not caused by cold parents.

More Information about Symptoms of Autism

Autism affects the way an individual perceives the world and makes communication and social interaction difficult. Autism spectrum disorders (ASD) are characterized by social-interaction difficulties, communication challenges and a tendency to engage in repetitive behaviors. However, symptoms and their severity vary widely across these three core areas. Taken together, they may result in relatively mild challenges for someone on the high functioning end of the autism spectrum. For others, symptoms may be more severe, as when repetitive behaviors and lack of spoken language interfere with everyday life.

It is sometimes said that if you know one person with autism, you know one person with autism.

While autism is usually a life long condition, all children and adults benefit from interventions, or therapies, that can reduce symptoms and increase skills and abilities. Although it is best to begin intervention as soon as possible, the benefits of therapy can continue throughout life. The long term outcome is highly variable. A small percentage of children lose their diagnosis over time, while others remain severely affected. Many have normal **cognitive skills**, despite challenges in social and language abilities. Many individuals with autism develop speech and learn to communicate with others. How your child is functioning now may be very different from how he or she will function later on in life.

The information following on the social symptoms, communication disorders and repetitive behaviors associated with autism is partially taken from the National Institute of Mental Health (NIMH) website.



Social symptoms

Typically developing infants are social by nature. They gaze at faces, turn toward voices, grasp a finger and even smile by 2 to 3 months of age. By contrast, most children who develop autism have difficulty engaging in the give-and-take of everyday human interactions. By 8 to 10 months of age, many infants who go on to develop autism are showing some symptoms such as failure to respond to their names, reduced interest in people and delayed babbling. By toddlerhood, many children with autism have difficulty playing social games, don't imitate the actions of others and prefer to play alone. They may fail to seek comfort or respond to parents' displays of anger or affection in typical ways.

Research suggests that children with autism are attached to their parents. However, the way they express this attachment can be unusual. To parents, it may seem as if their child is disconnected. Both children and adults with autism also tend to have difficulty interpreting what others are thinking and feeling. Subtle social cues such as a smile, wave or grimace may convey little meaning. To a person who misses these social cues, a statement like "Come here!" may mean the same thing, regardless of whether the speaker is smiling and extending her arms for a hug

or frowning and planting her fists on her hips. Without the ability to interpret gestures and facial expressions, the social world can seem bewildering.

Many people with autism have similar difficulty seeing things from another person's perspective. Most five-year-olds understand that other people have different thoughts, feelings and goals than they have. A person with autism may lack such understanding. This, in turn, can interfere with the ability to predict or understand another person's actions.

It is common – but not universal – for those with autism to have difficulty regulating emotions. This can take the form of seemingly “immature” behavior such as crying or having outbursts in inappropriate situations. It can also lead to disruptive and physically aggressive behavior. The tendency to “lose control” may be particularly pronounced in unfamiliar, overwhelming or frustrating situations. Frustration can also result in self-injurious behaviors such as head banging, hair pulling or self-biting.

Fortunately, children with autism can be taught how to socially interact, use gestures and recognize facial expressions. Also, there are many strategies that can be used to help the child with autism deal with frustration so that he or she doesn't have to resort to challenging behaviors. We will discuss this later.

Communication difficulties

Young children with autism tend to be delayed in babbling, speaking and learning to use gestures. Some infants who later develop autism coo and babble during the first few months of life before losing these communicative behaviors. Others experience significant language delays and don't begin to speak until much later. With therapy, however, most people with autism do learn to use spoken language and all can learn to communicate.

When language begins to develop, people with autism may use speech in unusual ways. Some have difficulty combining words into meaningful sentences. They may speak only single words or repeat the same phrase over and over. Some go through a stage where they repeat what they hear verbatim (echolalia).

Many parents assume difficulties expressing language automatically mean their child isn't able to understand the language of others, but this is not always the case. It is important to distinguish between expressive language and receptive language. Children with difficulties in expressive language are often unable to express what they are thinking through language, whereas children with difficulties in receptive language are often unable to understand what others are saying. Therefore, the fact that your child may seem unable to express him or herself through language does not necessarily mean he or she is unable to comprehend the language of others. Be sure to talk to your doctor or look for signs that your child is able to interpret language, as this important distinction will affect the way you communicate with him or her.

It is important to understand the importance of pragmatics when looking to improve and expand upon your child's communication skills. **Pragmatics** are social rules for using language in a meaningful context or conversation. While it is important that your child learns how to communicate through words or sentences, it is also key to emphasize both when and where the specific message should be conveyed. Challenges in pragmatics are a common feature of spoken language difficulties in children with autism. These challenges may become more apparent as your child gets older.

Some mildly affected children exhibit only slight delays in language or even develop precocious language and unusually large vocabularies – yet have difficulty sustaining a conversation. Some children and adults with autism tend to carry on monologues on a favorite subject, giving others little chance to comment. In other words, the ordinary “give-and-take” of conversation proves difficult. Some children with ASD with superior language skills tend to speak like little professors, failing to pick up on the “kid-speak” that's common among their peers.

Another common difficulty is the inability to understand body language, tone of voice and expressions that aren't meant to be taken literally. For example, even an adult with autism might interpret a sarcastic "Oh, that's just great!" as meaning it really is great.

Conversely, individuals affected by autism may not exhibit typical body language. Facial expressions, movements and gestures may not match what they are saying. Their tone of voice may fail to reflect their feelings. Some use a high-pitched sing-song or a flat, robot-like voice. This can make it difficult for others to know what they want and need. This failed communication, in turn, can lead to frustration and inappropriate behavior (such as screaming or grabbing) on the part of the person with autism. Fortunately, there are proven methods for helping children and adults with autism learn better ways to express their needs. As the person with autism learns to communicate what he or she wants, challenging behaviors often subside.

Repetitive behaviors

Unusual repetitive behaviors and/or a tendency to engage in a restricted range of activities are another core symptom of autism. Common repetitive behaviors include hand-flapping, rocking, jumping and twirling, arranging and rearranging objects and repeating sounds, words or phrases. Sometimes the repetitive behavior is self-stimulating, such as wiggling fingers in front of the eyes.

The tendency to engage in a restricted range of activities can be seen in the way that many children with autism play with toys. Some spend hours lining up toys in a specific way instead of using them for pretend play. Similarly, some adults are preoccupied with having household or other objects in a fixed order or place. It can prove extremely upsetting if

someone or something disrupts the order. Along these lines, many children and adults with autism need and demand extreme consistency in their environment and daily routine. Slight changes can be extremely stressful and lead to outbursts.

Repetitive behaviors can take the form of intense preoccupations or obsessions. These extreme interests can prove all the more unusual for their content (e.g. fans, vacuum cleaners or toilets) or depth of knowledge (e.g. knowing and repeating astonishingly detailed information about planes or astronomy). Older children and adults with autism may develop tremendous interest in numbers, symbols, dates or science topics.

Many children with autism need and demand absolute consistency in their environment.



Strengths and Challenges:

Created by Stephen Shore

It is important to note that this is a general list. For every strength and challenge, you will often find examples in people that prove the opposite. For example, clumsiness is a common challenge. However, some with autism have significant strengths in movement and balance, perhaps as a dancer.

Strengths:

- Attention to detail
- Often highly skilled in a particular area
- Deep study resulting in encyclopedic knowledge on areas of interest
- Tendency to be logical (helpful in decision-making where emotions may interfere)
- Less concern for what others may think of them (can be a strength and a challenge), also known as independent thinking. Often results in novel “big picture” insights due to different ways of looking at things, ideas, and concepts.
- Usually visual processing (thinking in pictures or video)
- Average to above average intelligence
- Often very verbal (propensity of giving detailed descriptions may be useful in providing directions to lost persons)
- Direct communication
- Loyalty
- Honesty
- Nonjudgmental listening

Challenges

- Grasping the “big” picture
- Uneven set of skills
- Difficulty developing motivation to study areas not of interest
- Difficulty perceiving emotional states of others
- Perceiving unwritten rules of social interaction, but can learn these rules through direct instruction and social narratives such as Power Cards (Gagnon, 2004)
- Difficulty processing in non-favorite modalities such as aural, kinesthetic, etc.
- Difficulty parsing out and summarizing important information for a conversation
- Sensory integration problems where input may register unevenly, distorted and difficulty in screening out background noise
- Generalization of skills and concepts
- Difficulty expressing empathy in ways that others expect or understand
- Executive functioning resulting in difficulties planning long-term tasks

Executive Functioning and Theory of Mind

Individuals with autism may often face challenges related to their ability to interpret certain social cues and skills. They may have difficulty processing large amounts of information and relating to others. Two core terms relating to these challenges are executive functioning and theory of mind. Executive functioning includes skills such as organizing, planning, sustaining attention and inhibiting inappropriate responses. Theory of mind refers to one's ability to perceive how others think and feel and how that relates to oneself. Both of these issues can impact the behavior of individuals with autism.

Difficulties in the area of executive functioning can manifest themselves in many different ways. Some individuals pay attention to minor details, but fail to see how these details fit into a bigger picture. Others have difficulty with complex thinking that requires holding more than one train of thought simultaneously. Others have difficulty maintaining their attention or organizing their thoughts and actions. Executive functioning difficulties can also be associated with poor impulse control.

Temple Grandin once said:

"I cannot hold one piece of information in my mind while I manipulate the next step in the sequence."

Individuals with autism often lack the ability to use skills related to executive functioning like planning, sequencing and self-regulation.

Theory of mind can be summed up as a person's inability to understand and identify the thoughts, feelings and intentions of others. Individuals with autism can encounter difficulty recognizing and processing the feelings of others, which is sometimes referred to as "mind-blindness". As a result of this mind-blindness, people with autism may not realize if another person's behaviors are intentional or unintentional. This challenge often leads others to believe that the individual with autism does not show empathy or understand them, which can create great difficulty in social situations.

Theory of mind deficits can oftentimes have a large impact on individuals with autism. In the book *Asperger Syndrome and Difficult Moments* by Brenda Smith Myles and Jack Southwick, the authors illustrate social deficits caused by theory of mind:

- 1. Difficulty explaining one's behaviors**
- 2. Difficulty understanding emotions**
- 3. Difficulty predicting the behavior or emotional state of others**
- 4. Problems understanding the perspectives of others**
- 5. Problems inferring the intentions of others**
- 6. Lack of understanding that behavior impacts how others think and/or feel**
- 7. Problems with joint attention and other social conventions**
- 8. Problems differentiating fiction from fact**

Ozonoff, Dawson and McPartland, in their book *A Parent's Guide to Asperger Syndrome and High Functioning Autism*, offer several suggestions for helping children with autism succeed in the classroom. To address challenges in the area of executive functioning, they offer the following suggestions:

- **Use a weekly homework log that is sent from school to home and back, keeping all parties informed of work due and progress**
- **Assignment checklists can be used to break large, often overwhelming tasks into manageable unites**
- **Day planners, including PDAs, can help organize your child**
- **A posted classroom schedule**
- **Allocation of sufficient time for instructions, repetition of instructions, and individual student assistance**
- **Preferential desk placement near teacher and away from distractions**

Physical and Medical Issues that May Accompany Autism

Seizure disorders

Seizure Disorder, also called **epilepsy**, occurs in as many as one third of individuals with autism spectrum disorder. Epilepsy is a brain disorder marked by recurring seizures or convulsions. Experts propose that some of the brain abnormalities that are associated with autism may contribute to seizures. These abnormalities can cause changes in brain activity by disrupting neurons in the brain. Neurons are cells in the brain that process and transmit information and send signals to the rest of the body. Overloads or disturbances in the activity of these neurons can result in imbalances that cause seizures.

Epilepsy is more common in children who also have **cognitive** deficits. Some researchers have suggested that seizure disorder is more common when the child has shown a regression or loss of skills. There are different types and subtypes of seizures and a child with autism may experience more than one type. The easiest to recognize are large “grand mal” (or **tonic-clonic**) seizures. Others include “petit mal” (or **absence**) seizures and **subclinical seizures**, which may only be apparent in an **EEG** (electroencephalogram). It is not clear whether subclinical seizures have effects on language, cognition and behavior. The seizures associated with autism usually start either early in childhood or during adolescence, but may occur at any time. If you are concerned that your child may be having seizures, you should see a neurologist. The neurologist may order tests that may include an **EEG**, an **MRI** (Magnetic Resonance Imaging), a **CT** (Computed Axial Tomography) and a **CBC** (Complete Blood Count). Children and adults with epilepsy are typically treated with **anticonvulsants** or seizure medicines to reduce or eliminate occurrences. If your child has epilepsy, you will work closely with a neurologist to find the medicine (or combination of medicines) that works the best with the fewest side effects and to learn the best ways to ensure your child’s safety during a seizure.

You can find more information about autism and epilepsy at autismspeaks.org/family-services/epilepsy.



Genetic disorders

Some children with autism have an identifiable genetic condition that affects brain development. These genetic disorders include Fragile X syndrome, Angelman syndrome, tuberous sclerosis, chromosome 15 duplication syndrome and other single-gene and chromosomal disorders. While further study is needed, single gene disorders appear to affect 15 to 20% of those with ASD. Some of these syndromes have characteristic features or family histories, the presence of which may prompt your doctor to refer your child to a geneticist or neurologist for further testing. The results can help increase awareness of associated medical issues and guide treatment and life planning.

Gastrointestinal (GI) disorders

Many parents report **gastrointestinal (GI)** problems in their children with autism. The exact prevalence of gastrointestinal problems such as **gastritis, chronic constipation, colitis** and **esophagitis** in individuals with autism is unknown. Surveys have suggested that between 46 and 85% of children with autism have problems such as chronic constipation or diarrhea. One study identified a history of gastrointestinal symptoms (such as abnormal pattern of bowel movements, frequent constipation, frequent vomiting and frequent abdominal pain) in 70% of the children with autism. If your child has similar symptoms, you will want to consult a **gastroenterologist**, preferably one who works with people with autism. Your child's physician may be able to help you find an appropriate specialist. Pain caused by GI issues is sometimes recognized because of a change in a child's behavior, such as an increase in self-soothing behaviors like rocking or outbursts of aggression or self-injury. Bear in mind that your child may not have the language skills to communicate the pain caused by GI issues. Treating GI problems may result in improvement in your child's behavior. Anecdotal evidence suggests that some children may be helped by dietary intervention for GI issues, including the elimination of dairy and gluten containing foods. *(For more information, see [Gluten Free Casein Free diet in the treatment section of this kit.](#))* As with any treatment, it is best to consult your child's physician to develop a comprehensive plan. In January 2010, Autism Speaks initiated a campaign to inform pediatricians about the diagnosis and treatment of GI problems associated with autism.

For additional information from the Official Journal of American Academy of Pediatrics, go to: pediatrics.aappublications.org/cgi/content/full/125/Supplement_1/S1.

For information that can be shared with your child's doctor, go to: autismspeaks.org/press/gastrointestinal_treatment_guidelines.php.



Sleep dysfunction

Is your child having trouble getting to sleep or sleeping through the night? Sleep problems are common in children and adolescents with autism. Having a child with sleep problems can affect the whole family. It can also have an impact on the ability of your child to benefit from therapy. Sometimes sleep issues may be caused by medical issues such as **obstructive sleep apnea** or **gastroesophageal reflux** and addressing the medical issues may solve the problem. In other cases, when there is no medical cause, sleep issues may be managed with behavioral interventions including **“sleep-hygiene”** measures, such as limiting the amount of sleep during the day and establishing regular bedtime routines. There is some evidence of abnormality of **melatonin** regulation in children with autism. While melatonin may be effective for improving the ability of children with autism to fall asleep, more research is needed. Melatonin or sleep aids of any kind should not be given without first consulting with your child's physician.

For additional information on sleep issues visit: autismspeaks.org/science/resources-programs/autism-treatment-network/tools-you-can-use/sleep-tool-kit.

Sensory Integration Dysfunction

Many children with autism experience unusual responses to **sensory stimuli** or input. These responses are due to difficulty in processing and integrating sensory information. Vision, hearing, touch, smell, taste, the sense of movement (**vestibular system**) and the sense of position (**proprioception**) can all be affected. This means that while information is sensed normally, it may be perceived much differently. Sometimes stimuli that seem “normal” to others can be experienced as painful, unpleasant or confusing by a child with **Sensory Integration Dysfunction (SID)**, the clinical term for this characteristic. (SID may also be called Sensory Processing Disorder or Sensory Integration Disorder.) SIDs can involve hypersensitivity (also known as **sensory defensiveness**) or hyposensitivity. An example of hypersensitivity would be an inability to tolerate wearing clothing, being touched or being in a room with normal lighting. **Hyposensitivity** might be apparent in a child’s increased tolerance for pain or a constant need for sensory stimulation. Treatment for Sensory Integration Dysfunction is usually addressed with occupational therapy and/or sensory integration therapy.

Pica

Pica is an eating disorder involving eating things that are not food. Children between 18 and 24 months of age often eat nonfood items, but this is typically a normal part of development. Some children with autism and other developmental disabilities persist beyond the developmentally typical timeframe and continue to eat items such as dirt, clay, chalk or paint chips. Children showing signs of persistent mouthing of fingers or objects, including toys, should be tested for elevated blood levels of lead, especially if there is a known potential for environmental exposure to lead. You should speak to your doctor about these concerns so he or she can help you with treatment. Your child’s doctor will help you to assess if your child needs a behavioral intervention or if it is something that can be managed at home.



Visit the Autism Speaks Tool Kits page to download tool kits with information and resources related to pica for both parents and professionals at autismspeaks.org/family-services/tool-kits.

Mental health

Oftentimes a child diagnosed with ASD may receive an additional diagnosis such as **Attention Deficit Hyperactivity Disorder (ADHD)**. **ADHD** and anxiety are quite common and addressing these diagnoses properly can help your child make great strides. Recent studies suggest that 1 in 5 children on the autism spectrum also has ADHD and 30% struggle with an **anxiety disorder** such as social phobia, separation anxiety, panic disorder and specific phobias. The classic symptoms of ADHD include chronic problems with inattention, impulsivity and hyperactivity. However, these or similar symptoms can likewise result from autism. For this reason, it is important that evaluation be made by someone with expertise in both disorders. A recent study found that just 1 in 10 children with autism and ADHD was receiving medication to relieve the ADHD symptoms.

In regards to anxiety, children with autism express anxiety or nervousness in many of the same ways as typically developing children. Understandably, many individuals with ASD have trouble communicating how they feel. Outward manifestations may be the best clues. In fact, some experts suspect that outward symptoms of anxiety – such as sweating and acting out – may be especially prominent among those with ASD. This can include a racing heart, muscular tensions and stomachaches. It is important for your child to be evaluated by a professional who has expertise in both autism and anxiety so he or she can provide the best treatment options for your child.



You, Your Family and Autism

How Will I Deal With the Diagnosis?

You are never prepared for a diagnosis of autism. It is likely that you will experience a range of emotions. It is painful to love so much, to want something so much and not quite get it.

Even though it is your child who has the autism diagnosis, it is important to acknowledge that autism “happens” to the whole family. It affects every member of the household. Autism can be difficult to deal with, both for the person diagnosed and for the family. It can lead to many changes in the family, both inside and outside the home. Luckily, with heightened awareness, there are many places to go for support and help. As you move forward with your child and your family as a whole, the staff at the Mayo Clinic has come up with the following advice to help you on your journey:

- **Learn about the disorder.** Just 15 years ago, many pediatricians hadn't heard of autism. Now, there are numerous books and websites dedicated to the disorder. Do some research so that you better understand your child's challenges and the range of services in your school district and state that may help.
- **Learn about your child.** The signs and symptoms of autism vary for each child, and young children have a hard time explaining their behaviors and challenges. But, with time and patience, you'll learn which situations and environments may cause problems for your child and which coping strategies work. Keeping a diary and looking for patterns may help.
- **Find a team of trusted professionals.** You'll need to make important decisions about your child's education and treatment. Find a team of teachers and therapists who can help evaluate the options in your area and explain the federal regulations regarding children with disabilities.
- **Help others help your child.** Most children with autism have no visible sign of disability, so you may need to alert coaches, relatives and other adults to your child's special needs. Otherwise, a well-meaning coach may spend time lecturing your child on “looking at him while he's talking” – something that can be very difficult for a child with autism.
- **Help your child turn his or her obsession into a passion.** The tendency to fixate on a particular narrow topic is one of the hallmarks of autism and it can be annoying to those who must listen to incessant talk about the topic every day. But a consuming interest can also connect a child with autism to schoolwork and social activities. In some cases, kids with autism can even turn their childhood fascination into a career or profession.



Caring for the Caregiver

Changing the course of the life of your child with autism can be a very rewarding experience. You are making an enormous difference in his or her life. To make it happen, you need to take care of yourself. Take a moment to answer these questions: *Where does your support and strength come from? How are you really doing? Do you need to cry? Complain? Scream? Would you like some help but don't know who to ask?*

Remember that if you want to take the best possible care of your child, you must first take the best possible care of yourself.

Parents often fail to evaluate their own sources of strength, coping skills or emotional attitudes. You may be so busy meeting the needs of your child that you don't allow yourself time to relax, cry or simply think. You may wait until you are so exhausted or stressed out that you can barely carry on before you consider your own needs. Reaching this point is not helping you or your family. You may feel that your child needs you right now, more than ever. Your "to do" list may be what is driving you forward right now. You may feel completely overwhelmed and not know where to start. There is no single way to cope. Each family is unique and deals with stressful situations differently. Getting your child started in treatment will help you feel better. Acknowledging the emotional impact of autism and taking care of yourself during this stressful period will help prepare you for the challenges ahead. Autism is a pervasive, multi-faceted disorder. It will not only change the way that you look at your child, it will change the way you look at the world. Maintaining open and honest communication with your partner and family as well as discussing your fears and concerns will help you to deal with the many changes in your life. As some parents may tell you, you may be a better person for it. The love and hope that you have for your child make you stronger than you realize.

Here are some tips from parents who have experienced what you are going through:

Get going.

Getting your child started in treatment will help. There are many details you will be managing in an intensive treatment program, especially if it is based in your home. If you know your child is engaged in meaningful activities, you will be more able to focus on moving forward. It may also free up some of your time so you can educate yourself, advocate for your child and take care of yourself.

Ask for help.

Asking for help can be very difficult, especially at first. Don't hesitate to use whatever support is available to you. People around you may want to help, but may not know how. Is there someone who can take your other kids somewhere for an afternoon? Or cook dinner for your family one night so that you can spend the time learning? Can someone pick a few things up for you at the store or do a load of laundry? Or let other people know you are going through a difficult time and could use a hand?

Talk to someone.

Everyone needs someone to talk to. Let someone know what you are going through and how you feel. Someone who just listens can be a great source of strength. If you can't get out of the house, use the phone to call a friend.

Consider joining a support group.

It may be helpful to listen or talk to people who have been or are going through a similar experience. Support groups can be great sources of information about what services are available in your area and who provides them. You may have to try more than one to find a group that feels right to you. You may find you aren't a "support group kind of person." For many parents in your situation, support groups provide valuable hope, comfort and encouragement.

You may also want to consider attending a recreational program for children with autism. This may be a good way to meet other parents just like you.

One study from Vanderbilt University, a part of the Autism Speaks Autism Treatment Network, found that mothers of children with autism benefit significantly from weekly stress-reduction classes led by other mothers. The classes reduced previously high levels of personal stress, anxiety and depression and improved the mom's interactions with their children.

“At my support group I met a group of women who were juggling the same things I was. It felt so good not to feel like I was from another planet!”

You may find a listing of support groups in the Autism Speaks Resource Guide at autismspeaks.org/resource-guide. Another avenue is through the local SEPTA (Special Education Parent Teacher Association) in your school district or online through the Autism Speaks Facebook page at facebook.com/autismspeaks.

My Autism Team, the social network for parents of kids with autism, is another great resource. On this site, parents of children with autism share their experiences, including their reviews of local service providers, to help inform the parents in their communities. Visit the site at myautismteam.com.

Try to take a break.

If you can, allow yourself to take some time away, even if it is only a few minutes to take a walk. If it's possible, getting out to a movie, going shopping or visiting a friend can make a world of difference. If you feel guilty about taking a break, try to remind yourself that this break will help you feel renewed for the things you need to do when you get back. Try to get some rest. If you are getting regular sleep, you will be better prepared to make good decisions, be more patient with your child and more able to deal with the stress in your life.

Consider keeping a journal.

Louise DeSalvo, in *Writing as a Way of Healing*, notes that studies have shown that: “Writing that describes traumatic events and our deepest thoughts and feelings about them is linked with improved immune function, improved emotional and physical health, and positive behavioral changes.” Some parents have found a journal to be a helpful tool for keeping track of their child's progress, what is working and what isn't. Be mindful of the time you spend on the internet. The internet will be one of the most important tools you have for learning what you need to know about autism and how to help your child.

Unfortunately, there is more information on the web than any of us have time to read in a lifetime. There may also be a lot of misinformation.

As a parent, always remember to trust your gut.

There are many paths to take, treatment options and opinions. You know your child best. Work with your child's treatment team to find what works best for your child and your family.

Right now, while you are trying to make the most of every minute, keep an eye on the clock and frequently ask yourself these important questions:

Is what I'm reading right now very likely to be relevant to my child?

Is it new information?

Is it helpful?

Is it from a reliable source?

Sometimes, the time you spend on the internet will be incredibly valuable. Other times, it may be better for you and your child if you use that time to take care of yourself.

The internet will be one of the most important tools you have for learning what you need to know about autism and how



Becoming Resilient During Times of Adversity

by **Dr. Peter Faustino**, school psychologist, state delegate to the **National Association of School Psychologists (NASP)** and member of the **Autism Speaks Family Services Committee**

Resiliency, or finding ways to properly adapt to challenges or stress in your life, is a process, not a character trait. Research has revealed several key elements in fostering resilience and by considering the following, you will find you are not only helping your child but yourself and your entire family.

Connectedness: One of the strongest pillars in resilience is having positive relationships or feeling connected to others. While the diagnosis of autism may be extraordinary at first, it no longer is synonymous with being alone or having few places to turn for help. This tool kit is only one example of the ways in which Autism Speaks can lend support. Regional chapters of Autism Speaks all across the country can open up doors to other parents, families and communities who have experience with navigating the autism diagnosis. When relationships with friends, neighbors and family are based on mutual, reciprocal support and care, they can bolster resiliency.

Competence: Whenever a challenge presents itself, individuals can feel a loss of control over the situation and their lives. Competence or at this early stage learning about autism and then taking action on realistic goals will help you gain a sense of control.

Having trustworthy information and feeling more competent (not only about autism but in other aspects of your life) can be critical in maintaining a hopeful outlook.

Care: Eventually, your journey will lead to a place where you can balance negative emotions with positive ones. Taking care to avoid seeing an event as unbearable or unchangeable versus looking for opportunities and considering the event in a broader context can be an important factor to resilience. Positive attitudes such as encouraging yourself to try, being determined to persevere until success is attained, applying a problem solving approach to difficult situations and fostering feelings of determination or grit are critical. Care also refers to parents attending to their own mind and body, exercising regularly, as well paying attention to basic needs and feelings.

Resilience is the result of individuals being able to interact with their environments and the processes that either promote wellbeing or protect them against overwhelming influence of risk factors. In many cases, adversity can act as a spring board for growth and success, not only in our children, but in ourselves as well.

“Is Your Son On the Spectrum?”

**In her own words,
Alysia K. Butler, who has a recently diagnosed son, describes her
experience being part of the autism community.**

The question was slightly jarring to me. My son and I had just walked into a gymnastics class for kids with autism. We had received his diagnosis only three weeks before and we hadn't shared our news with anyone except for close friends and family. It was the first time we had been anywhere that was just for kids like mine and I wasn't really ready to talk to a total stranger about it.

“Yes,” I answered, trying to keep the conversation short.

“Hi and welcome! That's my son over there and my name is Sandy. How old is your son? Do you live in town? How long have you known your son was on the spectrum? What was his diagnosis?” I really didn't want to answer her. I wasn't even sure we belonged at this class and all I wanted to do was pay attention to my son to see how he was responding to the class. I watched the other kids as they came in – six boys and one girl – and my first instinct was that we were in the wrong place. One little boy was crying, another was spinning in circles and another one was running in all different directions. My son's not like that, I thought to myself. This isn't us.

And then I looked at my Henry. I watched him hold tightly to his one-on-one helper's hand as they walked on a low balance beam, but he wouldn't look her in the eye when she talked to him. I watched him try to run away to jump into the comfort of the sensory foam blocks and become so focused on that foam pit that he couldn't move on to anything else. I listened to him babble while he swayed back and forth on the rings and saw the terror in his face when the noise level got up too high. The tears welled up

in my eyes. We did belong here. This was the right place for him. We had found a safe place for him to exercise and develop his muscles in an environment that understood his special needs. For so long we had avoided the “regular” gym classes, music classes and playgroups because of his behavior. No one here was giving me the usual disapproving looks we get when we're out places and Henry starts to act up. I took a deep breath and turned to the mom.

“Hi! My son Henry was diagnosed with PDD-NOS a few weeks ago. We do live in town. In fact, I've seen your son at the preschool that my son attends. How long has your son attended classes here?”

It took everything I had to have that conversation, but it was such a relief. This other mom was reaching out to make a connection – to find someone else who struggles on a daily basis like she does – something I myself had been desperate to do for weeks and months. I was instantly welcomed into a community of people who “get it.” No one batted an eye when Henry buried himself under the foam blocks at the end of class so he didn't have to leave. I got comforting looks of understanding from all the parents and teachers when he had a major meltdown leaving the gym and big thumbs up from everyone when we finally got our shoes on and went out the door. These were moms and dads who shared my daily difficulties of just getting out of the house. Finally, we were somewhere that felt like we belonged.

“Will we see you next week?” asked the mom.

“Absolutely,” I replied.

How Will This Affect Our Family?

Even though it is your child who has the diagnosis, it is important to acknowledge that autism affects the whole family. This section of your tool kit may help you anticipate some of the emotions you and other people in your family will experience.



Telling Family Members

The following article, adapted from *Does My Child Have Autism?*, by Wendy L. Stone, Ph.D., provides some helpful information for talking to your parents and close family members about the autism diagnosis.

Reactions vary widely. But whatever reaction you get, it will be very important to educate your parents about the nature of autism after you have told them about the diagnosis.

“You know those behaviors we’ve been confused about for so long? Well, now we have a name for them and an explanation for why they occur. Howie doesn’t act the way he does because he’s spoiled or because he’s shy or because he doesn’t like us – he acts that way because he has autism. Autism explains why he doesn’t speak or use gestures and why he doesn’t seem to understand what we say. It explains why he’s not as interested in interacting with us as the other children in the family have been and why he plays with spoons and bottles instead of toys. I know this is upsetting news for all of us. But the good news is that the disorder has been diagnosed early, and there are a lot of things we can do to help him. He’ll be starting some therapies soon, and I’ll be learning about things I can do to help him at home. I know that you will need some time to think about all of this. But if you have any questions as we begin his therapy, I’ll be glad to try my best to answer them. I know we’re all hoping for the best outcome possible.” After the initial conversation about this diagnosis, continue to keep your other children and your extended family in the information loop.

Telling Others

The following article from the book *Overcoming Autism*, by Lynn Kern Koegel, Ph.D. and Claire LaZebnik, offers a suggestion for how to tell people, and explains why for some people, it can make life easier for you and your friends.

You should, you know. Tell people. You don't have to walk up to strangers on the street or anything, but confide in the people who love you. That was one thing we did right: we told our families and our friends right away. First we called them, and then we copied a good comprehensive article someone wrote about autism and annotated it with specifics about Andrew, and we mailed it out to everyone we knew. (You could do the same things with sections from this book, by the way.) None of our good friends pulled away from us because our kid had autism. Just the opposite – our friends and families rallied around us in amazing ways and have continued to cheer Andrew's progress on year after year. In all honesty, telling people what we were going through only made our lives easier. Before then, we worried that Andrew's occasionally aberrant behavior was off-putting. But once he had a formal diagnosis, everyone cut us a lot of slack, and instead of wondering what the hell was wrong with us as parents, most people we knew admitted to a newfound respect for us for dealing with so much. Real friends don't love you more for being successful or less for having problems. If anything, it works the opposite way – we're all so busy that sometimes we forget to stay in touch with friends when everything's fine for them, but we rush forward when they need us. Now is the time to take advantage of that. Talk your friends' ears off, complain, bitch and moan to them. You're dealing with a huge challenge, take advantage of every minor plus it has to offer.



Telling Peers

Talking with peers and other students is crucial to helping a child with autism become more comfortable in school or social settings. If peers are aware of their classmate with autism and understand the reasons behind his or her sometimes odd behavior, this will increase acceptance and limit bullying or taunting. It is important to explain autism to children in a way that they will best understand their friend or classmate. For example, talk about the fact that many of us have challenges. While one classmate might be unable to see and might need glasses as a result, this other child has trouble in social situations and needs support as a result. It may help to identify one or two peers who can serve as “buddies” to help your child feel more comfortable in school.

Stephen Shore developed a four-step process for disclosing autism, which he has found effective in a number of settings. In essence, it's a tool for placing a child's autism in context and helping others to understand that autism is not a “handicap,” but rather a collection of strengths and challenges. Through accommodations and support, people with autism can not only succeed but can even thrive.

Four Step Process for Disclosing Autism

by **Stephen Shore**

Start by delineating your child’s strengths and challenges. Use the word “challenges” instead of “weaknesses” because you can address challenges. If Joe’s been in class for a little while, a parent might say “Joey is very good at following the rules. When there’s a change in the schedule, though, you’ll see Joey get a little anxious.”

Try to find a strength that your child uses to accommodate for a challenge. For example, during lecture parts of class, your child might use a computer to take notes. A parent might say “Joey finds that writing by hand is very tough, so this is how he takes notes.”

Talk about other people’s characteristics to place your child in a broader context. A parent might say, “Joey has these strengths; other people have other strengths. We all try to build on our strengths to lead to productive lives.”

Lastly, bring out the label. Explain that autism is a set of traits, strengths and challenges, and that doctors and scientists have identified these characteristics as autism.



Explaining the Diagnosis to Your Child

According to experts, it is essential for parents to explain the diagnosis to their children. Oftentimes, this can help put children on a path to self-acceptance and can allow them the time to understand and ask questions. With no knowledge of their diagnosis, children with autism can often compare themselves to others and come to unfounded conclusions about themselves and their own well-being.

Children younger than eight years of age often do not think they are different from their peers, so the bigger picture of a developmental disorder may be too complex for them to understand. When talking to your child, remember to use age appropriate words and to think about it from his or her perspective, in order to improve the communication between the two of you. It can help to talk to your child about being an individual and explain that differences exist between all people. Using play, and sometimes books, can also aid in helping children with autism to better understand themselves and their diagnosis. Be sure to emphasize your child’s strengths as well as his or her areas of challenge. It is helpful to point out that everyone has areas of strength and weakness.

“Our son, age 9, was recently diagnosed with autism. He knows something is up but we’re not sure how to explain it to him. Advice?”

In the piece below, clinical psychologist Lauren Elder, PhD, answers one parent’s question about how to tell her son about his autism:

Sharing your child’s diagnosis with him is a difficult situation shared by many parents. Children need to understand what’s going on, but the discussion needs to be appropriate for their age and level of development. Your openness will help your child feel comfortable coming to you with questions.

I recommend a series of ongoing conversations rather than a one-time discussion. Here are some tips for starting the conversation and preparing some answers for questions that your son may ask:

Explain autism in terms of your child’s strengths and weaknesses.

You may want to focus on what he’s good at, and then discuss what’s difficult for him. You can explain that his diagnostic evaluation provided important information on how to use his strengths to meet his challenges. Focus on how everyone has strengths as well as weaknesses. Give some examples for yourself, his siblings and other people he knows.

Provide basic information about autism.

Depending on your son’s maturity and understanding, you may want to continue by talking about what autism means. You want to give your child a positive but realistic picture.

It may help your son to hear that autism is common and that there are many children like him. This can open a discussion about the strengths and challenges that many children with autism share. You might likewise discuss how individuals with autism tend to differ from other children.

For instance, you might explain that many children with autism are very good at remembering things. Some excel at building things or at math. Also explain that many children with autism have difficulty making friends and communicating with other people.

Don’t make everything about autism.

It’s important to emphasize that your son’s autism-related strengths and challenges are just part of who he is and why you love him. Be sure to point out some of those special qualities that have nothing to do with his autism. This will help your child understand that autism is something that he has, not the sum total of who he is.

Assure your child of support.

Explain to your son why he’s receiving the services he’s getting. For instance, you could tell him that he sees a speech therapist to help him communicate more clearly, or that he’s seeing a behavioral therapist to improve how he makes friends. Help him understand how you, his therapists and his teachers all want to help him. You can point out that we all need some help to become the best we can be. Some children need extra help learning to read. Some get very sad and need help in that department, etc.

Expect to repeat these conversations!

All children – and especially those with autism – need to hear some information multiple times. This doesn’t mean he doesn’t understand what you’ve told him. Rather, revisiting these topics can be an important part of his processing the information.

Find role models and peers.

It’s important for children with autism to spend time with typically developing peers. However, for children your son’s age and older, it can be a wonderful experience to spend time with other children on the autism spectrum. Consider enrolling your son in a play group or social skills group specifically for children with autism.

15 Tips for Your Family

As a result of her work with many families who deal so gracefully with the challenges of autism, family therapist Kathryn Smerling, Ph.D., offers five tips for parents, five for siblings and five for extended family members:

5 tips for parents

1. *Learn to be the best advocate you can be for your child. Be informed. Take advantage of all the services that are available to you in your community. You will meet practitioners and providers who can educate you and help you. You will gather great strength from the people you meet.*

2. *Don't push your feelings away. Talk about them. You may feel both ambivalent and angry. Those are emotions to be expected. It's okay to feel conflicting emotions.*

3. *Try to direct your anger towards the disorder and not towards your loved ones. When you find yourself arguing with your spouse over an autism related issue, try to remember that this topic is painful for both of you; and be careful not to get mad at each other when it really is the autism that has you so upset and angry. Try to have some semblance of an adult life. Be careful to not let autism consume every waking hour of your life. Spend quality time with your typically developing children and your spouse and refrain from constantly talking about autism. Everyone in your family needs support and to be happy despite the circumstances.*

4. *Appreciate the small victories your child may achieve. Love your child and take great pride in each small accomplishment. Focus on what he or she can do instead of making comparisons with a typically developing child. Love your child for who he or she is.*

5. *Get involved with the autism community. Don't underestimate the power of "community". You may be the captain of your team, but you can't do everything*



yourself. Make friends with other parents who have children with autism. By meeting other parents you will have the support of families who understand your day to day challenges. Getting involved with autism advocacy is empowering and productive. You will be doing something for yourself as well as your child by being proactive.

"Learning more about my child's unique needs and abilities along with reaching out for support has enabled my husband and me to be better parents to our son and better partners for each other on this journey."

5 tips for brothers and sisters

1. Remember that you are not alone! Every family is confronted with life's challenges... and yes, autism is challenging...but, if you look closely, nearly everyone has something difficult to face in their families.

2. Be proud of your brother or sister. Learn to talk about autism and be open and comfortable describing the disorder to others. If you are comfortable with the topic...they will be comfortable too. If you are embarrassed by your brother or sister, your friends will sense this and it will make it awkward for them. If you talk openly to your friends about autism, they will become comfortable. But, like everyone else, sometimes you will love your brother or sister and sometimes you may not like him or her. It's okay to feel your feelings. And often it's easier when you have a professional counselor to help you understand them – someone special who is here just for you! Love your brother or sister the way he or she is!

3. While it is okay to be sad that you have a brother or sister affected by autism, it doesn't help to be upset and angry for extended periods of time. Your anger doesn't change the situation; it only makes you unhappier. Remember your Mom and Dad may have those feelings too.

4. Spend time with your parents alone. Doing things together as a family with and without your brother or sister strengthens your family bond. It's okay for you to want alone time. Having a family member with autism can often be very time-consuming and attention-grabbing. You need to feel important too. Remember, even if your brother or sister didn't have autism, you would still need alone time with Mom and Dad.



“At first I felt lost and confused about my brother but now that my parents have helped to explain things to me, I can be a better big brother and help my

5. Find an activity you can do with your brother or sister. You will find it rewarding to connect with your brother or sister, even if it is just putting a simple puzzle together. No matter how impaired he or she may be, doing something together creates a closeness. Your brother or sister will look forward to these shared activities and greet you with a special smile.

5 tips for grandparents and extended family members

1. Family members have a lot to offer. Each family member is able to offer the things he or she learned to do best over time. Ask how you can be helpful to your family. Your efforts will be appreciated whether it means taking care of the child so that the parents can go out to dinner or raising money for the special school that helps the child. Organize a lunch, a theatre benefit, a carnival or a card game. It will warm your family's hearts to know that you are pitching in to create support and closeness.

2. Seek out your own support. If you find yourself having a difficult time accepting and dealing with the fact that your loved one has autism, seek out your own support. Your family may not be able to provide you with that kind of support, so you must be considerate and look elsewhere. In this way you can be stronger for them, helping with the many challenges they face. Be open and honest about the disorder. The more you talk about the matter, the better you will feel. Your friends and family can become your support system...but only if you share your thoughts with them. It may be hard to talk about it at first, but as time goes on, it will be easier. In the end, your experience with autism will end up teaching you and your family profound life lessons.

3. Put judgment aside. Consider your family's feelings and be supportive. Respect the decisions they make for their child with autism. They are working very hard to explore and research all options and are typically coming to well thought out conclusions. Try not to compare children. (This goes for typically developing kids as well.) Children with autism can be brought up to achieve their personal best.

4. Learn more about autism. It affects people of all social and economic statuses. There is promising research, with many possibilities for the future. Share that sense of hope with your family, while educating yourself about the best ways to help manage this disorder.



5. Carve out special time for each child. You can enjoy special moments with both typically developing family members and the family member with autism. Yes, they may be different, but all of the children look forward to spending time with you. Children with autism thrive on routines, so find one thing that you can do together that is structured, even if it is simply going to a park for 15 minutes. If you go to the same park every week, chances are over time that activity will become easier and easier...it just takes time and patience. If you are having a difficult time trying to determine what you can do, ask your family. They will sincerely appreciate the effort that you are making.

There are also specialized tool kits for specific people in your life. To access them visit: autismspeaks.org/family-services/tool-kits/family-support-tool-kits.

“Talking to other grandparents helped me to feel part of a bigger community and to learn more about my granddaughter. I am now able to help my family the best I can and spend quality time with each of my grandchildren.”

How is Autism Treated?

The road ahead will be bumpy. There will be times when your progress stalls or takes an unexpected turn. When it does, try to remind yourself that these are speed bumps, not roadblocks. Take them one at a time. It is important that you start now. There are a variety of services available to treat and educate your child.

It is very important to remember that one method or intervention may not work for every child. Remember that your child is unique and work with his or her strengths to help him or her in the best way possible. Treatment of autism can help your child navigate through social challenges, capitalize on his or her strengths and be successful. Before we get into the types of therapies available, it is helpful to take a step back and look at the bigger picture. Although research and experience have revealed many of the mysteries surrounding autism, it remains a complex disorder that impacts each child differently. However, many children with autism have made remarkable breakthroughs with the right combinations of therapies and interventions.

Most parents would welcome a therapy that would alleviate all of the challenges that make life difficult for their child. Just as your child's challenges can't be summed up in one word, they can't be remedied with one therapy. Each challenge must be addressed with an appropriate therapy. No single therapy works for every child. What works for one child may not work for another. What works for one child for a period of time may stop working. Some therapies are supported by research showing their efficacy, while others are not. The skill, experience and style of the therapist are critical to the effectiveness of the intervention.

In their book *A Parent's Guide to Asperger Syndrome and High Functioning Autism*, Ozonoff, Dawson, and McPartland state that a guiding principle is learning to address your child's difficulties, while channeling your child's strengths. They point out that many people with autism have remarkable skills in one or more of the following areas:

- **Memory - especially rote memory**
- **Superior academic skills**
- **Visual thinking**
- **Recognizing order and following rules**
- **Have passion and conviction**
- **Comfort and compatibility with adults rather than children**

In fact, sometimes the symptoms of autism can instead be seen as "strengths" and can be used to help your child be successful in life. Other times, your child's unique behaviors can be channeled into strengths given the proper support, a little creativity and a shift in perspective.

In order to determine what treatments and interventions will be most effective for an individual with autism, a thorough assessment of all symptoms must be done. The evaluation must examine a wide variety of factors including behavioral history, current symptoms, communication patterns, social competence and neuropsychological functioning. It is crucial to look at the strengths and weaknesses of the child in each of these areas in order to paint a full and clear picture. An individual with autism may have completely different strengths and weaknesses than another individual with the same diagnosis.

One treatment that is the most significant and most effective for one child may be completely unnecessary and ineffective for another. As a result, treatments and interventions must be very individualized based on the information gathered from the thorough assessment.

An effective treatment program includes parents as part of the treatment process, builds on the child's interests, promotes self-esteem and offers a predictable schedule. Such a program also teaches tasks as a series of simple steps, actively engages the child's attention in highly structured activities, helps include the child in a typical social environment and provides regular reinforcement of behavior.

Treatment for the Core Symptoms of Autism

Most families use one type of intensive intervention that best meets the needs of their child and their parenting style. The intensive interventions described here require multiple hours per week of therapy and address behavioral, developmental and/or educational goals. They are developed specifically to treat autism. During the course of treatment, it may be necessary to reevaluate which method is best for your child.

Therapies are not always delivered in a "pure format." Some intervention providers who work primarily in one format may use successful techniques from another format.

Before you choose an intervention, you will need to investigate the claims of each therapy so that you understand the possible risks and benefits for your child. At first, all of these techniques – ABA, VB, PRT, DTT, ESDM, among others – may seem like alphabet soup to you. You may be confused now, but you will be surprised at how quickly you become "fluent" in the terminology of autism therapies.



For information on different treatment options, turn to the glossary in this kit or visit [AutismSpeaks.org](https://autismspeaks.org).

To view different treatments in video format please visit the Autism Speaks Autism Video Glossary at autismspeaks.org/what-autism/video-glossary.

You should also see your pediatrician for more information, so that you can be confident you are making informed choices as you begin to narrow down your options.

Applied Behavioral Analysis

Behavior analysis was originally described by B.F. Skinner in the 1930s. It is a scientifically validated approach to understanding behavior and how it is affected by the environment. In this context, “behavior” refers to actions and skills. “Environment” includes any influence – physical or social – that might change or be changed by one’s behavior. Behavior analysis focuses on the principles that explain how learning takes place.

Applied Behavior Analysis (ABA) is the use of these techniques and principles to bring about meaningful and positive change in behavior. There is a great deal of research that has demonstrated that ABA is effective for improving children’s outcomes, especially their cognitive and language abilities.

ABA is often difficult to understand until you see it in action. It may be helpful to start by describing what all of the different methods of ABA have in common.

ABA methods use the following three step process to teach:

An antecedent, which is a verbal or physical stimulus such as a command or request. This may come from the environment or from another person or be internal to the subject;

A resulting behavior, which is the subject’s (or in this case, the child’s) response or lack of response to the antecedent;

A consequence, which depends on the behavior, can include positive reinforcement of the desired behavior or no reaction for incorrect responses.

ABA targets the learning of skills and the reduction of challenging behaviors. Most ABA programs are highly structured. Each skill is broken down into small steps and taught using prompts that are gradually eliminated as the steps are mastered. The child is given repeated opportunities to learn and practice each step in a variety of settings. Each time the child

achieves the desired result, he or she receives positive reinforcement, such as verbal praise or something else that the child finds to be highly motivating, like a small piece of candy.

Effective ABA intervention for autism is not a “one size fits all” approach and should never be viewed as a “canned” set of programs or drills. On the contrary, a skilled therapist customizes the intervention to each learner’s skills, needs, interests, preferences and family situation. For those reasons, an ABA program for one learner might look somewhat different from a program for another learner. An ABA program will also change as the needs and functioning of the learner change. If the child isn’t making satisfactory progress, adjustments are made.

A **Board Certified Behavior Analyst (BCBA)** specializing in autism will write, implement and monitor the child’s individualized program. Individual therapists, often called “trainers,” (not necessarily board certified) will work directly with the child on a day-to-day basis. Most ABA programs consist of 25 to 40 hours per week of therapy. Families are also encouraged to use ABA principles in their daily lives.

To find more information on ABA, go to the Association for Behavior Analysis International website at ABAinternational.org or the Behavior Analyst Certification Board website at BACB.com.

Verbal Behavior

Verbal Behavior therapy teaches communication using the principles of Applied Behavior Analysis and the theories of behaviorist B.F. Skinner. By design, Verbal Behavior therapy motivates a child, adolescent or adult to learn language by connecting words with their purposes. The student learns that words can help obtain desired objects or other results.

Verbal Behavior therapy avoids focusing on words as mere labels (cat, car, etc.). Rather, the student learns how to use language to make requests and communicate ideas. Verbal Behavior therapy focuses on four word types. They are:

Mand:

A request, such as “Cookie,” to ask for a cookie

Tact:

A comment used to share an experience or draw attention, such as “airplane” to point out an airplane

Intraverbal:

A word used to answer a question or otherwise respond, such as “Where do you go to school?” “Castle Park Elementary”

Echoic:

A repeated, or echoed, word, such as “Cookie?” “Cookie!” (important as the student needs to imitate to learn)

Verbal Behavior therapy begins by teaching mands or requests as the most basic type of language. For example, the individual with autism learns that saying “cookie” can produce a cookie. Immediately after the student makes such a request, the therapist reinforces the lesson by repeating the word and presenting the requested item. The therapist then uses the word again in the same or similar context.

Importantly, children don’t have to say the actual word to receive the desired item. In the beginning, he or she simply needs to signal requests by any means. Pointing at the item represents a good start.

This helps the student understand that communicating produces positive results. The therapist builds on this understanding to help the student shape the communication toward saying or signing the actual word.

VB and classic ABA use similar behavioral formats to work with children. VB is designed to motivate a child to learn language by developing a connection between a word and its value. VB may be used as an extension of the communication section of an ABA program.

Verbal Behavior therapy is provided by VB-trained psychologists, special education teachers, speech therapists and other providers. VB programs usually involve 30 or more hours per week of scheduled therapy. Families are encouraged to use VB principles in their daily lives.

Pivotal Response Treatment

Pivotal Response Treatment, or PRT, is a behavioral intervention developed by Dr. Robert L. Koegel, Dr. Lynn Kern Koegel and Dr. Laura Shreibman at the University of California at Santa Barbara.

PRT is one of the best studied and validated behavioral treatments for autism. Derived from ABA, it is play-based and child-initiated. Its goals include the development of communication, language and positive social behaviors and relief from disruptive self-stimulatory behaviors.

Rather than target individual behaviors, the PRT therapist targets “pivotal” areas of a child’s development. These include motivation, response to multiple cues, self-management and the initiation of social interactions. The philosophy is that by targeting these critical areas, PRT will produce broad improvements across other areas of sociability, communication, behavior and academic skill building.

Motivation strategies are an important part of the PRT approach. These emphasize “natural” reinforcement. For example, if a child makes a meaningful attempt to request, say, a stuffed animal, the reward is the stuffed animal – not a candy or other unrelated reward.

Each program is tailored to meet the goals and needs of the individual learner and his or her school and home routines. A session typically involves six segments during which language, play and social skills are targeted with both structured and unstructured interactions. As the child progresses, the focus of each session changes to accommodate more advanced goals and needs.

PRT programs usually involve 25 or more hours per week. Everyone involved in the child's life is encouraged to use PRT methods consistently in every part of his or her life. PRT has been described as a lifestyle adopted by the affected family.

For more information on PRT, visit the UCSB Koegel Autism Center website at Education.UCSB.edu/autism or the UCSD Autism Research Program website at autismlab.ucsd.edu.

Relationship Development Intervention (RDI)

Like other therapies described in this tool kit, **Relationship Development Intervention (RDI)** is a system of behavior modification through positive reinforcement. RDI was developed by Dr. Steven Gutstein as a family-based behavioral treatment using dynamic intelligence and addressing autism's core symptoms. RDI aims to help individuals with autism form personal relationships by gradually strengthening the building blocks of social connections. This includes the ability to form an emotional bond and share experiences.

The six objectives of RDI are:

Emotional Referencing: the ability to use an emotional feedback system to learn from the subjective experiences of others

Social Coordination: the ability to observe and continually regulate one's behavior in order to participate in spontaneous relationships involving collaboration and exchange of emotions

Declarative Language: the ability to use language and non-verbal communication to express curiosity, invite others to interact, share perceptions and feelings and coordinate your actions with others

Flexible Thinking: the ability to rapidly adapt, change strategies and alter plans based upon changing circumstances



Relational Information Processing: the ability to obtain meaning based upon the larger context; solving problems that have no "right-and wrong" solutions

Foresight and Hindsight: the ability to reflect on past experiences and anticipate potential future scenarios in a productive manner

The program involves a systematic approach to working on building motivation and teaching skills while focusing on the child's current developmental level of functioning. Children begin work in a one-on-one setting with a parent. Gradually, additional children are added, as are the number of settings in which the children practice, in order to help the child form and maintain relationships in different contexts.

RDI is somewhat unique because it is designed to be implemented by parents. Parents, teachers and other professionals can be trained to provide RDI through training seminars, books and other materials and can collaborate with an RDI-certified consultant. Some specialized schools offer RDI in a private school setting.

Find more information on RDI on the Connections Center website at RDIconnect.com.

TEACCH

The TEACCH® Autism Program is a clinical, training and research program based at the University of North Carolina & Chapel Hill. TEACCH, developed by Drs. Eric Schopler and Robert Reichler in the 1960s, was established as a statewide program by the North Carolina legislature in 1972 and has become a model for other programs around the world.

TEACCH developed the intervention approach called “Structured TEACCHing”, an array of teaching or treatment principles and strategies based on the learning characteristics of individuals with ASD, including strengths in visual information processing and difficulties with social communication, attention and executive function.

In response to this profile of strengths and challenges, Structured TEACCHing includes:

External organizational supports to address challenges with attention and executive function

Visual and/or written information to supplement verbal communication

Structured support for social communication

Structured TEACCHing is not a curriculum, but instead is a framework to support achievement of educational and therapeutic goals. This framework includes:

Physical organization

Individualized schedules

Work (Activity) systems

Visual structure of materials in tasks and activities



The goal of Structured TEACCHing is to promote meaningful engagement in activities, flexibility, independence and self-efficacy. Structured TEACCHing strategies are integrated into other evidenced-based practices. TEACCH programs are usually conducted in a classroom setting. TEACCH-based home programs are also available and are sometimes used in conjunction with a TEACCH-based classroom program.

To find more information on TEACCH, go to the TEACCH Autism Program website at TEACCH.com.

Social Communication/ Emotional Regulation/ Transactional Supports (SCERTS)

Social Communication/Emotional Regulation/Transactional Support (SCERTS) is an educational model developed by Barry Prizant, PhD, Amy Wetherby, PhD, Emily Rubin and Amy Laurant. SCERTS uses practices from other approaches including ABA (in the form of PRT), TEACCH, Floortime and RDI. The SCERTS Model differs most notably from the focus of “traditional” ABA by promoting child-initiated communication in everyday activities. SCERTS is most concerned with helping children with autism to achieve “Authentic Progress,” which is defined as the ability to learn and spontaneously apply functional and relevant skills in a variety of settings and with a variety of partners.

The acronym “SCERTS” refers to the focus on:

“SC” Social Communication: *Development of spontaneous, functional communication, emotional expression and secure and trusting relationships with children and adults*

“ER” Emotional Regulation: *Development of the ability to maintain a well-regulated emotional state to cope with everyday stress and to be most available for learning and interacting*

“TS” Transactional Support: *Development and implementation of supports to help partners respond to the child’s needs and interests, modify and adapt the environment and provide tools to enhance learning (e.g., picture communication, written schedules and sensory supports)*

The SCERTS model favors having children learn with and from other children who provide good social and language models in inclusive settings, as much as possible. SCERTS is implemented using transactional supports put in place by a team, such as environmental accommodations and learning supports like schedules or visual organizers.

For more information on SCERTS, visit [SCERTS.com](https://www.scerts.com)

Cognitive Behavior Therapy

Cognitive Behavioral Therapy (CBT) is used primarily to help individuals with autism regulate their emotions, develop impulse control and improve their behavior as a result. CBT seeks to help individuals understand and become aware of their thoughts and feelings so they can learn to respond to them in a more effective way.

Cognitive behavior therapy has been shown to be helpful for reducing anxious and depressed feelings and behavior sometimes exhibited in individuals with autism by making changes in thoughts and perceptions of situations through a change in cognition. The key ingredient of CBT, which distinguishes it from regular behavior therapy, is working on this change in cognition or how thinking is processed. Therapists seek to reduce challenging behaviors, such as interruptions, obsessions, meltdowns or angry outbursts, while also teaching individuals how to become familiar with and manage certain feelings that may arise.

Cognitive behavioral therapy can be individualized for each patient, and as a result, is very effective at improving very specific behaviors and challenges in each child or young adult. Stabilizing emotions and improving behavior allows those with autism to prepare for and respond more appropriately in specific situations.

Related Services

The next section of this tool kit covers a number of what are frequently called “related services.” These services are therapies that address symptoms commonly associated with autism, but not specific to the disorder.

Speech-language therapy (SLT)

Most autism behavioral intensive therapy programs include **speech-language therapy**. With a variety of techniques, speech-language therapy addresses a range of challenges often faced by persons with autism. For instance, some individuals on the autism spectrum do not speak, while others love to talk but have difficulty using conversational speech and/or understanding the nuances of language and nonverbal cues when talking with others.

Speech-language therapy is designed to coordinate the mechanics of speech with the meaning and social use of language. Such a program begins with an individual evaluation by a speech-language pathologist to assess an individual’s verbal aptitudes and challenges. From this evaluation, the pathologist sets goals that may include mastering spoken language and/or learning nonverbal communication skills such as signs or **gestures**. In each case, the goal is to help the person communicate in more useful and functional ways.

The speech language pathologist can provide therapy one-on-one, in a small group or in a classroom setting. Therapists who work with children have additional specialized training.

One approach used in speech-language therapy is **Prompts for Restructuring Oral Muscular Phonetic Targets (PROMPT)**. PROMPT is a physical-sensory approach to therapy in which a therapist uses touch and pressure to an individual’s jaw, tongue and



lips to help him or her develop motor control and the proper oral muscular movements to speak. Speech therapists need to be fully trained in order to provide PROMPT therapy.

To learn more about PROMPT, visit promptinstitute.com.

Occupational therapy (OT)

Occupational therapy (OT) addresses a combination of cognitive, physical and motor skills. Its goals including helping a child or adult gain age-appropriate independence and participate more fully in life. For a person with autism, occupational therapy often focuses on skills for appropriate play or leisure skills, learning and self-care skills.

Therapy begins with a certified occupational therapist evaluating the person’s developmental level as well as related learning styles, social abilities and environmental needs. Based on this evaluation, the therapist determines goals and selects strategies and tactics for enhancing key skills. For instance, goals may include independent dressing, feeding, grooming and use of the toilet, along with improved social, fine motor and visual perceptual skills. Typically, occupational therapy involves half-hour to one-hour sessions with a frequency determined by the individual’s needs. In addition, the person with autism practices strategies and skills – with guidance – at home and in other settings including school. OT is provided by certified occupational therapists.

Sensory integration (SI) therapy

Many children and adults with autism have challenges in processing sensory information such as movement, touch, smell, sight and sound. **Sensory integration (SI) therapy** identifies such disruptions and uses a variety of techniques that improve how the brain interprets and integrates this information. Occupational therapy often includes sensory integration. Other times it is delivered as a stand-alone therapy.

Certified occupational and physical therapists provide sensory integration therapy. The therapist begins with an individual evaluation to determine a person's sensitivities. From this information, he or she plans an individualized program that matches sensory stimulation with physical movement to improve how the brain processes and organizes incoming information. As such, the therapy often includes equipment such as swings, trampolines and slides.

Sensory integration therapy can allow a child or adult with sensory integration difficulties to become more "available" for learning and social interactions. Family members and teachers often find that its techniques can help calm an affected child or adult, reinforce positive behavior and help with transitions between activities.

Physical therapy (PT)

Many children and adults with autism have challenges with motor skills such as sitting, walking, running and jumping. **Physical therapy (PT)** focuses on problems with movement that cause real-life limitations. In particular, physical therapy can improve poor muscle tone, balance and coordination.

Certified physical therapists deliver physical therapy beginning with an evaluation of a person's physical abilities and developmental level. They then design programs of activities that target areas of challenge. Typically therapy sessions run a half hour to an hour and include assisted movement, various forms of exercise and the use of orthopedic equipment. The needs of the child or adult receiving services should determine the frequency of these sessions.

Social skills

Difficulty with social skills is a hallmark of autism, especially for school age children. In recent years, social skills training, both one-on-one and in peer group settings, has become a very common treatment for this particular challenge. Though it may not seem this way, many children with autism have the same desire as other children to be social and make friends. They just need to be taught the skills required to form these bonds with others.

Social skills taught during training sessions range from simple skills like eye contact to more difficult skills like inviting a peer for a playdate. Studies have shown that this type of intervention program can significantly improve social competence and social skill development. Though social skills training is not an official or certified form of therapy, professionals like social workers, speech therapists and psychologists often focus largely on improving social skills when treating both children and adults with autism. In addition, parents, family members and other caregivers can be taught effective ways to improve the social skills of their loved ones with autism both inside and outside the home on a regular basis. It is important to make the social situations taught in training sessions as realistic as possible so the new skills can be easily applied in settings outside of the classroom.

Implementing social skills training and groups at school is a great way to help your child expand these skills that can lead to growth and improvement in other areas of his or her life. Talk to your child's teacher or guidance counselor about the best ways to use these opportunities to help your child grow and learn to better interact with others. One important factor to consider for effective social skills groups is the involvement of your child's neurotypical peers in these group settings. The presence of peer models has been found to increase the rate of initiating social interaction with others outside the group. These peers should be encouraged to model the skills, prompt the children with autism to use the skills and then praise them for the correct use of the skills. *A Program for Helping Peer Models Teach Social Skills to Children with Autism*, created by the University of Nebraska

Medical Center with a grant from Autism Speaks, is a great curriculum that can be found on the Autism Speaks website in the grants database.

Gluten free, casein free diet (GFCF)

Much has been said about the **gluten** free, **casein** free (GFCF) diet and its use to help individuals with autism. Many families with children newly diagnosed with autism wonder if it's something their child should follow. The GFCF diet was first developed for people with celiac disease, a disorder that involves a severe reaction to gluten in the diet. Gluten is found in wheat products such as bread and other bakery goods but also in a wide variety of other food products. Casein is a protein most associated with dairy products and has potential to cause severe reactions in certain individuals. When used appropriately, the GFCF diet is safe and can help avoid these severe health problems.

The theory behind its use in autism is that if a person is having GI responses to these products, the resulting inflammation may damage the lining of the intestine and as a result lead to absorption of molecules that are not normally absorbed by healthy intestines. Some evidence suggests that these molecules or the inflammation they cause can interact with the brain in ways that cause problems such as anxiety, mood abnormalities, mental difficulties and perhaps worsen the behavioral symptoms of autism. That said, while the GFCF diet has been used in the autism community for a couple of decades, there is minimal evidence that it improves autism-related behaviors.



Families choosing a trial of dietary restriction should make sure their child is receiving adequate nutrition by consulting his or her pediatrician or a nutrition specialist. Dairy products are the most common source of calcium and Vitamin D for young children in the United States. Many young children depend on dairy products for a balanced, regular protein intake. Alternative sources of these nutrients require the substitution of other food and beverage products, with attention given to the nutritional content. Substitution of gluten-free products requires attention to the overall fiber and vitamin content of a child's diet. Vitamin supplements may have both benefits and side effects. Consultation with a dietician or physician is recommended for the healthy application of a GFCF diet. This may be especially true for children who are picky eaters.

What about other medical interventions?

Right now you are itching to do everything possible to help your child. Many parents in your position are eager to try new treatments, even those treatments that have not yet been scientifically proven to be effective. Your hopes for a cure for your child may make you more vulnerable to the lure of untested treatments.

It is important to remember that just as each child with autism is different, so is each child's response to treatments.

It may be helpful to collect information about a therapy that you are interested in trying and speak with your pediatrician, as well as your intervention team members, in order to discuss the potential risks/benefits and establish measurable outcomes and baseline data. Parents of older children with autism can provide you with a history of therapies and biomedical interventions that have been promised to be cures for autism over the years. Some of them may have been helpful to a small number of children. Upon further study, none of them, so far, has turned out to be a cure for the vast majority. We do know that many children get better with intensive behavioral therapy. There is a large body of scientific evidence to support this theory. It makes sense to focus on getting your child engaged in an intensive behavioral program before looking at other interventions.

Strategies to Support Your Child with Autism

Positive Behavior Supports

Research has shown that the use of **Positive Behavior Supports** is an effective way to manage challenging behavior. PBS involves identifying the function of a problem or challenging behavior and then teaching the individual new skills to help correct the behavior and respond with a positive one instead. Therefore, it involves creating a structured plan that positively addresses behavior.

It is important to understand that most human behaviors serve a purpose and as a result, many of your child's challenging behaviors have underlying causes. Work with your child and his or her therapist(s) to try to identify these causes so you can develop a plan to teach him or her the positive skills and behaviors that can be used to respond to the problem. Look at each situation from your child's perspective – what is happening that may be causing him or her to respond in this way? Specific PBS systems should be put in place to respond to each problem situation or challenging behavior. Share your positive behavior support plans with your child's school, after school program, etc. so that the approach can be used across all situations and settings.

Visual Schedules

As previously discussed, one challenge faced by individuals with autism is their need for routine and strict adherence to schedules. **Visual Schedules** are a great tool to help create a more structured environment for your child, which can help with preparedness, anxiety and challenging behaviors. They can help with your child's understanding of time and transitions between activities and environments, as well as increase independence by allowing him or her to comprehend the sequence of events without your

prompting. Similarly, checklists can help manage your child's time and prepare him or her in advance of situations that may present difficulties. He or she can use the checklist to understand what is happening and what is coming up. For example, if your family is flying somewhere, a visual schedule that shows each step of the air travel experience – trip to the airport, check-in, security, waiting at the gate, etc. – or a checklist of those steps can help prepare your child for the process and keep him or her engaged throughout the experience.

Video Modeling

Another tool that has been found to be effective in teaching children with autism is **video modeling**. This strategy uses videos to help teach social skills and daily living skills and is often more effective than live modeling. In video modeling, individuals watch video demonstrations of positive behavior and then imitate the people in the videos. Another method used is showing individuals videos of themselves performing behaviors successfully and repeating them back. Video modeling is a fun way for individuals to learn and an effective way for teachers, caregivers and therapists to teach important skills.

Motivational Systems

Motivation is a critical component in helping to improve your child's areas of difficulty. It can help him or her to associate positive behaviors with positive feedback. Whereas a pat on the back or round of applause is an obvious indication of a positive behavior to a neurotypical child, children with autism may need additional motivation or reinforcement to understand the response a behavior elicits. Following up a behavior with positive reinforcement like specific verbal praise or a reward will make your child more likely to repeat the same behavior in the future. This system can help your child gradually build on simple skills like eye contact in order to learn more complex social skills.

Making It Happen

How Do I Choose the Right Intervention?

Choosing a treatment path for your child may feel overwhelming. Remember to work closely with your child's treatment team and explore all of your options. The two articles that follow may provide helpful information for you as you choose between methods of therapies for your child.

“Alleviate Stress by Actively Pursuing the Right Intervention” from *Overcoming Autism*

by Lynn Kern Koegel, PhD and Claire LaZebnik

It's scary to have to question your own child's potential, but the best way to relieve your fears is to take action with productive interventions. The first step is to be informed. Talk to people you trust - parents who've been there, experts in the field, doctors you have a relationship with and so on. There are a lot of fly-by-night procedures that prey on distraught parents who will do anything for their child. Make sure that the interventions you're using are scientifically sound and well documented. Make sure they've been tested with many children with autism and that they've been replicated by other experts and clinics. Also, make sure you understand their limitations – some interventions only work on a small number of symptoms or on a small subgroup of children with autism. If you're going to spend time and money for interventions, be informed about the degree and extent of the change they may bring about.



“Understanding Your Child’s Learning Style”

from ***Does My Child Have Autism?***

by Wendy Stone, PhD, and
Theresa Foy DiGeronimo, M.Ed

Finding the right intervention program begins with an understanding of your child’s learning style – which is quite different from the learning style of other children. You probably realize this as you’ve tried to get your child with autism to wave bye-bye using the same teaching strategies you used with your other children – that is, demonstrating the action, providing a verbal prompt by saying “wave bye-bye” and even moving his or her hand to demonstrate what to do. But when that approach didn’t seem to be working, you probably started to think that your child was being stubborn or uncooperative. After all, you’re teaching simple skills using methods that worked very well for your other children. But the reality is that your child isn’t being bad; he or she just has a different learning style from your other children. This difference in learning styles isn’t apparent only when you try to teach children with autism; it’s also evident in the way they learn (or don’t learn) on their own. There are lots of things that children without autism seem to learn effortlessly, without being taught, but that children with autism don’t pick up on as easily. For example, young children without autism somehow learn, without explicit teaching, how to use a pointing gesture to let you know what they want or to indicate where they want you to look. They learn to follow your point or eye gaze to figure out what you’re looking at or what you’re interested in. They figure out on their own how to use eye contact and facial expressions to convey their feelings—as well as to understand the meaning of your facial expressions and tone of voice. Social-communicative behaviors and skills like these just don’t come as naturally to young children with autism and often need to be taught explicitly.

Assembling Your Team

Your child's team will consist of many different members. They will help you to address all areas of your child's life and assist you in making decisions about your child's treatment, education, recreation and health. Below is some helpful information on how to assemble this group of professionals.

Medical team

Your child should be supported by a pediatrician who understands developmental issues and who will serve as your child's primary care provider. Depending on your child's needs, other medical team members may include a neurologist, geneticist, developmental pediatrician, gastroenterologist, psychiatrist or nutritionist.

Intensive intervention team

ABA, PRT, RDI, SCERTS, TEACCH and VB are all intensive interventions. Depending on the intensity of the primary intervention, there may be an intervention leader and several providers or therapists involved in providing the treatment as structured by the leader.

Related services team

Speech and language therapy, occupational therapy, physical therapy, sensory integration therapy and social skills instruction are all related services. All therapists working with your child should be communicating frequently and using a consistent method of teaching.

Hiring therapists

For parents hiring new therapists, you may want to consider the candidate as you would any other job applicant and handle the situation accordingly. Ask for resumes.

Specific Things to Look for on the Resume:

Past experience with children with autism approximately the same age as your child

Amount of experience the therapist has had

Kinds of experience the therapist has had, for example, whether he or she has worked in a school setting or in a private program

Educational background

Membership in professional autism organizations – if so, then he or she is most likely going to conferences, thus enhancing his or her skills in the profession

Conducting interviews

Conduct a "hands on" interview, during which the potential therapist works with your child to implement a skill acquisition program. It is important to see how the potential therapist takes direction and to see how flexible he or she is about changing approaches in his or her teaching. You will want a therapist to potentially be open to new ideas in terms of teaching approaches. It's a good idea to have him or her bring video of a therapy session conducted with another child. This offers yet another view of his or her teaching skills. If possible, observe the therapist working with another child.

Check references. Be sure to talk to previous supervisors and other parents for whom the therapist has worked. They are often good sources for finding additional therapists.

Consider a probation period. The therapist should be hired for a probation period, during which sessions are videotaped or observed directly until you and/or the home coordinator feel comfortable with the therapist and confident in his or her abilities.

Check clearances. Anyone working with your child will need to provide background clearances from the state you live in to establish that he or she does not have a criminal record. If you have chosen a home-based intervention program for your child, you will probably be required to submit copies of those clearances to the state, county or local agency providing services.

“When to Be Concerned About a Therapist”

from **Overcoming Autism** by Lynn Kern Koegel, PhD and Claire LaZebnik

There’s plenty of evidence showing that children with autism do better when parents are actively involved in the intervention and when programs are coordinated. Find programs that encourage you to be involved – you should be learning all the procedures and coordinating your child’s program across every environment. You can’t do that if you’re being shut out. If a treatment provider tells you that you can’t watch the sessions or that your child does better when you’re not there, this is a RED FLAG. It may be reasonable for a therapist to request a few sessions alone to bond with the child, but more than that just doesn’t make sense and the therapist needs to communicate fully with you so that you know exactly what’s going on at all times. If a clinician tells you that she’s not documenting any type of changes, be concerned – the only way to evaluate whether a treatment program is working is to analyze the changes your child is making. Also be wary of any therapist who says that he’s working on the “parent-child bond,” and that fixing your relationship with your child will improve her behavior. In other words, if your therapist is excluding you, blaming you or using techniques that do not have measurable outcomes, you should consider looking for another therapist or agency.

Managing your team

Participate in training. Be part of the team. Your participation in team training is vital so that you can increase your skills to successfully parent your child and understand the goals and techniques of his or her program. Knowing the techniques and objectives of your child’s intervention program will allow you to closely monitor his or her progress and guide and evaluate the members of your team. Intensive intervention programs often start with a one or two day training course where individual therapists are trained by the primary intervention leader.

Establishing team communication

There are two important ways your team will communicate. One is through a notebook in which each therapist records information after his or her session with your child. Each therapist reads the information recorded since the previous session before the next session with your child. Parents and supervisors can add information to the notebook as needed. The other way is through team meetings. Team meetings are often held at the home of the child, especially in the case of intervention programs that are home-based. These meetings should include as many members of your team as possible. This will ensure that your therapists are up to date on every aspect of the program and that they are all working with your child in consistent ways. At team meetings, you will discuss what is working, as well as areas in which there have not been progress, so that you can determine whether to make changes and what those changes should be. Teams usually meet once a month, but may meet more or less often as needed. Many team meetings include time for therapists to observe each other in action with your child and receive feedback on their techniques.

“Making Therapies Work for the Entire Family”

from **Overcoming Autism** by Lynn Kern Koegel, PhD and Claire LaZebnik

Always be sure you select interventionists who will view the family as teammates and will include you in the determination of target goals – your child needs to learn skills that will help the family function, fit into your lifestyle and be compatible with your cultural and religious values. For example, a clinician may feel that it’s important to work on answering the phone, while the family may feel that toilet training is a much more pressing and immediate goal. Both goals may well be valid, but the family needs to have a say in prioritizing them. Similarly, studies show that families who are required to implement drill type interventions have greater stress than when less rigid interventions are incorporated into daily family routines. How well the family functions as a whole is just as important as how well the child with special needs is doing and it’s your responsibility to work toward both kinds of success.

There are also currently apps and other technology resources out there that help parents manage their team and keep everyone informed and connected. One resource is My Autism Team (myautismteam.com), a social network that allows all professionals and family members involved in the care of an individual with autism to communicate and provide updates. Search the Autism Speaks Autism Apps database at autismspeaks.org/autism-apps for similar tools!

Autism and Insurance

While there are effective treatment options for autism, these services are not consistently covered by health insurance. Since 2007, Autism Speaks has focused its state advocacy efforts on passage of meaningful autism insurance reform. As of November 2014, 38 states have enacted laws that require certain health insurance plans to cover the treatment of autism, including Applied Behavior Analysis (ABA). These states appear in green on our state initiatives map at autismspeaks.org/advocacy.

Unfortunately, determining whether your insurance plan includes a meaningful autism benefit is not as easy as looking at a map. Not all plan types are subject to state law. Additionally, many state autism insurance laws further exclude certain plan types or impose age caps that may adversely affect your coverage.

Autism Speaks Insurance Link was developed to help families navigate the complexities of health insurance for autism. By answering a short series of questions, this online application will help parents determine whether their dependent is entitled to autism benefits under their health insurance plan. If not covered, Autism Speaks Insurance Link will provide parents with the tools to effectively advocate for meaningful coverage for the treatment of autism.

“While we were waiting for school district to complete the ‘evals’, my husband and I picked up two copies of the same book about autism and raced each other through it. By the time the tests were done, we’d learned a lot!”



It can sometimes be difficult to read some of the evaluations about your child's strengths and challenges. It's helpful to remember that your child is the same child as before the diagnosis and all of the evaluations.

Under the Affordable Care Act, if your employer's plan does not cover treatment, you may be able to get a child-only health insurance policy that does, depending on your state. These policies are sold to parents of children under the age of 21. Learn if you are eligible, when you can enroll and find out more about the Affordable Care Act policies in your state at autismspeaks.org/advocacy/insurance/affordable-care-act/states.

For more information about Autism Speaks efforts related to health insurance for autism, please email advocacy@autismspeaks.org.

And to access the Autism Speaks Insurance Link please visit autismspeaks.org/advocacy/insurancelink.

Autism and Wandering

Safety is a critical part of all of our lives, whether we are at home or out in the community, alone or with loved ones. Being aware of our surroundings and taking precautions to stay safe is even more important for individuals with autism and their families. Wandering is an especially prominent issue in the autism community. A 2012 study from the Interactive Autism Network confirmed that nearly half of all children with autism have attempted to wander or bolt from a safe, supervised place. Given the frequency of this problem, here are some tips that have been adapted from Autism Wandering Awareness Alerts Response Education Coalition (AWAARE) on how to prevent wandering:

1. Secure Your Home

Consider contacting a professional locksmith, security company or home improvement professional to promote safety and prevention in your home. You may find it is necessary to prevent your loved one from slipping away unnoticed by installing secure dead bolt locks that require keys on both sides, a home security alarm system, inexpensive battery-operated alarms on doors, hook and eye locks on all doors above your child's reach, a fence around your yard, printable STOP SIGNS on doors, windows and other exits, etc.

2. Consider a Locating Device

Check with local law enforcement for Project Lifesaver or Lo Jack SafetyNet services. These locating devices are worn on the wrist or ankle and locate the individual through radio frequency. Various GPS systems are also available.

3. Consider an ID Bracelet

Medical ID bracelets will include your name, telephone number and other important information. They may also state that your child has autism and is nonverbal if applicable. If your child will not wear a bracelet or necklace, consider a temporary tattoo with your contact information.

4. Teach Your Child to Swim

The leading cause of death of individuals with autism who wander is drowning. It is critical to teach your child both to swim and to understand the importance of water safety. Swimming lessons for children with special needs are available at many YMCA locations. The final lesson should be with clothes on. Remember that teaching your child how to swim does not mean your child is safe in water. If you own a pool, fence it. If neighbors have pools, let them know of these safety precautions and your child's tendency to wander. Remove all toys or items of interest from the pool when not in use.

Autism Speaks has a grant program that awards funding to organizations providing scholarships for swimming and water safety lessons for financially disadvantaged individuals with autism. Learn more at autismspeaks.org/family-services/grants/swimming.

5. Alert Your Neighbors

It is recommended that caregivers plan a brief visit with neighbors to introduce their loved one or provide a photograph. Knowing your neighbors can help reduce the risks associated with wandering.

6. Alert First Responders

Providing first responders with key information before an incident occurs may improve response. Informational handouts should include all pertinent information and be copied and carried with caregivers at all times. Circulate the handout to family, neighbors, friends and co-workers, as well as first responders. Always make sure to work with your child's team to express any concerns about safety issues, so that you can work together on a safety plan best suited for your loved one. More information about safety and wandering can be found at: awaare.org, autismspeaks.org/safety and autismspeaks.org/wandering-resources.

Wandering-related incidents among individuals with autism are far too common. In response to unfortunate incidents and the fears they have raised for parents in the autism community, we have put together a list of steps you can take to prevent wandering incidents and keep your child safe at school.

Seven steps you can take to prevent wandering at your child's school

1. If your child has a tendency to wander, it is critical to address wandering issues in his or her Individualized Education Program (IEP). If there is a history of wandering incidents, it's important to call a meeting with school staff, administrators and your child's IEP team to make them aware of these past situations, as well as educate them on the autism wandering issue in general. If something changes or an incident occurs, you as a parent have the right to amend the IEP and adjust the particular items, at any time.

2. Write a letter requesting that you always be informed, immediately and in writing, of any wandering incident on or off the campus. If your child requires 1-on-1 supervision, be sure to make this extremely clear to school staff – and clearly documented in the IEP – and emphasize that under no circumstances should your child be left alone at any time. A sample letter can be found at the end of this kit.

3. Carefully document all wandering-related incidents. Sharing this information with the staff at your child's school will help prepare them if such an incident occurs at school. For example, where has your child been found in the past? What are his or her fascinations or obsessions? Where would he/she most likely be drawn to near campus?

4. Try to eliminate all possible triggers that have led to wandering in the past. For example, if your child is drawn to water, be sure that all pools, lakes, etc. in the area of the school are blocked off so that there is no chance your child will be able to access them.

5. Ask what the school's policies are on wandering prevention. Understand any and all security measures used by the school. If you think something is missing (i.e. a barrier you find necessary that may not be in place), be sure to voice your concerns. Speaking up is often required to ensure your child's safety. A note from your child's doctor noting these incidents could help provide sound reasoning for strong security measures.

6. Introduce your child to all security staff. Provide the security team with more information about your child, such as how to calm him or her down, whether or not he or she responds well to touch, sound, etc. All security should be aware of your child's tendency to wander so they take extra note of the importance of keeping an eye on your child. An Elopement Alert Form to fill out with specific information about your child for all first responders including school security, can be found at the end of this kit.

7. In addition to including all wandering-related information, be sure that your child's IEP also includes safety skills and wandering-prevention measures. Include these skills in your child's therapy programs if you are able to do so.



Technology and Autism

Technology such as iPads, computers and smart phones have become valuable tools in the treatment and daily lives of individuals with autism. These devices can assist in areas ranging from behavior tracking to communication and more. There are many options for how to use technology to benefit each individual. Discuss the use of technology for your child with your treatment team.

The Autism Speaks Autism Apps database contains hundreds of helpful apps divided by age, platform and category. Categories include behavioral intervention, communication, social skills, educational, functional skills and more. Search the database at autismspeaks.org/autism-apps. Many of these apps have been found to help individuals with autism make great strides in their communication skills and abilities to express themselves.

Additionally, technology has been very helpful in allowing families of individuals with autism and their team members to track the child's progress and remain up to date on his or her schedule, improvements, strengths and challenges following treatments and interventions. Examples include:

My Medical App

This app stores complete medical histories for as many people as you wish, helps you keep critical and hard-to-remember information on hand all the time and allows you to track and chart tests results and vital signs and send the records to your doctors with the click of a button.

mymedicalapp.com

TherapyConnectApp

This app was developed by a team of speech-language pathologists and behavioral consultants dedicated to the service of children with disabilities including autism. It is a tool for both therapists/service providers and families who wish to maintain consistent treatment plans that work for their children by allowing the user to monitor the child or client's treatment plan from any iPad.

truetherapydata.com

AutismTrack™

Autism Track is a portable, customizable data tracking tool that empowers caregivers of those with autism to easily track interventions, behaviors and symptoms. Checkboxes allow daily recording of any therapy, medicine or diet.

handholdadaptive.com/AutismTrack.html

Identifor

Identifor, launched in November 2014, is a free website and app designed to help parents like you understand your child's (or help him or her understand his or her own) skills, abilities and interests using a variety of fun and interactive games.

identifor.com

You can find additional information on technology and the many ways it can assist individuals with autism at

autismspeaks.org/family-services/technology.

Search the Autism Speaks Apps database for helpful apps for your child at
autismspeaks.org/autism-apps.

Autism and the Classroom

Accessing Services: Your Child's Right to Public Education

Every child has the right to a free appropriate education. The Individuals with Disabilities Education Act (IDEA), enacted in 1975, mandates a public education for all eligible children and makes the schools responsible for providing the supports and services that will allow this to happen. IDEA was most recently revised in 2004 (and, in fact, renamed the Individuals with Disabilities Education Improvement Act, but most people still refer to it as IDEA). The law mandates that the state provide an eligible child with a free appropriate public education that meets his or her unique individual needs. IDEA specifies that children with various disabilities, including autism, are entitled to early intervention services and special education. In addition, the IDEA legislation has established an important team approach and a role for parents as equal partners in the planning for an individual child, and promotes an education in the least restrictive environment. In addition to the IDEA stipulations, the Americans with Disabilities Act of 1990 (ADA) sets forth, as a civil right, protections and provisions for equal access to education for anyone with a disability. Section 504 of the Rehabilitation Act of 1973 is another civil rights law that prohibits discrimination on the basis of disability in programs and activities, public and private that receive federal financial assistance. Generally, the individuals protected by these laws include anyone with a physical or mental impairment that substantially limits one or more life activities.

Advocating for your child's education is a very important role, and at times can seem overwhelming and confusing. Two books that may be helpful are *Wrightslaw: From Emotions to Advocacy - The Special Education Survival Guide*, by Pam Wright and Pete Wright and *How to Compromise with Your School District Without Compromising Your Child*, by Gary Mayerson. You will also find additional books and websites at the back of this kit that will also be helpful in this process.

You, as a parent, are entitled to be treated as an equal partner with the school district in deciding on an education plan for your child.

What is an Individualized Education Program (IEP)?

An **Individualized Education Program (IEP)** is the document that spells out the student's needs and how they will be met. The IEP describes your child's strengths and weaknesses, sets measurable goals and objectives and provides details about the supports and accommodations that will be used to meet them. Throughout your child's education, it will be essential for both you and your child's various educators to continue learning more about autism. You will need to collaborate during each school year and stay motivated to make certain that your child is excelling and feels comfortable in his or her learning environment. It is vital that your child's needs continue to be assessed and that you work with the team at school to set goals and objectives in your child's IEP.

Your child's IEP will be the road map for his or her education each year. As the parent, you will aid the school in crafting this plan and will sit in on all important meetings and evaluations. IEPs are formed by many members of the school staff, including teachers, therapists, psychologists and special education teachers. After your child's IEP is established, this team of educators will meet regularly to discuss your child's progress, both successes and struggles. These meetings will address not only academic concerns, but also social and emotional issues as well.

Questions to Consider in Developing Your Child's Draft IEP

**From *Individualized Education Program: Summary, Guide and Practical Tips*,
a tool kit created for Autism Speaks by lawyers at Goodwin Procter LLC**

Classroom and Peers

- Should my child be in a mainstream or special education class? Both?
- Should he/she be partially or fully mainstreamed?
- What transition plan should be in place for mainstreaming?
- What type of special education class would be ideal?
- If special education is appropriate, what are the educational classifications and cognitive and maturity levels of fellow classmates?
- How many other students should be in the classroom?
- How old should the other students be? What range of skill level should they have?
- What extra-curricular activities should be available?
- How far is the class from home? What distance am I comfortable with?
- What type of classroom or behavioral or teaching support(s) and accommodations does my child need to be supported in the least restrictive environment? (whether in a self-contained, mainstream or hybrid inclusion classroom)

Teachers and Other Staff

- How many teachers should be in the classroom? How many aides?
- What is the ideal student/teacher ratio?
- What kind of special experience or training should the teachers have? The aides?

Class Content

- What specific topics do I want in the curriculum? What don't I want?
- Are there specific known programs that would work for my child?
- Will my child take any statewide assessment exams? What accommodations will be necessary?

Related Services

- What specific support services does my child need?
 - Transportation
 - Development services
 - Corrective services
 - Artistic services, art therapy
 - Music or dance therapy
 - After school or weekend services
 - Assistive (augmentative) technology and consultative support
 - The "transition" services point should add a parenthetical qualified: "(generally at age 14 and older)"

Goals

- What specific and measurable goals are appropriate?

Transition Services

- What services does my child need to be ready to (consider if appropriate)...
 - Live on his/her own?
 - Go on to higher education?
 - Work?

Prior to the IEP planning meeting, the school professionals will offer guidance and evaluate your child. The official planning meeting will then take place. IEPs generally contain goals for your child (both long- and short-term), and services that will be provided throughout the year. In addition to the goals set for your child, the IEP must also include ways that these goals will be measured and steps that will be taken for your child to accomplish them. The IEP will be designed each year according to your child's progress and needs.



What is a “Free and Appropriate Public Education” (FAPE)?

As described previously, IDEA provides for a **“free and appropriate public education”** for all children with disabilities. Each word in this phrase is important, but “appropriate” is the one that relates specifically to your special needs child. Your child is entitled to an education that is tailored to his or her special needs and a placement that will allow him or her to make educational progress. Although you and your child's teachers or therapists may want to provide your child with the best and optimal programs and services, the school district is simply required to provide an appropriate education. One of the challenges here is working with the school district to determine what is appropriate and, therefore, what will be provided for your child. This is a collaborative process and may require considerable negotiation in order to secure the appropriate services from the school.

What is “Least Restrictive Environment” (LRE)?

IDEA also provides that children with disabilities are entitled to experience the **“least restrictive environment”** in schools. This means that a school district is required to educate a student with a disability in regular classrooms, with his or her non-disabled peers.

The child must be educated in the school he or she would attend if not disabled, to the maximum extent appropriate, and supported with the aids and services required to make this possible. This does not mean that every student has to be in a general education classroom, but the objective is to place the student in as natural a learning environment as possible, within his or her home community. This decision is made by the members of the IEP team, with consideration of the myriad of issues related to appropriate environment and supports for the student. Placements and the LRE for a particular student may change over time.

The participation of children with disabilities in the general education environment is often referred to as “mainstreaming” or “inclusion.” Inclusion does not mean that a child with special needs should be placed into a general education setting just like a typical learner; a variety of special education supports should be provided in order to create a successful environment and positive experience for everyone involved. Careful planning and training are essential to providing modifications or accommodations and to successfully situating a child with a disability in the least restrictive setting. These supports might include providing a specially trained classroom or one-on-one paraprofessional, altering testing environments or expectations, adapting curriculum, providing visual supports or adaptive equipment, etc. The special education department should provide training, strategies and support for general education staff and others in the general school community who may interact with students with special needs. It is important to note that philosophies about inclusion vary considerably

among school districts, staff and parents of students with and without special needs.

IDEA provides for a team approach to planning so that the objectives of all members of the team can be considered and the necessary supports can be put in place to maximize inclusion. Not all parents will feel that a mainstream environment will enhance the growth and development of their student with special needs and allowances need to be made to accommodate various perspectives. Additionally, not all students will be ready for full inclusion all of the time. The anxiety and sensory issues related to inclusion may mean that efforts should begin with small steps to generate ongoing success and increase participation within the local student body and community.

Medical vs. Educational Diagnosis

Eligibility for services in school is based on an educational evaluation and diagnosis, not simply a medical diagnosis under the DSM-5 from your child's health-care provider. Unfortunately, a medical diagnosis of autism does not automatically entitle a student to special education services under IDEA.

To get an educational diagnosis and access to services, an educational determination of disability must be made by a multidisciplinary team of school professionals. It is important to request a school evaluation for your child after your child's medical diagnosis so he or she can access special education services as soon as possible. This evaluation is based on the impact the medical diagnosis of autism has on the student's ability to learn in school. The information from a medical assessment is included in the review, but specific attention in the evaluation is paid to the student's performance in school and how the diagnosis affects his or her educational performance.

The evaluation includes an assessment of academic achievement, observation of behaviors in school settings, family interviews, reports of problem behaviors by family members and school professionals and more. The results determine the student's IEP plan, as well as his or her rights to the special education services that will provide the student with an effective free and appropriate public education. Under IDEA, a re-evaluation must take place at least every three years and can take place more often if you or your child's teacher makes a written request based on feelings that his or her needs have changed. These re-evaluations help when modifying your child's IEP so that he or she has continued access to the special education services that will help achieve the best possible outcomes.

Setting Up Services and Supports in School

Throughout your child's educational process, it is important to remember that each child has a unique set of abilities and challenges. Educating both yourself and your child's educational team at school will be fundamental to your child's success in the classroom. Since children with autism can be diagnosed at all different stages of the education process, it is imperative to make sure that the proper accommodations are given to them no matter when they are diagnosed. Individuals with autism may show evidence of distinct issues; they may struggle more with social interactions and communication than with their studies and schoolwork. Since each child is different, the parents and educators need to work collaboratively in order to play on the child's strengths and enable him or her to have a positive and successful educational experience.

Once your child is diagnosed, it is crucial to make sure he or she has the proper supports in school. As you work with your school system, it is important to remember that your child's program should be designed individually, as each child has unique needs,

even if the diagnosis is the same as that of another child. Acquiring these services will help your child and will also ensure that his or her teacher can provide the best and most effective education possible.

When telling your child's teachers and other school professionals about his or her diagnosis, be sure to provide them with helpful information about autism if they aren't informed and to cover both your child's strengths and weaknesses when discussing the best ways to support him or her in the school environment. You may need to communicate frequently with school professionals to make sure your child's needs are being met in a successful and supportive way.

The Autism Speaks School Community Tool Kit is a very helpful resource for you to share with your school to assist all members of the school community in understanding and supporting students with autism like your child. The kit provides helpful information about students with autism, as well as tools and strategies to achieve positive interactions and increase learning for your child, his or her peers, teachers, school administrators and more. It contains information for everyone from peers to paraprofessionals to bus drivers, security officers, nurses and more.



Download the School Community Tool Kit for free at autismspeaks.org/school.

Six Steps to Success for Educators and Service Providers

In the classroom, the student and the teacher will face different challenges. The Organization for Autism Research (OAR) offers the following six step plan for teachers, which is included in their comprehensive kit entitled, *An Educator's Guide to Asperger Syndrome*, to help support your child in the classroom and throughout his or her years in school. It may be helpful to share these tips with your child's teacher. Note that the term Asperger Syndrome in the original piece has been replaced by the word "autism," as a result of the DSM-5 changes.

Step 1: Educate Yourself

Different behaviors are a large part of autism. Learning about autism and the specific characteristics of your student will help you effectively manage the behaviors. Here are some helpful hints that can guide everyday school life for students with autism.

Operate on "autism time." "Autism time" means "Twice as much time, half as much done." Students with autism often need additional time to complete assignments, gather materials, and orient themselves during transitions.

Manage the environment. Any change can increase anxiety in a student with autism. Strive to provide consistency in the schedule and avoid sudden changes.

Create a balanced agenda. Make a visual schedule that includes daily activities for students with autism. Some parts of the daily schedule or certain classes or activities should be monitored or restructured, as needed.

Simplify language. Keep your language simple and concise, and speak at a slow, deliberate pace. Students with autism have difficulty "reading between the lines," understanding abstract concepts like sarcasm, or interpreting facial expressions. Be clear and specific when providing instructions.

Manage change of plans. Make sure the student with autism understands that sometimes planned activities can be changed, canceled, or rescheduled. Have backup plans and share them with the child with autism.

Be generous with praise. Find opportunities throughout the day to tell the student with autism what he or she did right. Compliment attempts as well as successes. Be specific to ensure that the student with autism knows why you are providing praise.

Step 2: Reach Out to the Parents

The parents of your student with autism are your first and best source of information about their child; they can provide you with information about their child's behavior and daily activities. Ideally, this partnership will begin with meetings before the school year. After that, it is critical to establish mutually agreed-upon modes and patterns of communication with the family throughout the school year.

Step 3: Prepare the Classroom

Having learned about the individual sensitivities and characteristics of your student with autism, you now have the information you need to organize your classroom appropriately. You can manipulate the physical aspects of your classroom, making it more comfortable for children with autism without sacrificing your general plans for the class. *The Educator's Guide to Asperger Syndrome* contains information about specific approaches for structuring the academic and physical environment to address the needs of your student with autism.

Step 4: Educate Peers and Promote Social Goals

Children with autism have social deficits that make it difficult for them to establish friendships. However, with appropriate assistance, they can engage with peers and establish mutually enjoyable and lasting relationships.

The characteristics of autism can cause peers to perceive a child with the disorder as odd or different. This can lead to situations that involve teasing or bullying. Children with autism often cannot discriminate between playful versus mean-spirited teasing. Teachers and school staff must be aware that students with autism are potentially prime targets of bullying or excessive teasing, and must watch for signs.

Many social interactions occur during unstructured times in settings outside the classroom where students with autism may end up isolated. You may want to create a "circle of friends," a group of responsible peers for the student with autism, who will not abandon him, serve as a model of appropriate social behavior, and protect against teasing or bullying. This tactic can also be encouraged outside of school.

Six Steps to Success for Educators and Service Providers

continued...

Step 5: Collaborate on the Educational Program Development

Step 6: Manage Behavioral Challenges

School is a stressful environment. Commonplace academic and social situations may create extreme stress for students with autism. The stressors may include difficulty predicting events because of changing schedules, tuning into and understanding teacher's directions, interacting with peers, anticipating changes, such as classroom lighting, sounds/noises, odors, and so on.

Tantrums or meltdowns (terms that are often used interchangeably) typically occur in three stages that can be of variable length. Students with autism rarely indicate that they are under stress. While they may not always know when they are near a stage of crisis, most of their meltdowns do not occur without warning. There is a pattern of behavior, which is sometimes subtle, that suggests an imminent behavioral outburst. Prevention through the use of appropriate academic, environmental, social, and sensory supports and modification to environment and expectations is the most effective method.

There are many strategies that can be used to help your child avoid tantrums or meltdowns. By using a "functional behavior assessment," a professional trained in ABA, education, or psychology can help you determine what triggers the tantrum, change the environment to reduce the stress it is causing, and teach your child to express his or her desires or feelings in a more adaptive manner.



Bullying and Autism

Unfortunately, children with autism are often vulnerable to bullying. In a 2012 study, the Interactive Autism Network found that a total of 63% of 1,167 children with autism, ages six to 15, had been bullied at some point in their lives. There are many tools and resources available to help prevent bullying of your child at school. Autism Speaks is proud to partner with National Center for Learning Disabilities, PACER's National Bullying Center and Ability Path, as well as the documentary film BULLY, to raise awareness about how bullying affects children with special needs.

Information below as adapted from a Special Needs Anti-Bullying Tool Kit produced by the partnership. Learn more at specialneeds.thebullyproject.com.

Sometimes children with autism may not realize they are being bullied. It is important to teach your child the differences between friendly behavior and bullying and to let him or her know that if another student's behavior is hurting or harming him or her, either emotionally or physically, it is bullying and needs to be addressed. If you suspect your child might be being bullied at school, do not be afraid to have an honest conversation with him or her in the most effective way you see fit based on his or her needs and behaviors. Be sure to emphasize that he or she is not alone and that you are here to help put an end to it.

Your child's IEP can be a helpful tool in instituting a bullying prevention plan at school. If you learn your child is being bullied, contact school staff right away. Documenting the incidents in writing is critical to getting the best response.

Letters to inform your school can be found at specialneeds.thebullyproject.com/parents.

PACER's National Bullying Prevention Center has put together Top 10 Facts Parents, Educators and Students Need to Know about Bullying and Harassment of Studies with Disabilities, summarized below:

- 1. The Facts** – Students with disabilities are much more likely to be bullied than his or her nondisabled peers.
- 2. Bullying affect's a student's ability to learn.** When students with disabilities are bullied, it can directly impact their education.
- 3. The Definition** – Bullying based on a student's disability may be considered harassment.
- 4. The Federal Laws** – Disability harassment is a civil rights issue. Parents have legal rights when their child with a disability is the target of bullying or disability harassment.
- 5. The State Laws** – Students with disabilities have legal rights when they are a target of bullying.
- 6. The adult response is important.** Parents, educators and other adults are the most important advocates that a student with disabilities can have.
- 7. The Resources** – Students with disabilities have resources that are specifically designed for their situation – including their IEP, a 'Dear Colleague' letter, template letters from PACER.org and more.
- 8. The Power of Bystanders** – More than 50 percent of bullying situations stop when a peer intervenes.
- 9. The Importance of Self-advocacy** – Students need to be involved in the steps taken to address a bullying situation.
- 10. You are not alone.** When students have been bullied, they often believe they are the only one this is happening to, and that no one else cares. In fact, they are not alone.

Transition Services

As your child enters his or her teenage years, you will begin to think about how you will approach the future. Some individuals with autism move on to college, some go right into the workforce and others have alternative plans. Regardless of the path chosen, making a plan to move forward after high school is the first step on the journey to adulthood.

Putting in place a transition plan for your child will allow you and your family to work with the school to plan for life beyond graduation. Investigating possibilities for the future will familiarize you and your child with different based on his or her unique skills and interests. You will work together with your child's educational team to identify long- and short-term goals. These goals will enable your child and your family to compartmentalize the steps to ensure future success. Playing on the strengths of your child will help you plan for the future successfully.

A successful transition will lead your child with autism on the path to a fulfilling life that enables him or her to learn and grow. This type of planning should take place around 14 years of age. The transition plan will begin with individuals assessing their own skills and interests with their families. This will allow them the time and space to reflect on the best way to hone their skills on things that interest and excite them.

Two great transition resources from Autism Speaks are the Transition Tool Kit and the Community-based Skills Assessment. The Transition Tool Kit is a guide for families of children between the ages of 14 and 22 to help with the road to adulthood. The Community-based Skills Assessment is designed to help parents and professionals assess your child's strengths, skills and challenges in order to develop a personalized and comprehensive transition plan so your child can achieve the greatest possible outcomes.



These tools can be accessed at:
autismspeaks.org/family-services/tool-kits/transition-tool-kit and autismspeaks.org/csa.

Some individuals with autism may decide to move on to college as part of their transition plan. Making this decision will require research to find out which institutions of higher learning offer the best supports for individuals with autism. Since each individual's needs are unique, it will be important for these young adults to see what their strengths are and what type of environment they will thrive in. For young adults who go directly into the employment world, it will also be critical for them to focus on their strengths and what brings them the greatest joy. They will want to explore different areas of the job market. Different work environments may help different individuals to excel. Learn about options for postsecondary education and employment in the Autism Speaks Postsecondary Educational Opportunities Guide and our Employment Tool Kit which



Conclusion

The time after an autism diagnosis is likely a difficult time for you. It is important to remember that you are not alone. Others have gone down this road before you. You are stronger than you think. You will learn how to overcome challenges and best meet your child's needs so that he or she can live as full and independent of a life as possible. You will also begin to experience the world in a new way; your priorities may shift and you will meet some incredible people who are dedicated to helping those with autism to succeed. Keep in mind that great strides are being made every day in the field of autism research, including many studies looking into new treatments and interventions.

There are a multitude of resources and tool kits on the Autism Speaks website to help you navigate this journey with your child. The 100 Day Kit is only the beginning. In addition, the **Autism Response Team** is available to answer your questions and connect you with resources. Please call **888-288-4762 (en Español 888-772-9050)** or email familyservices@autismspeaks.org and they are happy to help you at every step of the way.

Please do not hesitate to reach out.

Your feedback is important to us. To share your comments on the kit - What was helpful? What additional information could be included? please email your comments to familyservices@AutismSpeaks.org with the word "feedback" in the subject line.

**Have more questions or need assistance?
Please contact the Autism Response Team for
information, resources and tools.**

TOLL FREE: 888-AUTISM2 (288-4762)

EN ESPAÑOL: 888-772-9050

Email: FAMILYSERVICES@AUTISMSPEAKS.ORG

WWW.AUTISMSPEAKS.ORG

Text ART to 30644

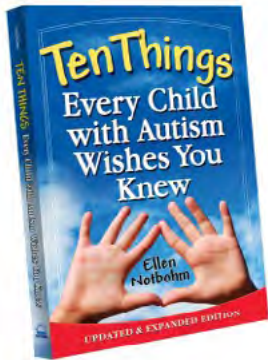


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It's time to listen.

www.AutismSpeaks.org

Autism Speaks is the world's leading autism science and advocacy organization. It is dedicated to funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families. Autism Speaks was founded in February 2005 by Suzanne and Bob Wright, the grandparents of a child with autism. Mr. Wright is the former vice chairman of General Electric and chief executive officer of NBC and NBC Universal. Since its inception, Autism Speaks has committed more than \$500 million to its mission, the majority in science and medical research. Each year Walk Now for Autism Speaks events are held in more than 100 cities across North America. On the global front, Autism Speaks has established partnerships in more than 40 countries on five continents to foster international research, services and awareness.

To learn more about Autism Speaks, please visit AutismSpeaks.org.



Ten Things Every Child with Autism Wishes You Knew

by Ellen Notbohm

From the book Ten Things Every Child with Autism Wishes You Knew, 2nd edition (2012, Future Horizons, Inc.) Reprinted in its entirety with permission of author.

Some days it seems the only predictable thing about it is the unpredictability. The only consistent attribute—the inconsistency. Autism can be baffling, even to those who spend their lives around it. The child who lives with autism may look “normal” but his behavior can be perplexing and downright difficult. Autism was once labeled an “incurable disorder,” but that notion has crumbled in the face knowledge and understanding that increase even as you read this. Every day, individuals with autism show us that they can overcome, compensate for and otherwise manage many of autism’s most challenging characteristics. Equipping those around our children with simple understanding of autism’s basic elements has a tremendous impact on their ability to journey towards productive, independent adulthood.

Autism is a complex disorder but for purposes of this article, we can distill its myriad characteristics into four fundamental areas: sensory processing challenges, speech/language delays and impairments, the elusive social interaction skills and whole child/self-esteem issues. And though these four elements may be common to many children, keep front-of-mind the fact that autism is a spectrum disorder: no two (or ten or twenty) children with autism will be completely alike. Every child will be at a different point on the spectrum. And, just as importantly, every parent, teacher and caregiver will be at a different point on the spectrum. Child or adult, each will have a unique set of needs.

Here are ten things every child with autism wishes you knew:

1. I am a child.

My autism is part of who I am, not all of who I am. Are you just one thing, or are you a person with thoughts, feelings, preferences, ideas, talents, and dreams? Are you fat (overweight), myopic (wear glasses) or klutzy (uncoordinated)? Those may be things that I see first when I meet you, but you’re more than just that, aren’t you?

As an adult, you have control over how you define yourself. If you want to single out one characteristic, you can make that known. As a child, I am still unfolding. Neither you nor I yet know what I may be capable of. If you think of me as just one thing, you run the danger of setting up an expectation that may be too low. And if I get a sense that you don’t think I “can do it,” my natural response will be, why try?

2. My senses are out of sync.

This means that ordinary sights, sounds, smells, tastes, and touches that you may not even notice can be downright painful for me. My environment often feels hostile. I may appear withdrawn or belligerent or mean to you, but I’m just trying to defend myself. Here’s why a simple trip to the grocery store may be agonizing for me.

My hearing may be hyperacute. Dozens of people jabber at once. The loudspeaker booms today’s special. Music blares from the sound system. Registers beep and cough, a coffee grinder chugs. The meat cutter screeches, babies wail, carts creak, the fluorescent lighting hums. My brain can’t filter all the input and I’m in overload!

My sense of smell may be highly sensitive. The fish at the meat counter isn't quite fresh, the guy standing next to us hasn't showered today, the deli is handing out sausage samples, the baby in line ahead of us has a poopy diaper, they're mopping up pickles on aisle three with ammonia. I feel like throwing up.

And there's so much hitting my eyes! The fluorescent light is not only too bright, it flickers. The space seems to be moving; the pulsating light bounces off everything and distorts what I am seeing. There are too many items for me to be able to focus (my brain may compensate with tunnel vision), swirling fans on the ceiling, so many bodies in constant motion. All this affects how I feel just standing there, and now I can't even tell where my body is in space.

3. Distinguish between won't (I choose not to) and can't (I am not able to).

It isn't that I don't listen to instructions. It's that I can't understand you. When you call to me from across the room, I hear “*^%\$#@, Jordan. #%^*^&^%\$&*.” Instead, come over to me, get my attention, and speak in plain words: “Jordan, put your book in your desk. It's time to go to lunch.” This tells me what you want me to do and what is going to happen next. Now it's much easier for me to comply.^{20 21}

4. I'm a concrete thinker. I interpret language literally.

You confuse me by saying, “Hold your horses, cowboy!” when what you mean is, “Stop running.” Don't tell me something is “a piece of cake” when there's no dessert in sight and what you mean is, “This will be easy for you to do.” When you say, “It's pouring cats and dogs,” I see pets coming out of a pitcher. Tell me, “It's raining hard.”

Idioms, puns, nuances, inferences, metaphors, allusions, and sarcasm are lost on me.

5. Listen to all the ways I'm trying to communicate.

It's hard for me to tell you what I need when I don't have a way to describe my feelings. I may be hungry, frustrated, frightened, or confused but right now I can't find those words. Be alert for body language, withdrawal, agitation or other signs that tell you something is wrong. They're there.

Or, you may hear me compensate for not having all the words I need by sounding like a little professor or movie star, rattling off words or whole scripts well beyond my developmental age. I've memorized these messages from the world around me because I know I am expected to speak when spoken to. They may come from books, television, or the speech of other people. Grown-ups call it echolalia. I may not understand the context or the terminology I'm using. I just know that it gets me off the hook for coming up with a reply.

6. Picture this! I'm visually oriented.

Show me how to do something rather than just telling me. And be prepared to show me many times. Lots of patient practice helps me learn.

Visual supports help me move through my day. They relieve me of the stress of having to remember what comes next, make for smooth transition between activities, and help me manage my time and meet your expectations.

I need to see something to learn it, because spoken words are like steam to me; they evaporate in an instant, before I have a chance to make sense of them. I don't have instant-processing skills. Instructions and information presented to me visually can stay in front of me for as long as I need, and will be just the same when I come back to them later. Without this, I live the constant frustration of knowing that I'm missing big blocks of information and expectations, and am helpless to do anything about it.

7. Focus and build on what I can do rather than what I can't do.

Like any person, I can't learn in an environment where I'm constantly made to feel that I'm not good enough and that I need fixing. I avoid trying anything new when I'm sure all I'll get is criticism, no matter how “constructive” you think you're being. Look for my strengths and you will find them. There is more than one right way to do most things.

8. Help me with social interactions.

It may look like I don't want to play with the other kids on the playground, but it may be that I simply do not know how to start a conversation or join their play. Teach me how to play with others. Encourage other children to invite me to play along. I might be delighted to be included.

I do best in structured play activities that have a clear beginning and end. I don't know how to read facial expressions, body language, or the emotions of others. Coach me. If I laugh when Emily falls off the slide, it's not that I think it's funny. It's that I don't know what to say. Talk to me about Emily's feelings and teach me to ask, "Are you okay?"

9. Identify what triggers my meltdowns.

Meltdowns and blow-ups are more horrid for me than they are for you. They occur because one or more of my senses has gone into overload, or because I've been pushed past the limit of my social abilities. If you can figure out why my meltdowns occur, they can be prevented. Keep a log noting times, settings, people, and activities. A pattern may emerge.

Remember that everything I do is a form of communication. It tells you, when my words cannot, how I'm reacting to what is happening around me. My behavior may have a physical cause. Food allergies and sensitivities sleep problems and gastrointestinal problems can all affect my behavior. Look for signs, because I may not be able to tell you about these things.

10. Love me unconditionally.

Throw away thoughts like, "If you would just—" and "Why can't you—?" You didn't fulfill every expectation your parents had for you and you wouldn't like being constantly reminded of it. I didn't choose to have autism. Remember that it's happening to me, not you. Without your support, my chances of growing up to be successful and independent are slim. With your support and guidance, the possibilities are broader than you might think.

Three words we both need to live by: Patience. Patience. Patience.

View my autism as a different ability rather than a disability. Look past what you may see as limitations and see my strengths. I may not be good at eye contact or conversation, but have you noticed that I don't lie, cheat at games, or pass judgment on other people?

I rely on you. All that I might become won't happen without you as my foundation. Be my advocate, be my guide, love me for who I am, and we'll see how far I can go.



Award-winning author and mother of sons with ADHD and autism, Ellen Notbohm's books and articles have informed and delighted millions in more than nineteen languages. Her work has won a Silver Medal in the Independent Publishers Book Awards, a ForeWord Book of Year Honorable Mention and two finalist designations, a Mom's Choice Gold Award, Learning magazine's Teacher's Choice Award, two iParenting Media awards, and an Eric Hoffer Book Award finalist designation. She is a contributor to numerous publications, classrooms, conferences and websites worldwide.

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A Week by Week Plan for the Next 100 Days

Getting Organized

The first thing you will need to do is get yourself organized. You may already find you've accumulated a lot of paperwork about your child and about autism in general. Organizing the information and records that you collect for your child is an important part of managing his or her care and progress. If you set up a simple system, things will be much easier over time. You may need to stop by an office supply store to pick up a binder, dividers, some spiral notebooks, loose leaf paper or legal pads and pens.

The Binders

Many parents find that binders are a great tool for keeping the mountains of paperwork down to a more manageable, mole hill size and for sharing information. You may want to organize by subject or by year. In either case, here are some of the subjects that you are likely to want to have at your fingertips:

Contacts

A section for service providers, caregivers and others

Schedules

A section for therapy times, program start and end dates, deadlines

Diagnosis

A section for medical documents and any prescriptions

Therapy

A section for speech, occupation therapy, SI and so on (multiple or sub sections may be necessary)

Individualized Education Plan (IEP)

A section for your child's IEP and related documents

We've included a sample contact list, phone log and weekly planner in this kit so you can copy and use them as needed. You may also want to summarize your child's progress in therapy and at school with cover sheets in each section; sample summary sheets are also in the Resources Section.

Using your Weekly Planner

The timeframe and action items will vary depending on your child's symptoms, age, where you live and what you have already accomplished. Even if you are very on top of this, it may take a while to be able to access additional evaluations and the services that your child needs.

Start
now.

Week 1

Complete Evaluations

If your child has not had a complete work up, schedule the remainder of necessary evaluations (see Getting Services below).

Getting Services

Because your child is age five or older, you'll start with your local school district. Call to begin the process of getting services. Your school district may want to conduct evaluations of your child (at their expense). This can be a long and time consuming process, but may be useful in further determining the services that are needed.

Keep a Phone Log

Try to set aside some time each day to make the phone calls necessary to set up the evaluations and to start the process of getting services. There may be a waiting list for services and evaluations, so make the calls as soon as possible and follow up as needed—and don't hesitate to put your name on multiple lists so you can get the earliest appointment possible. Some of the professionals who provide services through Early Intervention or Special Education may take a specified number of days to complete evaluations or begin services.

Start a Video Record

Try a variety of settings and show a range of behavior. Note both good and not-so-good behavior so that, in the future, you will be able to recognize where your child was at that point in time. Make a new recording every three months at home, in therapy sessions, wherever. These video "snapshots" can be used to track your child's progress and help show what effect a particular therapy or intervention may have had. Label the tapes or discs with your child's name and the dates they were recorded.

Week 2

Getting Support

Find a support group or a parent mentor. If your child is in school, you may also want to find out if your district has a Special Education Parent Teacher Association (SEPTA), which may offer informational meetings and parent outreach.

Getting Services (Follow Up)

Follow up on services. Continue to check status on waiting lists and available programs.

Research Treatment Options

Start to read material, join online groups and ask questions that will help you understand the treatment options that are available and what might be right for your child and your family.

Week 3

Getting Services

(Continue to Follow Up)

Follow Up on Services

Continue to check status on waiting lists and available programs. Keep using your phone log to record the dates you contacted service providers and track when you may need make another call.

Look Into After School Programs

Recreation activities/after-school social skills groups are a great way for your child to interact with others and work on his or her social and communication abilities, while also having fun.

Set Aside Sibling Time

The siblings of children with autism are affected by the disorder as well. Consider spending time talking together about their feelings. Start a “Joy Museum” together of happy memories. Talking about these times can help them remember that their lives involve a lot more than autism.

Week 4

Build Your Team

By this time, your child’s team of therapists, educators and caregivers is probably taking shape. Continue to look for service providers and observe as many therapy sessions as possible to identify new recruits for your child’s team. Talk to other parents who may know of therapists with time available for your child. You don’t have to wait until every member of the team is in place before beginning therapy.

Create a Safety Plan

You may already have had to adapt your home because of your child’s behaviors or needs. You’ve probably already read the section of this kit called Create a Safety Plan. If not, carve out some time to survey your home for possible problems and begin contacting local safety personnel to plan ahead to ensure your child’s safety.

Check In With Your Child

Sit down with your child and check in as best you can. Communicate about how therapy is going, what is happening at school, what types of supports he or she is receiving, etc. Many children with autism aren’t as likely to share what’s happening at school, especially with regard to bullying. Make sure you have a consistent open dialogue with your child to make sure he or she understands what types of behaviors from peers as well as professionals is or isn’t appropriate. Establishing that open communication early on will make a big difference.

Plan Some Time Away

Plan some time away from your child. You will do a better job helping your family if you take care of yourself. Even if it’s just going for a walk alone, you are going to need a break so that you can come back with a clear head.

Week 5

Build Your Team

See Week 4.

Review Your Insurance

Investigate your insurance coverage to see what if any therapies are covered and make sure that you are getting the most from your provider. Your health insurance may cover therapies or services not covered by your child's IEP. You may need to create a separate binder to keep track of insurance claims. Document everything.

Get to Know Your Child's Legal Rights

Familiarize yourself with your child's rights. There is a wealth of information available. You may find out your child is entitled to services you weren't aware of or hadn't considered.

Do Something for You

You've made it through a month, and it may have been one of the most challenging months of your life. Remember to take care of yourself. Remember who you were before the diagnosis. Spend some time on an activity that you enjoy. You will find it helps you face the challenges ahead. There are probably friends and family in your life who would love to help, but may not know what you need. Don't be afraid to ask for help.

Week 6

Continue Building Your Team

Follow Up On Services

Continue to check status on waiting lists and available programs. Keep using your phone log to record the dates you contacted service providers and track when you may need make another call.

Look Into After School Programs

Recreation activities/after-school social skills groups are a great way for your child to interact with others and work on his or her social and communication abilities, while also having fun.

Set Aside Sibling Time

The siblings of children with autism are affected by the disorder as well. Consider spending time talking together about their feelings. Start a "Joy Museum" together of happy memories. Talking about these times can help them remember that their lives involve a lot more than autism.

Week 7

Become Competent in the Intervention Methods You Have Chosen for Your Child

Take advantage of parent training. Therapists often provide parent training that will help bring the methods used at therapy into your home and help your child's progress.

Create a Schedule

Having a written weekly schedule for your child's therapy will help you see if you've scheduled your time as well. It will also help you plan for the other members of your household.

Continue Learning About Treatments and Services

Consult the Autism Speaks website for contacts in your area.

Spend Some Time Organizing Your Paperwork

Organize any paperwork that may have piled up. Try to eliminate any materials you won't need.

Week 8

Check Your Progress

Look back through this action item list. Is there anything you started that needs follow up?

Investigate Recreational Activities for Your Child

Add a recreational activity, such as gymnastics or swimming, to broaden your child's development.

Plan More Sibling Time

Your typically-developing children will no doubt be richer for having a sibling with autism. But maintaining as much normalcy as possible will help them reach their potential too.

Make Contact with Friends and Family

Stay connected. Make contact with your friends and family and participate in community events. Keeping up your social life will help you safeguard against feelings of isolation.

Spend Time Alone with Your Spouse

Plan a relaxing and fun activity with your partner. After all, you've just made it through month two.

Week 9

Round Out Your Team

Continue to evaluate service providers and therapists.

Use the Internet

Get e-savvy. Spend time researching online resources that will keep you up-to-date. Add useful websites to your favorites, register for e-newsletters and join list-servs where parents and professionals share information.

Continue to Connect with Other Parents

Stay active with a support group or, if possible, socialize with other parents of children with autism. Being around other adults who understand what your family is going through will help you stay strong.

Check in on Your Child's Sessions

Continue to observe therapy. Your child should be getting used to their therapy routine at this point.

Week 10

Schedule a Team Meeting

It's team meeting time again. Schedule a meeting to discuss progress and strategies. Stay involved with your team by continuing to attend as many sessions as possible.

Rally the Troops

Encourage your team. Let them know you appreciate everything they are doing for your child.

Plan a Family Outing

Plan a family outing. Schedule an activity designed to include your child with autism and utilize strategies you've picked up from therapy. Ask your child's therapist to help you with specific strategies to make the outing a success.

Brush Up On the Law

Continue to learn about your child's legal rights.

Week 11

Check Your Child's Progress

Look for progress. Hopefully, your child has been through a consistent month of therapy at this point. Review your binder and videos to see if you notice improvements. Continue to attend sessions too. Take notes on what you see. Keep a copy in your binder and bring them to your next team meeting.

Dig Deeper into Treatment Options

Set aside time to do some research and reading on additional treatments and therapies. Make notes and copy useful information to include in your binder.

Week 12

Reconnect with Your Spouse

Take some one-on-one time to enjoy each other's company. If communication has been difficult, consider scheduling time with a counselor to keep your relationship healthy.

Continue Connecting with Other Parents

Keep going to support groups. Parents are amazing resources and will help provide emotional and practical support. Look into additional groups in your area if you don't feel like you've found the right one for you.

Sign Up for More Training

Using the methods you are learning from your child's therapists will help create a productive environment at home so your child will have the best chance of obtaining his or her goals.

Week 13

Hold a Team Meeting

Check on progress again. You should continue to see progress after at least six weeks of consistent therapy. If there has been little or no progress, call another team meeting to brainstorm and make adjustments to your child's routine.

Continue Learning

Keep learning about autism. Books, seminars, movies, websites – all sorts of sources can help you deepen your understanding of autism and your child. See the Suggested Reading List in this kit for ideas.

Do Something for You

Enjoy some “me” time. Do something nice for yourself – you've made it through 100 days!

Comparing Treatment Methods & Providers

Adapted from: Does My Child Have Autism? By Wendy L. Stone, Ph.D. with Theresa Foy DiGeronimo

ABOUT THE PROGRAM

Name of Program/Provider	
Method	
Location	
Phone Number	
Email	
Website	
Hours per Week	
Cost	
Reimbursement	
Recommended by	

PROGRAM CONTENT

What are the developmental areas of focus? (language, communication, peer play, social interactions, behavior, pre-academic skills, parent training, etc.)	
How specific are the goals identified for each child?	
How are behaviors and skills prioritized?	
What kind of teaching is used?	
How are behaviors managed?	

MEASURING PROGRESS

How will I know if my child is making progress?	
How long will it be before I see changes?	
What types of improvements should I expect?	

How often will you assess progress and how is it measured?	
What will happen if my child doesn't make progress with this treatment?	

THERAPIST QUALIFICATIONS

How many children with autism have you worked with? What ages?	
Do you serve children over three years old?	
What are your qualifications? What type of training do you have?	
Do you have a professional degree or certificate? (Ask for details.)	
Are you affiliated with a professional organization? (Ask for details.)	
What do you see as your strongest skill in working with children with autism?	
Are there issues or problems you consider to be outside of your realm of expertise?	

SCIENTIFIC EVIDENCE OF EFFECTIVENESS

Is there research to support the effectiveness of this type of treatment? (Ask for details as well as copies of published articles.)	
Has research shown this treatment to be better than other types of treatment?	

PROFESSIONAL INVOLVEMENT

Who will be providing the direct intervention with my child?	
What type of training does he/she have?	
Who will be supervising him/her and how?	
How often will you see my child personally?	

PARENT INVOLVEMENT

Will I be able to participate in the treatment?	
Will you teach me how to work with my child? How?	
What skills will you teach me? (Ask for examples.)	

COMPATIBILITY WITH OTHER TREATMENTS

How many hours per week of your treatment will my child need?	
Is your treatment compatible with other interventions my child is participating in?	
How do you collaborate with other therapy providers on my child's team? (Get examples.)	

Service Provider Planner

Agency & Contact	Phone #	Date Called	Requested Services	Requested # of Sessions and Duration	Availability	Status	Follow-Up	Other Info

Service Provider Planner

Agency & Contact	Phone #	Date Called	Requested Services	Requested # of Sessions and Duration	Availability	Status	Follow-Up	Other Info

CONTACTS: MEDICAL

Specialty	
Name of Contact	
Name of Practice	
Phone Number	
Address	
Email Address/ Website	

Specialty	
Name of Contact	
Name of Practice	
Phone Number	
Address	
Email Address/ Website	

Specialty	
Name of Contact	
Name of Practice	
Phone Number	
Address	
Email Address/ Website	

Specialty	
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Name of Practice	
Phone Number	
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Email Address/ Website	

Specialty	
Name of Contact	
Name of Practice	
Phone Number	
Address	
Email Address/ Website	

CONTACTS: THERAPY

Specialty	
Name of Contact	
Name of Practice	
Phone Number	
Address	
Email Address/ Website	

Specialty	
Name of Contact	
Name of Practice	
Phone Number	
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Email Address/ Website	

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CONTACTS: SUPPORT

Specialty	
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CONTACTS: OTHER

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Specialty	
Name of Contact	
Name of Practice	
Phone Number	
Address	
Email Address/ Website	

PHONE LOG

NAME OF CONTACT: _____

PHONE NUMBER: _____

Date/Time	
Summary of Call	
Follow-up Required	

Date/Time	
Summary of Call	
Follow-up Required	

Date/Time	
Summary of Call	
Follow-up Required	

Date/Time	
Summary of Call	
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Date/Time	
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PHONE LOG

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Summary of Call	
Follow-up Required	

PHONE LOG

NAME OF CONTACT: _____

PHONE NUMBER: _____

Date/Time	
Summary of Call	
Follow-up Required	

Date/Time	
Summary of Call	
Follow-up Required	

Date/Time	
Summary of Call	
Follow-up Required	

Date/Time	
Summary of Call	
Follow-up Required	

Date/Time	
Summary of Call	
Follow-up Required	

ASSESSMENT TRACKING Type of Therapy _____

Date	Test Administered	Evaluator	Standard Score	Age Equivalent	Change in Standard Score	Change in Age Equivalent

ASSESSMENT TRACKING **Type of Therapy** _____

Date	Test Administered	Evaluator	Standard Score	Age Equivalent	Change in Standard Score	Change in Age Equivalent

Sample Bullying Response Letter

Your street address
City, state zip code

Date

Name of Principal
Name of School
School street address
City, state zip code

RE: First and last name of child

Dear (name of Principal),

My child, first name of child is in the (grade level) at (name of school). At school (s/he) has been bullied and harassed by (name of harasser(s)). This has occurred on (date or approximate period of time) when (describe as many details of the incident(s) as can be recalled). When this happened, (name of witness(es)) heard or saw it and (their response(s)). We became aware of this incident when (describe how you were notified).

(First name of child) was hurt by this bullying and harassment. (S/He) had (describe physical injuries, emotional suffering and any medical or psychological treatment required). As you are likely aware, (first name of child) has an IEP (Individual Education Plan).

(I/we) became aware of three federal laws (Section 504 of the Rehabilitation Act of 1973, Title II of the Americans with Disabilities Amendment Act (ADAAA) of 2008, and Individuals with Disabilities Education Act (IDEA)) that protect the rights of a child with a disability against bullying behavior that is based on the child's disabilities and that interferes with or denies the child the opportunity to participate in or benefit from an educational program.

Please send (me/us) a copy of the District policies on bullying and harassment, investigate this problem and correct it as soon as possible. Please let (me/us) know, in writing, of the actions you have taken to rectify the situation and to ensure it does not happen again. If this does not resolve this issue, (I/we) will request an IEP meeting to be held as quickly as possible. I expect a response within 5 business days.

Thank you for your prompt attention to this serious problem.

Sincerely,
(sign in this area)
Your Name

CC: Name of Director of Special Education
Name of Superintendent of Schools

From PACER's National Bullying Prevention Center®, Minneapolis, MN. PACER.org

Sample Request for Special Education Eligibility Evaluation

Date:

To:

Re: (Child's name), Request for Evaluation

Dear (Director of Special Education),

My name is (name) and I am writing to you because my child, (child's name), is having some troubles in school. I believe that special education programs could help with (his/her) difficulties.

I am formally requesting that the school immediately begin process for instituting a special education program. I understand that this process begins with the initial evaluation to determine eligibility and that you will send me an evaluation plan that explains the tests you will administer to (child's name). If possible, I would like to receive the plan within 10 days so that I have time to prepare for the process. Once I have given my consent for the plan, please let me know the date you set for the evaluation. I would greatly appreciate any other information you have regarding the evaluation process, including your criteria for determining eligibility and general IEP framework.

Thank you for your time and your help in this matter. I look forward to working with the school to make sure (child's name) gets the education (he/she) needs.

Sincerely,

(Your signature)

(Your name)

GOAL TRACKING: IEP GOALS

Date	Comments	Goals Mastered	Goals Making Progress	Goals Just Started	Goals Not Started

Safety Log

In the chart below, include any wandering incidents, attempts or interactions that put your child at risk. Keep track of what was going on before, during and after the incident to try and determine antecedents, triggers and possible prevention methods. Ask your child's behavioral team, teachers and other caregivers to complete the log as needed.

Date	Location	Description	Possible Triggers	Changes Noted	Suggested Next Steps

Autism Elopement Alert Form Part 1



PERSON-SPECIFIC INFORMATION FOR FIRST RESPONDERS

Individual's Name _____

(First)

(M.I.)

(Last)

Address

(Street)

(City)

(State)

Zip)

Date of Birth _____ Age _____ Preferred Name _____

Does the individual live alone? _____



Date Submitted:

Individual's Physical Description:

_____ Male _____ Female Height: _____ Weight: _____ Eye color: _____ Hair color: _____

Scars or other identifying marks: _____

Other Relevant Medical Conditions in addition to Autism (*check all that apply*):

_____ No Sense of Danger _____ Blind _____ Deaf _____ Non-Verbal _____ Mental Retardation

_____ Prone to Seizures _____ Cognitive Impairment _____ Other

If Other, Please Explain: _____

Prescription Medications Needed: _____

Sensory or Dietary Issues, If Any: _____

Additional Information First Responders May Need: _____

EMERGENCY CONTACT INFORMATION

Name of Emergency Contact (*Parents/Guardians, Head of Household/Residence, or Care Providers*):

Emergency Contact's Address: _____

(Street)

(City)

(State)

Zip)

Emergency Contact's Phone Numbers:

Home: _____ Work: _____ Cell Phone: _____

Name of Alternative Emergency Contact: _____

Home: _____ Work: _____ Cell Phone: _____

INFORMATION SPECIFIC TO THE INDIVIDUAL

Favorite attractions or locations where the individual may be found:

Atypical behaviors or characteristics of the Individual that may attract the attention of Responders:

Individual's favorite toys, objects, music, discussion topics, likes, or dislikes:

Method of Preferred Communication. *(If nonverbal: Sign language, picture boards, written words, etc.):*

Method of Preferred Communication II. *(If verbal: preferred words, sounds, songs, phrases they may respond to):*

Identification Information. *(i.e. Does the individual carry or wear jewelry, tags, ID card, medical alert bracelets, etc.?):*

Tracking Information. *(Does the individual have a Project Lifesaver or LoJack SafetyNet Transmitter Number?):*

Police Officer Laurie Reyes of Montgomery County Police Department has responded to dozens of autism wandering emergencies, and recommends providing this letter to trusted neighbors to inform them of your child with autism's tendency to wander.



Dear Neighbor,

We have a child with autism. About half of children with autism have a tendency to wander from safety.

We watch our child very carefully, but sometimes he/she unpredictably wanders away from safety.

Our child's name is _____. He/she is _____ years old as of today, _____. He/she is _____ tall and weighs about _____ lbs. He/she usually wears _____.

WHAT TO DO?

We kindly ask if you see our child alone, please stay with him/her and immediately call:

_____. We are probably already looking for him/her. Please also call 911 and tell them that you have found our child.

Our child, _____, does not speak very well and does not appreciate danger. He/she might walk into the street without looking. He/she may be dangerously drawn to bodies of water like lakes, rivers or swimming pools and could drown. He/she might walk in your house or yard if a door or gate is open. He/she will become lost very easily and not know he/she is lost. If you ask our child a question he/she will likely not answer.

Our child may appear to be deaf. However, our child can hear. But he/she may not react to things that he/she hears or sees or respond to your verbal commands.

Our child sometimes has outbursts where he/she might scream or shake his/her hands, or act in other unusual ways for a few moments. Please don't misinterpret any of these motions. He/she does not intend to hurt anyone. If you see our child please stay with him/her and call us, then 911 right away.

We have included a recent picture of our child.

Thank you,

_____ (Parent Name)

_____ (Address)

_____ (Phone)

To learn more about autism, please visit www.autismspeaks.org.

Glossary

Note: Visit the Autism Speaks Video Glossary at [AutismSpeaks.org/what-autism/video-glossary](https://www.autismspeaks.org/what-autism/video-glossary) to see video of the items in blue.

A

Absence Seizure, *see Seizures*.

Americans with Disabilities Act (ADA) is the US law that ensures rights of persons with disabilities with regard to employment and other issues.

Angelman Syndrome is a genetic disorder causing developmental delays and neurological problems, often accompanied by seizures. Children often display hyperactivity, small head size, sleep disorders and movement and balance disorders.

Anticonvulsant is a type of drug used to prevent or stop seizures or convulsions; also called antiepileptic.

Anxiety Disorder is a disorder that affects an estimated 30% of individuals with autism and includes social phobia, separation anxiety, panic disorder and specific phobias. An individual suffering from anxiety may experience strong internal sensations of tension such as a racing heart, muscular tensions and stomachache.

Applied Behavior Analysis (ABA) is a style of teaching using series of trials to shape desired behavior or response. Skills are broken into small components and taught to child through a system of reinforcement.

Asperger Syndrome is a developmental disorder on the Autism spectrum defined by impairments in communication and social development and by repetitive interests and behaviors, without a significant delay in language and cognitive development. The diagnosis is no longer used in DSM5, but DSM5 indicates that individuals with a “well-established diagnosis” of these conditions “should be given the diagnosis of autism spectrum disorder.”

Attention Deficit Hyperactivity Disorder (ADHD) is a disorder that affects approximately 1 in 5 children with autism. Symptoms include chronic problems with inattention, impulsivity and hyperactivity.

Audiologist is a professional who diagnoses and treats individuals with hearing loss or balance problems.

Auditory Integration Training, or sound therapy, is used to treat children with difficulties in auditory processing or sound sensitivity and involves the individual listening to electronically modified music through headphones during multiple sessions.

Autism Diagnostic Observation Schedule (ADOS) is a test considered to be current gold standard for diagnosing ASD and, along with information from parents, should be incorporated into a child’s evaluation.

Autism Speaks Insurance Link is a tool to help families in the autism community determine whether an individual is entitled to coverage for the treatment of autism under their health insurance plan.

Autism Speaks Toddler Treatment Network (TTN) supports a consortium of research sites studying behavioral interventions appropriate for children under 18 months of age.

Autism Spectrum Disorder and autism are both general terms for a group of complex disorders of brain development. These disorders are characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors. With the May 2013 publication of the DSM-5 diagnostic manual, all autism disorders were merged into one umbrella diagnosis of ASD.

B

C

Casein is protein found in milk, used in forming the basis of cheese and as a food additive.

Celiac Disease is a disease in which there is an immunological reaction within the inner lining of the small intestine to gluten, causing inflammation that destroys the lining and reduces the absorption of dietary nutrients. It can lead to symptoms of nutritional, vitamin and mineral deficiencies.

Childhood Disintegrative Disorder is a disorder in which development begins normally in all areas, physical and mental. At some point between 2 and 10 years of age, the child loses previously developed skills. The child may lose social and language skills and other functions, including bowel and bladder control. The diagnosis is no longer used in DSM5, but DSM5 indicates that individuals with a “well-established diagnosis” of these conditions “should be given the diagnosis of autism spectrum disorder.”

Chronic Constipation is an ongoing condition of having fewer than three bowel movements per week.

Cognitive Skills are any mental skills that are used in the process of acquiring knowledge; these skills include reasoning, perception and judgment.

Colitis is inflammation of the large intestine.

Complete Blood Count (CBC) is a lab test reporting number of white blood cells, red blood cells, platelets, hemoglobin, hematocrit and other values reflecting overall blood health.

Compulsions are deliberate repetitive behaviors that follow specific rules, such as pertaining to cleaning, checking or counting. In young children, restricted patterns of interest may be early sign of compulsions.

Computed Axial Tomography (CT) examines organs by scanning with X rays and using computer to construct series of cross-sectional scans. Called “CAT” scan.

D

Declarative Language is used to communicate what the mind is producing. It is what is most common in conversation, whereas Imperative Language is used to ask questions, make commands or give instructions.

Developmental Disorder refers to several disorders that affect normal development. May affect single area of development (specific developmental disorders) or several (pervasive developmental disorders).

Developmental Individual Difference Relationship (DIR) is a type of therapy, known as Floortime, that seeks to move the child toward increasingly complex interactions through mutually shared engagement.

Developmental Milestones are skills or behaviors that most children can do by a certain age that enable the monitoring of learning, behavior and development.

Developmental Pediatrician is a medical doctor who is board-accredited and has received sub-specialty training in developmental-behavioral pediatrics.

Diagnostic and Statistical Manual of Mental Disorders (DSM-5) is the official system for classification of psychological and psychiatric disorders published by the American Psychiatric Association in 2013 that, among other changes, established new criteria for an autism diagnosis, eliminated the previously separate subcategories on the autism spectrum, including Asperger Syndrome, PDD-NOS, Childhood Disintegrative Disorder and Autistic Disorder and added a new category called Social Communication Disorder (SCD).

Discrete Trial Training (DTT) is a technique incorporating principles of ABA, including positive reinforcement used to teach behaviors in one-to-one setting. Concepts are broken down into small parts.

E

Early Autism Risk Longitudinal Investigation (EARLI) is a network of research sites that enrolls and follows a large group of mothers of children with autism at the start of another pregnancy and documents the newborn child's development through three years of age.

Early Intervention (EI) is a state-funded program designed to identify and treat developmental problems or other disabilities as early as possible. Eligibility for EI is from birth to three years of age.

Early Start Denver Model (ESDM) is a comprehensive behavioral early intervention approach for children with autism, ages 12 to 48 months, that uses a developmental curriculum that defines the skills to be taught at any given time and a set of teaching procedures used to deliver this content.

Echolalia is repeating words or phrases heard previously, either immediately after hearing word or phrase or much later. Delayed echolalia occurs days or weeks later. Functional echolalia is using quoted phrase in a way that has shared meaning, for example, saying "carry you" to ask to be carried.

Electroencephalogram (EEG) is a test using electrodes on scalp to record electrical brain activity. For diagnoses of seizure disorder or abnormal brain wave patterns.

Epilepsy (seizure disorder) is a pattern of repeated seizures, causes include head injury, brain tumor, lead poisoning, genetic and infectious illnesses. Cause is unknown in 50% of cases.

Esophagitis is inflammation of the esophagus, the soft tube-like portion of the digestive tract connecting the pharynx with the stomach.

Expressive Labeling is the communication of a name for an object or person, see expressive language.

Expressive Language is communication of intentions, desires or ideas to others, through speech or printed words and includes gestures, signing, communication board and other forms of expression.

Extended School Year (ESY) Services are provided during breaks from school, such as during summer vacation, for students who experience substantial regression in skills during school vacations.

F

Free Appropriate Public Education (FAPE) means that education must be provided to all children ages three to twenty-one at public expense.

Floortime is a developmental intervention for children with autism involving meeting a child at his current developmental level and building upon a particular set of strengths.

Fragile X syndrome is a genetic disorder that shares many of the characteristics of autism. Individuals may be tested for Fragile X.

G

Gastritis is inflammation of the stomach.

Gastroenterologist is a doctor specializing in diagnosis and treatment of disorders of GI tract, including esophagus, stomach, small intestine, large intestine, pancreas, liver, gallbladder and biliary system.

Gastroesophageal Reflux is the return of stomach contents back up into the esophagus which frequently causes heartburn due to irritation of the esophagus by stomach acid.

Gastrointestinal pertains to the digestive tract, including the mouth, throat, esophagus, stomach, small intestine, large intestine and rectum.

Geneticist refers to a medical doctor who specializes in genetic problems. Genes are the unit in the chromosome that contain the blueprint for the transmission of inherited characteristics.

Gestures are hand and head movements, used to signal to someone else, such as a give, reach, wave, point or head shake. They convey information or express emotions without the use of words.

Global Developmental Delay is diagnosis in children younger than 5, characterized by delay in two or more developmental domains, sometimes associated with mental retardation.

Gluten is a protein present in wheat, rye and barley.

Grand mal seizure, see Seizures.

H

High Risk Baby Siblings Research Consortium (BSRC) is a joint venture between Autism Speaks and the National Institute of Child Health and Human Development that is focused on making discoveries that will help researchers develop new ways to treat or even prevent debilitating symptoms by intervening at an early age.

Hyperlexia is the ability to read at an early age. To be hyperlexic, a child does not need to understand what he or she is reading.

Hyperresponsiveness, *hypersensitivity*, see *Sensory Defensiveness*.

Hyporesponsiveness, hyposensitivity, is abnormal insensitivity to sensory input. Could be exhibited by a child who appears to be deaf, whose hearing is normal, is under reactive to sensory input, may have a high tolerance to pain, may be clumsy, sensation seeking and may act aggressively.

I

Incidental Teaching teaches a child new skills while in their home or community, in natural context or “in the moment,” to help make sense of what they learn during formal instruction and generalize new skills.

Individual Family Service Plan (IFSP) is developed by a multidisciplinary team including family as primary participant. Describes child’s level of development in all areas; family’s resources, priorities and concerns, services to be received and the frequency, intensity and method of delivery. Must state natural environments in which services will occur.

Individualized Education Plan (IEP) identifies student’s specific learning expectations, how school will address them with appropriate services and methods to review progress. For students 14 and older, must contain plan to transition to postsecondary education or the workplace or to help the student live as independently as possible in the community.

Individuals with Disabilities Education Act (IDEA) is the US law mandating the “Free and Public Education” of all persons with disabilities between ages 3 and 21.

Inclusion involves educating all children in regular classrooms, regardless of degree or severity of disability. Effective inclusion takes place with planned system of training and supports; involves collaboration of multidisciplinary team including regular and special educators.

J

Joint Attention is the process of sharing one’s experience of observing an object or event, by following gaze or pointing gestures. Critical for social development, language acquisition, cognitive development. Impairment in joint attention is a core deficit of ASD.

K

L

Least Restrictive Environment (LRE) is setting that least restricts opportunities for child with disabilities to be with peers without disabilities. The law mandates that every child with a disability be educated in a Least Restrictive Environment.

M

Magnetic Resonance Imaging (MRI) is a diagnostic technique using powerful electromagnets, radio frequency waves and a computer to produce well defined images of the body’s internal structures.

Mainstreaming is where students are expected to participate in existing regular ed classes, whereas in an inclusive program classes are designed for all students. May be gradual, partial or part-time process (e.g., student may attend separate classes within regular school or participate in regular gym and lunch only).

Melatonin is a hormone produced by pineal gland, involved in regulating sleeping and waking cycles. Sometimes used for chronic insomnia. Consult your child's physician before giving melatonin; it is not recommended for all patients with sleep problems.

Modified Checklist of Autism in Toddlers (MCHAT) is a screening tool for identifying young children who may be referred to specialist for further evaluation and possible Autism Spectrum Disorder diagnosis.

Motor deficits are physical skills that a person cannot perform or has difficulty performing.

Motor function (or motor skills) is the ability to move and control movements.

N

Neurologist refers to a doctor specializing in medical problems associated with the nervous system, specifically the brain and spinal cord.

Nonverbal Behaviors are things people do to convey information or express emotions without words, including eye gaze, facial expressions, body postures and gestures.

O

Obsessions are persistent and intrusive repetitive thoughts. Preoccupations with specific kinds of objects or actions may be an early sign of obsessions.

Obstructive Sleep Apnea breathing disorder interrupting breathing during sleep when air flow cannot flow through the nose or mouth although efforts to breathe continue. Throat collapses during sleep causing snorting and gasping for breath. May cause daytime sleepiness. May increase risk of hypertension and heart problems.

Occupational Therapy assists development of fine motor skills that aid in daily living. May focus on sensory issues, coordination of movement, balance and self-help skills such as dressing, eating with a fork, grooming, etc. May address visual perception and hand-eye coordination.

Occupational Therapist helps minimize impact of disability on independence in daily living by adapting child's environment and teaching sub-skills of the missing developmental components.

Operant Conditioning is the modification of behavior through positive and/or negative reinforcement.

P

Perseveration is repetitive movement or speech or sticking to one idea or task, that has a compulsive quality to it.

Pervasive Developmental Disorders (PDD) is group of conditions involving delays in development of many basic skills, including ability to socialize with others, to communicate and use imagination. Includes Autism, Asperger Syndrome, Childhood Disintegrative Disorder, Rett Syndrome and Pervasive Developmental Disorder - Not Otherwise Specified. Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS) a category of PDD referring to children having significant problems with communication and play and some difficulty interacting with others, but are too social for diagnosis of autism. The diagnosis is no longer used in

DSM5, but DSM5 indicates that individuals with a “well-established diagnosis” of these conditions “should be given the diagnosis of autism spectrum disorder.”

Petit Mal Seizure, see *Seizures*.

Physical Therapy uses specially designed exercises and equipment to help patients regain or improve their physical abilities.

Physical Therapist designs and implements physical therapy programs and may work within a hospital or clinic, in a school or as an independent practitioner.

Pica is persistent eating or mouthing of non-nutritive substances for at least 1 month when behavior is developmentally inappropriate (older than 18-24 months). Substances may include items such as clay, dirt, sand, stones, pebbles, hair, feces, lead, laundry starch, wood, plastic and more.

Picture Exchange Communication System (PECS) is an alternative communication system using picture symbols taught in phases starting with simple exchange of symbol for desired item. Individuals learn to use picture symbols to construct complete sentences, initiate communication and answer questions.

Pivotal Response Treatment (PRT) is a therapeutic teaching method using incidental teaching opportunities to target and modify key behaviors related to communication, behavior and social skills.

Pragmatics are social rules for using functional spoken language in a meaningful context or conversation. Challenges in pragmatics are a common feature of spoken language difficulties in children with ASD.

Prevalence is the current number of people in a given population who have a specific diagnosis at a specified point in time. As of May 2014, the U.S. Centers for Disease Control and Prevention estimated autism prevalence as 1 in 68 children, including 1 in 42 boys and 1 in 189 girls.

Prompts for Restructuring Oral Muscular Phonetic Targets (PROMPT) is an approach used in speech-language therapy that manually guides an individual’s jaw, tongue and lips through a targeted word, phrase or sentence to develop motor control and proper oral muscular movements, while eliminating unnecessary muscle movements such as jaw sliding.

Proprioception is the receiving of stimuli originating in muscles, tendons and other internal tissues.

Prosody is the rhythm and melody of spoken language expressed through rate, pitch, stress, inflection or intonation. Some children with ASD have unusual intonation (flat, monotonous, stiff or “sing songy” without emphasis on the important words).

Psychiatrist is a doctor specializing in prevention, diagnosis and treatment of mental illness who has received additional training and completed a supervised residency in specialty. May have additional training in specialty, such as child psychiatry or neuropsychiatry and can prescribe medication, which psychologists cannot do.

Psychologist is a professional who diagnoses and treats diseases of the brain, emotional disturbance and behavior problems. May have a master’s degree (M.A.) or doctorate (Ph.D.) in psychology. May have other qualifications, including Board Certification and additional training in a specific type of therapy.

Q

R

Receptive Labeling, *see receptive language*.

Receptive Language is the ability to comprehend words and sentences and begins as early as birth and increases with each stage in development. By 12 months of age, a child begins to understand words and responds to his or her name and may respond to familiar words in context. By 18 to 20 months, a child identifies familiar people by looking when named (e.g., Where's mommy?), gives familiar objects when named (e.g., Where's the ball?) and points to a few body parts (e.g., Where's your nose?). These skills commonly emerge slightly ahead of expressive language skills.

Reinforcement or reinforcer, is any object or event following a response, increasing or maintaining the rate of responding. Positive reinforcer may be produced by or added after a response.

Relationship Development Intervention (RDI) is a therapeutic teaching method based on building intelligence competencies of social connection – such as referencing, emotion sharing, coregulation and experience sharing – that normally develop in infancy and early childhood.

Respite Care is temporary, short-term care provided to individuals with disabilities, delivered in the home for a few short hours or in an alternate licensed setting for an extended period of time. Respite care allows caregivers to take a break in order to relieve and prevent stress and fatigue.

Rett Syndrome is a very rare disorder in which patients have symptoms associated with PDD along with problems with physical development. They generally lose many motor or movement skills – such as walking and use of hands – and develop poor coordination. The condition has been linked to a defect on the X chromosome and as a result, almost always affects girls.

S

Seizure refers to uncontrolled electrical activity in the brain, which may produce a physical convulsion, minor physical signs, thought disturbances or a combination of symptoms.

Seizure, absence, takes the form of a staring spell as the person suddenly seems “absent” and has a brief loss of awareness. May be accompanied by blinking or mouth twitching. Absence seizures have very characteristic appearance on EEG. Also called a petit mal seizure.

Seizure, atonic, is a seizure marked by the person losing muscle tone and strength and unless supported, falls down. Atonic means lack of muscle tone and strength.

Seizure, subclinical (Electrographic Seizures) are visible on the EEG, but the patient does not exhibit clinical symptoms. Electroencephalography often detects subclinical seizures during sleep.

Seizure, tonic clonic, involves two phases – tonic phase when body becomes rigid and clonic phase of uncontrolled jerking. May be preceded by aura and is often followed by headache, confusion and sleep. May last for seconds or continue for several minutes.

Self-Regulation and self-control are related but not the same. Self-regulation refers to both conscious and unconscious processes that have an impact on self-control, but regulatory activities take place more or less constantly to allow us to participate in society, work and family life. Self-control is a conscious activity.

Sensory Defensiveness is a tendency, outside the norm, to react negatively or with alarm to sensory input which is generally considered harmless or non-irritating to others. Also called hypersensitivity.

Sensory Input, *see sensory stimuli*.

Sensory Integration is the way the brain processes sensory stimulation or sensation from the body and then translates that information into specific, planned, coordinated motor activity.

Sensory Integration Dysfunction a neurological disorder causing difficulties processing information from the five classic senses (vision, hearing, touch, smell and taste), sense of movement (vestibular system) and positional sense (proprioception). Sensory information is sensed normally, but perceived abnormally. May be a disorder on its own or with other neurological conditions.

Sensory Integration Therapy is used to improve ability to use incoming sensory information appropriately and encourage tolerance of a variety of sensory inputs.

Sensory Stimulus Agent, action or condition, internal (e.g., heart rate, temperature) or external (e.g., sights, sounds, tastes, smells, touch and balance) that elicits physiological or psychological response. Response depends on ability to regulate and understand stimuli and adjust emotions to demands of surroundings.

Sleep Hygiene a set of practices, habits and environmental factors critically important for sound sleep, such as minimizing noise, light and temperature extremes and avoiding naps and caffeine.

Social Communication Disorder (SCD) is a new diagnostic category established in the DSM-5 that applies to individuals who have deficits in the social use of language, but do not have the restricted interests or repetitive behavior you see in those with autism spectrum disorders.

Social Communication/Emotional Regulation/Transactional Support (SCERTS) is an educational model of treatment that differs notably from the focus of “traditional” ABA by promoting child-initiated communication in everyday activities.

Social Reciprocity is back-and-forth flow of social interaction. How behavior of one person influences and is influenced by behavior of another and vice versa.

Social Stories, developed by Carol Gray, are simple stories that describe social events and situations that are difficult for a child with a PDD to understand. For example, a social story might be written about birthday parties if the child appears to have a difficult time understanding what is expected of him or how he is supposed to behave at a birthday party.

Social Worker is a trained specialist in the social, emotional and financial needs of families and patients. Social workers often help families and patients obtain the services they have been prescribed.

Special Education is specially designed instruction, at no cost to families, to meet unique needs of child with disability, including instruction conducted in the classroom, in the home, in hospitals and institutions and in other settings and instruction in physical education.

Speech-Language Therapist or Speech Language Pathologist, specializes in human communication. The focus is on communication, not speech, to increase child's ability to impact and understand their environment.

Speech-Language Therapy is provided with the goal of improving an individual's ability to communicate. This includes verbal and nonverbal communication. The treatment is specific to the individual's need.

Spoken Language (also referred to as expressive and receptive language) is the use of verbal behavior or speech, to communicate thoughts, ideas and feelings with others. Involves learning many levels of rules - combining sounds to make words, using conventional meanings of words, combining words into sentences and using words and sentences in following rules of conversation.

Stereotyped Behaviors refer to an abnormal or excessive repetition of an action carried out in the same way over time. May include repetitive movements or posturing of the body or objects.

Stereotyped Patterns of Interest or restricted patterns of interest refer to a pattern of preoccupation with a narrow range of interests and activities.

Stimming or "self-stimulating" behaviors, are stereotyped or repetitive movements or posturing of the body that stimulate ones senses. Some "stims" may serve a regulatory function (calming, increasing concentration or shutting out an overwhelming sound).

Subclinical Seizure, *see Seizures*.

Symbolic Play is where children pretend to do things and to be something or someone else. Typically develops between the ages of 2 and 3 years. Also called make believe or pretend play.

Syndrome is a set of signs and symptoms that collectively define or characterize a disease, disorder or condition.

T

Tactile Defensiveness is a strong negative response to a sensation that would not ordinarily be upsetting, such as touching something sticky or gooey or the feeling of soft foods in the mouth. Specific to touch.

TEACCH is a therapeutic approach broadly based on the idea that individuals with autism more effectively use and understand visual cues.

Tonic-clonic seizure, *see Seizures*

Typical Development (or healthy development) describes physical, mental and social development of a child who is acquiring or achieving skills according to expected time frame. Child developing in a healthy way pays attention to voices, faces and actions of others, showing and sharing pleasure during interactions and engaging in verbal and nonverbal back-and-forth communication.

U

V

Verbal Behavior is a method of Applied Behavioral Analysis (ABA) for teaching children with autism, based on B.F. Skinner's description of the system of language.

Vestibular System refers to the body's system for maintaining equilibrium.

W

X

Y

Z

Resources

BOOKS

1001 Great Ideas for Teaching and Raising Children with Autism Spectrum Disorder

by Veronica Zysk and Ellen Notbohm

Activity Schedules for Children with Autism: Teaching Independent Behavior

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by Chantal Sicile-Kira

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by Paula Kluth

WEBSITES

Autism Speaks
autismspeaks.org

Asperger/Autism Network
aane.org

Autism Research Institute
Autism.com

AWAARE: Autism Wandering Awareness Alerts Response and Education Collaboration
awaare.org

The BULLY Project
specialneeds.thebullyproject.com

Center for Autism & Related Disorders
centerforautism.com

Center for Parent Information and Resources
parentcenterhub.org

Interactive Autism Network
ianproject.org

Leading the Way: Autism-Friendly Youth Organizations – A Guide from Autism Speaks
autismspeaks.org/family-services/youth-organizations

My Autism Team: Autism Support Online
myautismteam.com

My Job Chart: Where Kids, Work and Reward Click
myjobchart.com

Organization for Autism Research
researchautism.org

School Community Tool Kit from Autism Speaks
autismspeaks.org/school

Transition Tool Kit from Autism Speaks
autismspeaks.org/family-services/tool-kits/transition-tool-kit

Wrightslaw: The Special Ed Advocate
wrightslaw.com

Your Child's Rights from Autism Speaks (including Individualized Education Program: Summary, Process and Practical Tips from Goodwin Procter LLC)
autismspeaks.org/what-autism/your-childs-rights