



100 Day Kit

For Families of School Age Children Newly Diagnosed with Autism

My Autism Guide
SIGN UP



Information
based on
your needs

guide.autismspeaks.org

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*Overcoming Autism: Finding the Answers, Strategy and Hope That Can Transform a Child's Life
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Section 1

Introduction

- *Why was my child diagnosed with autism?*
- *How does an autism diagnosis benefit my child?*
- *How is autism diagnosed?*

Why was my child diagnosed with autism? What does it mean?

Your child has been diagnosed with **autism spectrum disorder (ASD)** and you have asked for help. This is an important turning point in a new chapter of your family's life. For some families, it may be the moment 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 felt that an evaluation would prove otherwise. Maybe it was a teacher, doctor or friend of yours who suggested you get your child evaluated and you are surprised that their concerns and suspicions were accurate.

Many families report mixed feelings when their child is diagnosed. You may feel relieved to know that the concerns you have for your child are valid. You also may feel upset or overwhelmed. Whatever it is you feel, know that thousands of families share this journey. You are not alone. 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 from parents like you. As you begin your journey or continue on a path you have already started, remember your child is still the same person they were before the diagnosis.

How does an autism diagnosis benefit my child?

Parents are usually the first to notice the signs of autism. You may have noticed that your child was developing differently from their 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 subtle and first recognized by a teacher or medical professional.

Great strides have been made in autism research in recent years, and new findings are being discovered every day. Some of the most brilliant minds of our time have turned their attention toward understanding autism.

Your child is the same unique, lovable, wonderful person they were before the diagnosis.





There are several reasons why having a diagnosis is useful to you and your child. A thorough and detailed diagnosis can:

- Provide important information about your child's behavior and development
- Give you a better understanding of the challenges you have faced with parenting
- Motivate you to learn new ways to help your child grow and develop
- Help create a roadmap for treatment by identifying your child's specific strengths and challenges
- Provide useful information about needs and skills to target for effective intervention
- Help connect you with local and long-distance resources as your child grows

In addition, a diagnosis is often required to access autism-specific services through your local school district.

How is autism diagnosed?

We don't have a blood test or medical test that can diagnose autism. Instead, autism is diagnosed based on careful observation of your child's behavior, their history of development and by gathering information from you and other people with whom your child regularly interacts.

As the symptoms of autism vary, so do the routes to getting a **diagnosis**. You may have raised questions with your pediatrician. A teacher may have spoken to you first about concerns that you may not have recognized yet. Some children are identified as having **developmental delays** before getting 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 child's doctor resulting in a delayed diagnosis. Autism Speaks and other organizations are working hard to educate parents and physicians so that autism in children is identified as early as possible.

An evaluation by healthcare professionals with varying specialties can be helpful for diagnosing autism and other challenges that often come with autism, such as delays in motor skills. Your child may have been diagnosed by a:

- **Developmental pediatrician:** a pediatrician with additional training and expertise in treating children with developmental, learning or behavioral differences
- **Neurologist:** a doctor who diagnoses and treats disorders that affect the brain
- **Psychiatrist:** a doctor who diagnoses and treats mental, emotional and behavioral disorders
- **Psychologist:** a doctor trained to help people learn to cope more effectively with life issues and mental health problems and evaluate developmental concerns

In some states, other professionals with advanced training in the clinical criteria of autism may provide a diagnosis, such as advanced practice nurses and speech-language pathologists.

In some cases, a team of specialists may have evaluated your child and provided recommendations for treatment. The team may have included a(n):

- **Audiologist** to rule out hearing loss
- **Speech-language pathologist** to determine language skills and needs
- **Occupational therapist** to evaluate physical and motor skills, as well as sensory challenges

If your child has not been evaluated by a **multi-disciplinary team**, ask for one to help 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 your child has a formal diagnosis, 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 first appointment as it may take some time to compile. But follow up and pick up the report as soon as it's ready. Don't be afraid to ask the doctor to explain the diagnosis and recommendations for next steps. You may have to revisit these recommendations as your child grows older and may need additional supports.



Section 2

What is autism?

- *Definition*
- *Diagnostic criteria*
- *Prevalence*
- *Causes*

ASD and autism are 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 inflexible, repetitive behaviors.

With the May 2013 publication of the fifth edition of the **American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-5)**, all autism disorders were merged into one umbrella diagnosis of ASD. Before the DSM-5, they were recognized as distinct subtypes, including:

- **Autistic disorder**
- **Childhood disintegrative disorder**
- **Pervasive developmental disorder-not otherwise specified (PDD-NOS)**
- **Asperger syndrome**

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 autism.

The DSM is the main diagnostic reference used by mental health professionals and insurance providers in the United States. Under the current DSM-5, the diagnosis of autism requires that:

- At least six developmental and behavioral characteristics are observed.
- Problems are present before the age of 3.
- There is no evidence of certain other conditions that are similar.

The first two diagnostic criteria for ASD are:

1. Persistent deficits in **social communication** and interaction across multiple settings, including difficulty (either in the past or in the present) in these three areas:
 - **Social-emotional reciprocity**
 - **Nonverbal communicative** behaviors used for social interaction
 - Developing, maintaining and understanding relationships
2. **Restricted and repetitive patterns of behavior**, interests or activities. A person must show at least two types, including:
 - Stereotyped or repetitive motor movements
 - Insistence on sameness or inflexible adherence to routines
 - Highly restricted, fixated interests
 - **Over- or under-reactivity to sensory input** or unusual interest in sensory aspects of the environment

Symptoms can be currently present or reported in past history but should have been present early in life.

In addition to the diagnosis, each person evaluated is described in terms of:

- Any known genetic cause (for example, **Fragile X syndrome, Rett syndrome**)
- Level of language and **intellectual disability**
- Presence of medical conditions such as **seizures, anxiety, depression** and/or **gastrointestinal (GI) problems**

If your child is diagnosed with autism, experts recommend they have genetic testing. Some genes linked with autism also carry risks for other health conditions. Knowing these genetic links can help your child's healthcare team screen for health problems and treat them quickly.

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

Severity levels of autism

Autism affects everyone differently, and the extent to which it may create challenges in daily life is also different for each person. The DSM-5 also includes new guidelines that break down the diagnosis into three levels based on the amount of support the person might need. A health care provider will look at many factors to choose a severity level. The level is based on communication skills and types of restrictive, repetitive behaviors.

Level 1: Requiring support

For example, a person who uses full sentences but has trouble with a back-and-forth conversation.

Level 2: Requiring substantial support

For example, a person who uses short sentences, talks only about a narrow set of their interests, and whose body language or nonverbal communication is not typical.

Level 3: Requiring very substantial support

For example, a person with few or no words who rarely starts a conversation, only engages to meet a need, and/or who uses very unusual approaches to interact with other people.

To read the whole DSM-5 criteria, visit [autismspeaks.org/autism-diagnosis-criteria-dsm-5](https://www.autismspeaks.org/autism-diagnosis-criteria-dsm-5).



How common is autism?

Autism statistics from the **U.S. Centers for Disease Control and Prevention (CDC)** released in March 2020 identify around 1 in 54 American children on the autism spectrum, a more than 10-fold increase in **prevalence** in 40 years, and a 10 percent increase since the last prevalence numbers were released two years before. Studies also show that autism is over four times more common among boys than girls. An estimated 1 out of 34 boys and 1 in 144 girls are diagnosed with autism in the United States. ASD affects over 3 million people in the U.S. and tens of millions worldwide.

Moreover, U.S. government statistics suggest that prevalence rates have increased 10 to 17 percent annually in recent years. We don't yet know all the reasons for the increase in prevalence.

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 more than 100 **autism-risk genes**. In about 15 to 30 percent of cases, a specific **genetic** cause of a person’s autism can now 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, non-genetic or environmental influences may 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, especially those involving lack of oxygen to the baby
- Mother’s exposure to high levels of pesticides and air pollution

These factors by themselves do not cause autism. Rather, in combination with genetic risk factors, they appear to modestly increase risk.

Increasingly, researchers are looking at the role of the **immune system**, **metabolic factors**, the **microbiome** (all the bacteria and other organisms that live on our skin and inside our **digestive tract**), and other biological processes. 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 on the autism spectrum and their families.

Language in the autism community

Children and adults with autism and their families all have very different experiences from one another. As a result of these unique experiences, there are different perspectives across the community on a variety of subjects, including language and terminology. Many people who meet the criteria for ASD have adopted the term “autistic” to describe their differences. Many self-described autistics prefer that their behavior not be depicted as pathological, but rather as a natural variation in human behavior. While we intentionally use medical language to describe ASD throughout this kit, we also recognize that for some, autism can be thought of simply as a difference in social behavior.

There are also conversations in the community about the preference of identity-first language (such as “autistic adult”) compared to person-first language (such as “adult with autism spectrum disorder”). Many advocates feel autism is a part of who they are as a person and not only a diagnosis. This highlights the need for sensitivity, understanding and acceptance of autistic people of all ages and their preferences for how they describe themselves.

Similarly, health care providers will use medical terminology when discussing your child’s diagnosis and treatment plans. Some of this language will be important when advocating for your child. You may choose to use different language when talking about autism outside of medical or other settings. Your family’s experience is unique and you can talk about autism however you’d like!

Section 3

Core signs and symptoms of autism

- *Social symptoms*
- *Communication difficulties*
- *Repetitive behaviors*
- *Common strengths*
- *Physical and mental issues that might accompany autism*

Autism affects the way your child perceives the world and may make communication and social interaction difficult. ASD is 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 some people on the autism spectrum. For others, symptoms may be more severe, as when repetitive behaviors or lack of spoken language interfere with everyday life.

“If you’ve met one person with autism, you’ve met one person with autism.”

- Dr. Stephen Shore



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 are on the autism spectrum have difficulty engaging in the give-and-take of everyday human interactions. By 8 to 10 months of age, many infants who are eventually diagnosed with 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. To parents, it may seem as if their child is disconnected. They may not seek comfort or respond to family members’ 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 may look different compared to non-autistic children.

Some social symptoms of autism might include:

Difficulty interpreting what others are thinking and feeling

Subtle **social cues**, such as a smile, a wave or a frown, may not convey meaning to an autistic person in the way that those without autism interpret them. For example, a child with autism may not know or indicate they understand your full meaning when you say “Come here!” with your arms extended out for a hug, or when you say it with a frown on your face. Without the ability to interpret **gestures** and facial expressions, the social world can seem bewildering.

Difficulty seeing things from another person’s perspective

Most 5-year-old children understand that other people have thoughts, feelings and goals that may be different from their own. A person with autism may not show such understanding. This, in turn, can interfere with the ability to predict or understand another person’s actions.

Difficulty regulating emotions

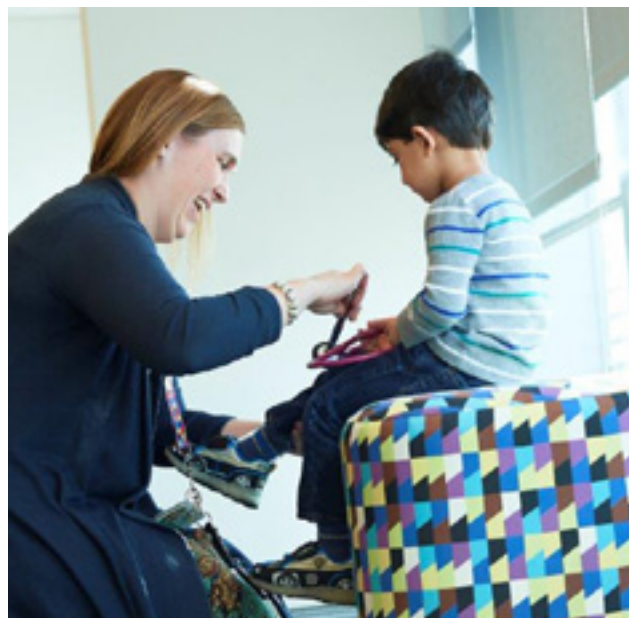
Some autistic children experience challenging behaviors, such as outbursts or crying in contexts when they don’t seem warranted or make sense to others. It’s helpful to know that challenges in regulating emotions may be attempts to communicate when situations are overwhelming, unexpected or new. Some behaviors can become disruptive or physically **aggressive** in such overwhelming or frustrating situations. **Self-injurious behavior**, such as head banging, hair pulling or self-biting, may also occur.

Fortunately, autistic children can be taught how to socially interact, use gestures and recognize facial expressions. Also, there are many strategies that can help a child with autism respond to frustrations and learn to communicate their needs, so they don’t have to express those feelings and needs through challenging or potentially unsafe behaviors.

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 autistic people do learn to use spoken language, and all can learn to communicate in their own way. Many nonverbal or nearly nonverbal children and adults learn to use communication systems, such as pictures, **sign language**, electronic word processors or even **speech-generating devices**.



Unusual speech

When language begins to develop, an autistic person 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 repeat what they hear verbatim. This is called **echolalia**.



Expressive and receptive language

Many parents assume that a child who is unable to express language is also unable to understand the language of others. But this is not always the case. It is important to distinguish between expressive language and receptive language.

- **Expressive language** is how a person communicates their feelings, thoughts and needs. Children with difficulties in expressive language are often unable to express what they are thinking through language.
- **Receptive language** is how a person understands information. Children with difficulties in receptive language are often unable to understand what others are saying.

The fact that your child may seem unable to express themselves through language does not necessarily mean they are unable to comprehend the language of others. Be sure to talk to your doctor or look for signs that your child can interpret language, as this important distinction will affect the way you communicate with them.

Pragmatics

Pragmatics are social rules for using language in a meaningful context or conversation. Examples include taking turns in conversation, changing the way a person talks to different listeners, and using eye contact and gestures when speaking or listening.

Challenges in pragmatics are a common feature of spoken language difficulties in children with autism, including in children with no language delays and highly fluent speech. These challenges may become more apparent as your child gets older.

Ordinary conversations

Some autistic children exhibit only slight delays in language. They might even develop advanced language with large vocabularies, yet they also may have difficulty sustaining a conversation. Some children and adults with autism may talk for a significant amount of time about a favorite subject, yet may not have the ability or tools they need to manage the “to and fro” of conversation. In other words, the ordinary “give and take” of conversation proves difficult. Some autistic children with superior language skills may sound like “little professors” or may not pick up on the “kid-speak” that’s common among their peers.

Indirect communication

Another common difficulty is interpreting nonverbal communication, such as **body language**, tone of voice and facial expressions. For example, a person with autism might interpret a sarcastic, “Oh, that’s just great!” as meaning it really is great.

Conversely, some autistic individuals may not use typical body language. Facial expressions, movements and gestures may not match what they are saying. Their tone of voice may not 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 think, feel or need.

When attempts to communicate don’t work, it can lead to frustration for the person with autism and could escalate to a behavioral outburst, such as screaming or grabbing. Fortunately, there are proven methods for helping autistic children and adults learn more productive ways to express their needs. Learning and understanding what your child is trying to communicate in certain circumstances will also help with these behaviors. As an autistic person learns to communicate what they want, feel and think, and you learn to better understand their efforts to communicate, challenging behaviors often subside.

Autistic children often have difficulty letting others know what they would like to express until they are taught how to communicate through speech, gestures or other means.



Repetitive behaviors

Unusual repetitive behaviors and a tendency to engage in a restricted range of activities are other core symptoms of autism. Common repetitive behaviors include:

- Arranging and re-arranging objects
- Hand-flapping
- Jumping and twirling
- Repeating sounds, words or phrases
- Rocking
- **Self-stimulating** behavior, such as wiggling fingers in front of the eyes

Need for sensory stimulation

Sometimes the repetitive behavior, such as staring at lights, fans or running water, is related to a need or desire for certain types of **sensory stimulation**. Under-responsiveness and over-responsiveness to sensory stimulation are another form of repetitive behavior. For example, many children with autism are very sensitive to loud noises or even to noises that don’t seem too loud (over-responsiveness). Or they may not respond as expected to pain when they fall or hurt themselves (under-responsiveness).

Restricted range of activities

Many autistic children play with toys in a restricted way. For example, some spend hours lining up toys in a specific way instead of using them for pretend play. Similarly, some adults can become preoccupied with having household or other objects in a fixed order or place. It may be upsetting to them when something disrupts the order. Many autistic children and adults need and demand consistency in their environment and daily routine. Slight changes can be extremely stressful and lead to anxiety or outbursts.

Extreme interests

Repetitive behaviors can also take the form of intense **preoccupations** or **obsessions**. These extreme interests might strike others as unusual, such as a fascination with fans, vacuum cleaners or toilets. Some autistic people have a strong depth of knowledge in specific topics. For example, a child or adult may know and share astonishingly detailed information about a favorite cartoon or the subject of astronomy. Older people with autism may develop interest in numbers, symbols, dates or science topics. For some, these interests can be viewed as a strength and used in different ways as the child ages, including in potential employment opportunities.



Executive Functioning and Theory of Mind

People with autism 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. Both of these issues can impact their behavior.

Executive functioning refers to a person's ability to process information.

Theory of mind refers to a person's ability to understand and identify the thoughts, feelings and intentions of others.

Executive Functioning

Difficulties in the area of executive functioning can manifest themselves in many different ways, such as:

- Challenges with complex thinking that requires holding more than one train of thought at the same time
- Difficulty seeing how minor details fit into a bigger picture
- Difficulty maintaining attention or organizing thoughts and actions
- Poor impulse control
- Inability to use skills related to self-regulation
- Difficulty inhibiting inappropriate responses

Temple Grandin once said: "I cannot hold one piece of information in my mind while I manipulate the next step in the sequence."

Theory of Mind

People with autism can encounter difficulty recognizing and processing the feelings of others, which is sometimes referred to as "mind-blindness." It can be difficult for them to understand that others may have different feelings from their own.

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:

- Difficulty explaining one's behaviors
- Difficulty understanding emotions
- Difficulty predicting the behavior or emotional state of others
- Problems understanding the perspective of others
- Problems inferring the intentions of others
- Lack of understanding that behavior impacts how others think and/or feel
- Problems with joint attention and other social conventions
- Problems differentiating fiction from fact

As a result of these challenges, autistic people may not realize if another person's behaviors are intentional or unintentional. This often leads others to believe that the person with autism does not have empathy or understand them, which can create great difficulty in social situations.

Helping a person with autism learn to better understand feelings, as well as reasons for certain behaviors can improve these challenges.

Strengths and Challenges

Created by Stephen Shore, Ed.D.

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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.
- 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
- Difficulty perceiving unwritten rules of social interaction, but can learn these rules through direct instruction and social narratives
- 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

Physical and medical issues that may accompany autism

A range of physical and mental health conditions frequently accompany autism. It is helpful to learn more about these issues so that you can learn to read the signs. Oftentimes, caregivers and professionals might automatically attribute certain challenges to the autism diagnosis, when the child or adult may actually have another treatable condition that is causing the difficulties. It is also important to remember that though these issues are more common among autistic people, not all children and adults diagnosed with ASD will have another diagnosis. These issues, often called **comorbid conditions**, include, but are not limited to:

Seizure disorder

Seizure disorder, also called **epilepsy**, occurs in as many as a third of individuals with autism. 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 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 have more than one type. The easiest to recognize are large **grand mal** (or **tonic-clonic**) **seizures**. People with these seizures have stiffening and spasming of muscles and typically lose consciousness.

Others include **petit mal** (or **absence**) **seizures**, which may look like a vacant stare, typically for up to 15 seconds. **Subclinical seizures** are so subtle that they may only show up in an **electroencephalogram (EEG)**. It is not clear whether subclinical seizures have effects on language, understanding and behavior.

Seizures associated with autism usually start early in childhood, or during adolescence, but they may occur at any time. If you are concerned that your child may be having seizures, tell your child's health care provider. They may order tests that may include an EEG, a **Magnetic Resonance Imaging (MRI) scan**, **Computed Axial Tomography (CAT) scan** and a **Complete Blood Count (CBC)**. Children and adults with epilepsy are often treated with **anticonvulsants** or seizure medicines to reduce or eliminate seizures. If your child has epilepsy, work closely with a neurologist to find the medicine or combination of medicines that works best for your child with the fewest side effects. You can also learn the best ways to ensure your child's safety during a seizure.

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**
- Other **single-gene** and **chromosomal disorders**

While further study is needed, single-gene disorders appear to affect 15 to 20 percent of those with ASD. Some of these syndromes have characteristic features or family histories. Experts recommend that all people with an autism diagnosis get genetic testing to find these genetic changes. It may prompt your doctor to refer your child to a **geneticist** or neurologist for further testing. The results can help guide treatment, awareness of associated medical issues and life planning.

Gastrointestinal disorders

Many parents report gastrointestinal (GI) problems in their children with autism. Surveys have suggested that between 46 and 85 percent of children with autism have problems such as **chronic constipation** or **diarrhea**. One study found 70 percent of children with autism had a history of gastrointestinal symptoms, such as:

- Abnormal pattern of bowel movements
- Frequent constipation
- Frequent vomiting
- Frequent abdominal pain

The exact prevalence of GI problems, such as **gastritis**, chronic constipation, **colitis** and **esophagitis**, in people with autism is unknown.

If your child has GI symptoms, talk with their health care provider. They may want to consult a **gastroenterologist**, ideally one who works with people with autism. 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 and relieving that discomfort may reduce the frequency or intensity of behavioral challenges.

Some evidence suggests that children may be helped by **dietary intervention** for GI issues, including the elimination of dairy- and **gluten**-containing foods. Ask your child's health care provider to develop a comprehensive treatment plan for your child. In January 2010, Autism Speaks initiated a campaign to inform pediatricians about the diagnosis and treatment of GI problems associated with autism.

Sleep problems

Sleep problems are common in children and adolescents with autism. Sleep problems can affect the whole family's health and well-being. They can also have an impact on the benefits of therapy for your child. Sleep problems may be caused by medical issues, such as **obstructive sleep apnea** or **gastroesophageal reflux**. Addressing the medical issues may solve the problem.

When there's no medical cause, sleep issues may be managed with **behavioral interventions**. These include **sleep-hygiene measures**, such as limiting sleep during the day and establishing regular bedtime routines. If sleep habits don't improve, cognitive behavioral therapy is a type of therapy that can help problem-solve sleep issues.

If additional help is needed, a pharmaceutical-grade melatonin supplement has also been shown to be effective and safe in children in the short-term, for up to three months. Don't give your child melatonin or other sleep aids without talking to your child's health care provider.

For additional information on sleep issues, visit autismspeaks.org/sleep.

Sensory processing disorder

Many autistic children have unusual responses to sensory stimuli and process sensory input differently than non-autistic people. This means that while information is sensed normally, it may be perceived much differently. Sensory systems that can be affected include:

- Vision
- Hearing
- Touch
- Smell
- Taste
- Sense of movement (vestibular system)
- Sense of position (proprioception and interoception)

Sensory Processing Disorder (SPD), formerly referred to as **Sensory Integration Dysfunction (SID)**, is when sensations that feel normal to others are experienced as painful, unpleasant or confusing. Although SPD is not currently recognized as a distinct medical diagnosis, it is a term commonly used to describe a set of symptoms that can involve **hypersensitivity** (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 sensory defensiveness.) or **hyposensitivity** (lack of a behavioral response, or insufficient intensity of response, to sensory stimuli considered harmful and irritating to others). An example of hypersensitivity is an inability to tolerate wearing clothing, being touched or being in a room with normal lighting. Hyposensitivity may be apparent in a child's increased tolerance for pain or a constant need for sensory stimulation.

Treatment for SPD is usually addressed with occupational therapy and/or **sensory integration** therapy. Sensory integration therapy helps people with SPD by exposing them to sensory stimulation in structured, repetitive ways so they can learn to respond in new ways. SI therapy is most often play-based and is provided by an occupational therapist.

Pica

Pica is an eating disorder involving eating things that are not food. Children between 18 and 24 months of age often eat non-food items, and this is typically a normal part of development. Some children with autism and other developmental disabilities beyond this age continue to eat non-food items, such as dirt, clay, chalk and paint chips. Children with 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. If you're worried about pica, contact your child's health care provider. They can help you assess if your child needs a behavioral intervention or if it is something you can manage at home.

Download the Pica Guide for Parents at autismspeaks.org/tool-kit/atnair-p-pica-guide-parents.

Mental and behavioral health disorders

Some children diagnosed with ASD will receive an additional mental health-related diagnosis, such as **attention deficit hyperactivity disorder (ADHD)** or **anxiety disorder**. Studies suggest that 20 percent of autistic children also have ADHD, and 30 percent struggle with an anxiety disorder, including:

- **Social phobia** (also called social anxiety disorder): characterized by an intense, persistent fear of being watched and judged by others
- **Separation anxiety**: characterized by an extreme fear of being separated from a specific person, such as a parent or teacher
- **Panic disorder**: characterized by spontaneous seemingly out-of-the-blue panic attacks, which create a preoccupation with the fear of a recurring attack
- Specific **phobias**: characterized by excessive and unreasonable fears in the presence of or in anticipation of a specific object, place or situation

Symptoms of ADHD include ongoing problems with:

- **Inattention**
- **Impulsivity**
- **Hyperactivity**

However, these symptoms also can result from autism. For this reason, evaluation for ADHD and anxiety should be done by someone with expertise in both disorders. One study found that just 1 in 10 children with autism and ADHD were receiving medicine to relieve the ADHD symptoms.

Children with autism express anxiety or nervousness in many of the same ways as typically developing children. But they may have trouble communicating how they feel. Outward signs may be the best clues. In fact, some experts suspect that signs of anxiety, such as sweating and acting out, may be especially prominent among those with ASD. Symptoms can include a racing heart, muscular tension and stomach aches. It is important for your child to be evaluated by a professional who has expertise in both autism and anxiety to provide the best treatment options for your child.

Section 4

How do I respond to this diagnosis?

- *Reacting to the diagnosis*
- *Caring for the caregiver*
- *Supporting your other children*
- *Fifteen tips for families*

Even before an evaluation, some parents have a feeling that their child has autism. Other parents have no idea, and the diagnosis can be very unexpected. Either way when your child is diagnosed you may feel a range of emotions. For example you may feel:

- Overwhelmed
- Relieved
- Anxious
- Sad
- Unsure



All of your feelings are valid. Give yourself time to process your feelings. Getting therapy and finding a support network can help you work through your emotions.

At the same time, remember that you have the same unique child you did before the diagnosis. You just have more information about the way your child thinks, processes and experiences the world.

Just because your child can or cannot do certain things right now does not mean they never will. Autistic people follow their own path and reach milestones at their own pace. The best thing you can do is continue loving and supporting your child, meeting them where they are, and finding the therapies and supports that will enable them to learn and grow.

Reacting to the diagnosis

No matter how you may feel about the diagnosis, concerns that many parents share are similar:

- Worrying about your child's future
- Not knowing what to expect
- Feeling like you don't know how to help

Your child needs you. You are the best person to provide them with the help, support and love they need. You don't have to know everything about autism to be the person who knows your child best. Even if you don't feel qualified, or you know nothing about autism, you can do this. It won't always be easy, but there is a whole community of parents and people with autism who have walked this path.

If you find that sadness is interfering with your daily life or you have other symptoms of depression, consult your healthcare provider who can recommend treatment. These symptoms might include:

- Weight loss or gain
- Social withdrawal
- Sleep difficulties
- Low self-esteem
- Loss of interest in daily activities

While emotions vary across parents and family members, some might experience sadness at first. The time after an autism diagnosis can be challenging for all families. Autism is a complex disorder. It may not only change the way that you look at your child, it may change the way you look at the world. Accepting the diagnosis simply means that you are ready to advocate for your child.

Parents, siblings and other family members may each react to the diagnosis in different ways and at different rates. Give yourself time to adjust. Be patient. It will take some time to understand your child's autism and how you can best support them.

Strategies for support

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.



Stages of autism

Dr. Stephen Shore, a professor of special education and Autism Speaks board member on the autism spectrum, talks about four stages of autism that lead toward meaningful and rewarding lives for individuals with autism. Every stage involves multiple steps, and everyone advances at their own pace.

Stage 1. Awareness

You're already in this stage as you're reading this tool kit and becoming aware of your child's diagnosis. For many years, advocacy groups have made big pushes for autism awareness. More than a decade later, many groups have felt they successfully achieved this stage by promoting awareness in many ways. By increasing awareness of autism spectrum disorder and the many different manifestations of this condition, there have been more conversations on the subject. This awareness has resulted in many autism diagnoses for those who were under diagnosed or even misdiagnosed over the years.

Stage 2. Acceptance

Many organizations also strive to promote autism acceptance. This involves caring for autistic individuals in all their strengths and challenges and not trying to make a person into someone they are not. Acceptance also involves a respect for the differences that autism brings into the lives of everyone involved, as well as the full spectrum of autism. An important aspect of this stage is working with the characteristics of the autistic person rather than against.

Stage 3. Appreciation

When working on appreciation, we can look at the gifts of those on the spectrum and moments others may never understand the significance of. How many people really take the time to cherish every day, appreciate our support networks, and look at our own resilience and the value of how far we have come? Our children with autism one day may go on to college, live by themselves or find their dream job after years of hard work and support. These are moments we appreciate more than others may ever understand. Autistic people are valued for who we are and the contributions we make to society.

Stage 4. Action

This stage glues together the work done in the previous three, where we actively work with a person's strengths and interests to help them live a life they want to have. Everyone has different goals in life, and a child's goals may change as they grow up. Let's put those skills and supports to use as we take action to help promote self-determination, self-advocacy, as well as making fulfilling and productive lives for autistic individuals the rule rather than the exception.

Caring for the caregiver

Providing care and support for an autistic child can require a lot of time and effort, but it can also be incredibly rewarding. To make it happen, though, you need to take care of yourself.

Take a moment to ask yourself:

- Where does my support and strength come from?
- How am I really doing?
- Do I need to cry? Complain? Scream?
- Would I like some help but don't know who to ask?

If you want to take the best possible care of your child, first take care of yourself.

Parents often fail to evaluate their own sources of strength and emotions. 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 seem endless. You may feel completely overwhelmed and not know where to start. There may never be a convenient time to care for yourself, but it is essential to build self-care into your everyday life – even if it is just five or 10 minutes at a time.

Each family is unique and deals with stressful situations differently. It is important to find the people, activities and routines that work best for you.

Getting your child started in treatment can help you feel better. Acknowledging the emotional impact of autism and taking care of yourself during this time can help prepare you for the road ahead. Maintaining open and honest communication with your partner and family, as well as discussing your concerns, can 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 is probably stronger than you realize.

Here are some tips from parents who have experienced these first days of understanding the diagnosis.

Get going. Get your child started in therapies and activities. There are many details for you to manage in an intensive treatment program, especially if it is based in your home. If you know your child is engaged in meaningful activities, you can better focus on moving forward. It may also free up time to educate yourself, advocate for your child and take care of yourself. Getting started with therapies and interventions can help to build a team of people who care for your child and want to see them succeed.

Ask for help. Asking for help can be hard, 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?
- Cook dinner for your family one night so that you can spend the time learning?
- Pick a few things up for you at the store or do a load of laundry?
- Let other people know you are going through a transitional time and could use a hand?

Talk to someone. Everyone needs someone to talk to. Tell someone 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, call someone. Many parents find online groups and communities helpful. You may also want to consider seeking professional help.

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 services and providers available in your area. You may have to try more than one to find a group that feels right to you. For many parents like you, support groups offer hope, comfort and encouragement. You may also want to consider getting your child involved in local recreational programs for children with autism. This may be a good way to meet other parents like you.

One way to find support groups is through the local **Special Education Parent Teacher Association (SEPTA)** in your school district or online through the Autism Speaks Facebook page at facebook.com/autismspeaks.

Take a break. If you can, take some time away, even if it is only a few minutes to take a walk. 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 can help you feel renewed for things you need to do when you get back. Also, try to get some rest. If you are getting regular sleep, you are better prepared to make good decisions, be more patient with your child and manage stress.

Keep a journal. Some parents find a journal to be a helpful tool for keeping track of their child's progress, including what is working and what isn't. It can help to keep a journal of how you are feeling as well.

Trust your gut as a parent. There are many paths to take, treatment options and opinions. You know your child best. Work with the people in your child's life to find what works best for your child and your family.

Learn more. The internet can be an important tool for learning about autism and how to help your child. Unfortunately, there is more information on the web than you may have time to read. And there may be a lot of misinformation. As you're looking for resources, ask yourself these questions:

- Is what I'm reading right now relevant to my child?
- Is it new information?
- Is it helpful?
- Is it from a reliable source?
- Is it evidence-based?

Share this kit with family members and close friends. Download the kit at autismspeaks.org/tool-kit/100-day-kit-school-age-children.

We also offer tool kits for specific people in your life. Visit: autismspeaks.org/tool-kit for resources for parents, siblings, grandparents and friends.



Disclosure

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 8 years old 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 their 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 help children with autism to better understand themselves and their diagnosis. Be sure to emphasize your child's strengths as well as their areas of challenge. It is helpful to point out that everyone has areas of strength and weakness.

Telling Your Child

In the piece below, clinical psychologist Lauren Elder, Ph.D., shares suggestions for how to tell your child about their diagnosis.

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 child'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 child to hear that autism is common and that there are many children like them. 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.

Your child should be the one to decide if they want their diagnosis disclosed and how. If as a family you do choose to share with others, be sure your child is part of the process.

Telling peers

Talking with peers and other students is crucial to helping an autistic child become more comfortable in school or social settings. It is important to involve your child in these discussions to the greatest extent possible.

Making peers aware of your child's autism and helping them understand the reasons behind their sometimes different behavior will increase acceptance and limit bullying. It is important to explain autism to children in a way that will help them understand their friend or classmate to the best extent possible. 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 thrive.

Four Step Process for Disclosing Autism

by Stephen Shore, Ed.D.

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.



Telling Others

From *Overcoming Autism*

by Lynn Kern Koegel, Ph.D. and Claire LaZebnik, 2014.

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 and moan to them. You're dealing with a huge challenge; take advantage of every plus it has to offer.

Supporting your other children

As the parent of a child with autism, it may seem like there is never enough time to do everything that needs to be done. So much focus and attention is placed on the child with autism, that it is common for parents to have less time and energy left to focus on their other children.

Brothers and sisters of children with autism frequently face their own challenges. Much more may be expected from these siblings. They often need help understanding the emotional reactions they are experiencing as a result of the many changes occurring in their lives. This support is essential to their future well-being.

Strategies for supporting your other children:

Help your other children understand autism and what is going on with their sibling. Talk with them early and often in age-appropriate ways. Many books and other resources are available to help them to understand this diagnosis, including [Autism Speaks Siblings Guide to Autism](#).

Help your children learn how to play and form relationships with their sibling with autism. There are a few simple things that you can do that will help with this, including teaching your other children how to get their sibling's attention and give simple instructions. It's also important to praise all your children when they play well together.

Find a sibling support group. Support groups can help them build friendships and relate to other peers who have a sibling with autism. Don't hesitate to consult a professional if you feel your child is internalizing most of their feelings or beginning to act out. The earlier you address this, the better.

Find more about supporting your other children and other parenting challenges in [Autism Speaks Parents Guide to Autism](#).

15 tips for families

by Kathryn Smerling, Ph.D., LCSW

Five tips for parents

- 1. Create a team for your child.** Be your child's best advocate. Stay informed. Take advantage of services that are available to you both locally and statewide. There are many professionals who can help and educate you and your family. Remember, it takes a village!
- 2. Practice self-care.** You are going to need resilience and resources for yourself. Don't push your feelings away. Have compassion for yourself. It's okay to seek professional help to process any conflicting emotions you may have.
- 3. Find joy.** Find joy in spending quality time with your children and your spouse. Try not to let autism consume every waking hour of your life. Look for joy in everyday experiences.
- 4. Celebrate small victories.** Love your child and take great pride in each accomplishment. Focus on what they can do instead of making comparisons with a typically developing child. Love them for who they are rather than what you think they should be.
- 5. Build a community.** Get involved with the autism community. Don't underestimate the power of this community. In the past years, the autism community has gained much knowledge and practical information which they would love to share with you.

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 and support each other. Connecting with other parents will enable you to give and receive support from families who understand your day-to-day challenges. It is empowering and productive to get involved with autism advocacy.

“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.”



Five tips for siblings

- 1. You're not alone.** 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 to face difficult family situations.
- 2. Be open.** Be proud of your brother or sister. Learn to talk about autism to your friends. If you are comfortable with the topic, they will be comfortable too. If you are embarrassed by your brother or sister's differences, your friends will sense this and it will make it awkward for them. 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 who is here just for you!
- 3. Manage your feelings.** While it is okay to be sad sometimes that you have a brother or sister affected by autism, it doesn't help to be upset and angry for extended periods of time. Remember your mom and dad may have these feelings too. It may be helpful to find a professional person to talk to your family about how autism affects all of you.
- 4. Spend quality time with your parents.** Spend time with your parents alone. 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 your mom and dad.
- 5. Share with your sibling.** 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. These shared activities will be something you both can look forward to!

“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 sister and help my brother when he needs it.”



Five tips for extended family members

- 1. Connect.** Ask how you can be helpful. 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 they attend. You can organize a lunch, a theatre benefit, a carnival, a card game, or a bake sale. Your efforts will be appreciated more than you can imagine.
- 2. Find support.** Seek out your own professional support if you find yourself having a difficult time accepting the fact that your loved one has autism. Be open and honest about the diagnosis. 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.
- 3. Be judgment-free.** Put judgment aside. Consider your family's feelings and be supportive. Respect the decisions they make for their child with autism.
- 4. Educate yourself.** Learn more about autism. 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 support your family.
- 5. Make time.** Carve out special time for each child. 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.

“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.”

10 Dos and Don'ts After an Autism Diagnosis

This post is by Lisa Smith, mother of seven children, two with special needs. Her son Tate has autism. Lisa blogs about her experiences and can be found on Facebook at *Quirks and Chaos* or at quirks-and-chaos.blogspot.com.

Over 10 years ago, my son Tate was diagnosed with autism and my life was forever changed. I am regularly asked for advice from parents of children newly diagnosed with autism. The diagnosis can be intimidating and parents are sometimes unsure of where to turn or what to do. I don't have all the answers. But I do remember the panic, fears, denial, and the distress I felt when my own son was diagnosed. I know now so many things I did not know then. I can honestly say that the life we are living is not scary at all. And so I tried to put into words some of the things that I thought might help a parent of a child newly diagnosed with autism.

1. Don't let the autism diagnosis intimidate you.

Do give yourself some time. Do some reading. Ask some questions. Do not jump to conclusions. Do not let all the doctors, therapists, educators, or the price tag that comes with autism intimidate you.

2. Don't let the autism diagnosis cause you to feel sorry for yourself. Do count your blessings.

In reality there are things so much worse than an autism diagnosis. Now, roll up your sleeves. Your role as your child's advocate is going to keep you busy. Things are going to be okay.

3. Don't let the autism diagnosis cause you to forget. Do remember that sweet baby you fell in love with!

He/she is still that child! Don't become so caught up in the present or so fearful of the future that you forget what's important. Don't forget that you are your child's parent first and his teacher/therapist second.

4. Don't let the autism diagnosis leave you feeling self-conscious or paranoid. Do understand there is no guilt to be had or blame to be placed.

There is nothing you could have done differently to prevent your child's autism. Don't let people who are uneducated about autism cause you to feel humiliated. Know this: It *does* get easier with time.

5. Don't let the autism diagnosis isolate you.

Do reach out for help. If you find yourself in need of understanding, find a parent who has already walked a few miles in your shoes. There is a lot of camaraderie in the autism community. Reach out. We help each other.

6. Don't let autism keep you from your other children.

Do explain autism to your children and what it means to your family. Reassure your other children often and show them how important they are to you. When possible try to include all your children in the therapies and activities your child with autism needs.

7. Don't let the autism diagnosis steal your joy.

Do maintain a sense of humor. You have a choice. You can dwell on all the what-ifs and the should-have-beens or you can accept what is and look for the joyous moments around you. Don't let autism silence the laughter in your home.

8. Don't let the autism diagnosis squash your hope.

Do be willing to dream a little differently. If, as your child ages, it becomes clear some of the things you envisioned for his life will not be happening, then modify your expectations. But stay motivated to help your child become the best that he can be.

9. Don't let the autism diagnosis cause you to doubt your faith. Do take advantage of the things autism can teach you.

Many parents of children with autism report they have become much more patient and understanding people since their child's autism diagnosis.

10. Don't let the autism diagnosis pull you into frivolous debates. Do use your time and energy wisely.

You have got important things to be doing. Focus your attention, time and energy on your children and their needs. Don't get caught up in the autism community debates that lead to nowhere. These kinds of disputes are not helpful and only cause division in the autism community. Don't get involved. Your time is much too valuable.

Section 5

How is autism treated?

- *Treatment options*
- *Applied Behavior Analysis*
- *Treatment for associated condition*
- *Choosing the right treatment*
- *Autism and insurance*

Each child and adult with autism is unique, so each autism intervention plan should be tailored to address specific needs. Treatment for autism is usually a very intensive, comprehensive undertaking that involves the child's entire family and a team of professionals. Some programs may take place in your home. They also may include training for you to serve as a therapist for your child under the supervision of a professional. Some programs are delivered in a specialized center or classroom. It is not unusual for a family to choose to combine more than one treatment method.

The words treatment, therapy and intervention all mean the same thing.

Your child's pediatrician, developmental pediatrician, psychologist or social worker can make suggestions or help you prioritize therapies based on your child's strengths and challenges identified in their evaluation. Once you have narrowed down therapy options, learn more about each to help you decide about treatments.

For many children, autism is complicated by medical conditions and symptoms that are not exclusive to autism.

If your child has biological or medical conditions, these will need to be treated, too. Examples include:

- **Allergies**
- **Food intolerances**
- **Gastrointestinal issues**
- **Sleep disturbances**

Treatment programs may combine therapies for both core symptoms of autism and these associated symptoms. For example, if sleep disturbances are not caused by a medical issue, a behavioral intervention might also be used to address them.

Many children benefit from receiving multiple therapies provided in the same learning format. Intervention can include:

- Time spent in a developmental program
- Speech-language therapy
- Occupational therapy
- Physical therapy
- One-on-one or small group sessions
- Parent-delivered interventions

Therapies include tools, services and teaching methods that can help your child reach their full potential.

Talk to your child's pediatrician for more information about therapies. Learn more about recommended therapies before your child begins treatment. Talk to experienced parents, look into the research supporting it and make sure you have a good understanding of what is involved before beginning any therapy for your child.

Research and experience have revealed a great deal of information about autism. But it remains a complex disorder that impacts each person differently. Many autistic children make remarkable progress with the right combination of services and supports. Just as your child's challenges can't be summed up in one word, they may not be remedied with one therapy. Each challenge must be addressed with an appropriate therapy. No single approach works for every child.

For more information on different treatment options, visit autismspeaks.org/treatments.

Treatment options

Many families choose one type of intervention that best meets the needs of their child and their parenting style. All of the services your child receives then are based on that specific intervention type. These interventions were developed just to treat autism. They require many hours per week and address behavioral, developmental and/or educational goals. During treatment, you may need to re-evaluate which method is best for your child.

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



Applied Behavior Analysis

Behavior analysis was originally described by psychologist B.F. Skinner in the 1930s. The principles and methods of behavior analysis have been applied effectively in many circumstances to develop a wide range of skills in learners with and without disabilities.

Behavior analysis is a scientifically validated approach to understanding behavior and how it is affected by the environment. In behavior analysis, “behavior” refers to actions and skills. “Environment” includes any influence that may change or be changed by one’s behavior. This includes aspects of the physical setting, such as sights, sounds, smells, as well as the social setting, such as who is present and how they might be communicating. Behavior analysis has helped many kinds of learners acquire many different skills – from healthier lifestyles to learning a new language.

Behavior analysis focuses on the principles that explain how learning takes place. **Positive reinforcement** is one of these principles. When a behavior is followed by some sort of reward, the behavior is more likely to be repeated and strengthened. Through decades of research, experts have developed many techniques for increasing useful behaviors and reducing those that may cause harm or interfere with learning.

Applied Behavior Analysis (ABA) is the use of these techniques and principles to bring about meaningful and positive change in behavior. Since the early 1960s, thousands of therapists have used ABA to teach new skills and reduce problem behaviors in learners with autism. These skills include:

- Communication
- Play
- Social
- Academic
- Self-care
- Work
- Community living

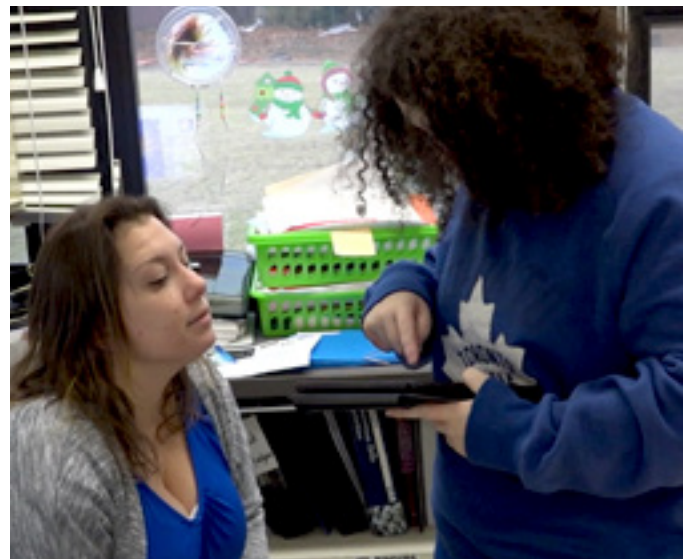
Research has demonstrated that ABA is effective for improving children’s outcomes, especially their **functional skills** (daily living skills), and can also improve **cognitive ability** and language in young children. Cognitive abilities include anything related to thinking and learning. Over the past several decades, different models using ABA have emerged, all of which use strategies that are based on Skinner’s work.

ABA may be hard to understand until you see it in action. It may be helpful to start by describing what all the different methods of ABA have in common. All ABA methods use a three-step process to teach:

1. An **antecedent**. This is a verbal or physical stimulus, such as a command or request. This may come from the child, the environment or another person.
2. A resulting behavior. This is the child’s response or lack of response to the antecedent.
3. A **consequence**. This depends on the behavior. The consequence 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. Targeted skills and behaviors are based on an established curriculum. ABA therapists break down each skill into small steps and teach them using **prompts** that are gradually eliminated as the steps are mastered. They give the child repeated opportunities to learn and practice each step in a variety of settings. Each time the child achieves the desired result, they get positive reinforcement, such as verbal praise or something else that is motivating. The therapist then builds on these skills so that the child learns how to learn in a natural environment.

In young children, ABA programs often include support for the child in a school setting with a one-on-one aide. Therapists measure success by direct observation and data collection and analysis – all critical components of ABA.



Effective ABA for autism is not a “one size fits all” approach and is not a “canned” set of programs or drills. Instead, a skilled therapist customizes the intervention to each child’s skills, needs, interests, preferences and family situation. So an ABA program for one learner looks different than a program for another learner. ABA changes as the needs of the learner change. Families can use ABA principles in their daily lives.

There are a number of specific ABA techniques and approaches used by providers to treat children with autism. The most traditional technique used in early childhood is **Discrete Trial Training (DTT)**, which involves teaching individual skills one at a time using several repeated teaching trials and reinforcements that may or may not be related to the skill that is being taught. **Pivotal Response Treatment (PRT)** and **Early Start Denver Model (ESDM)** are two other approaches that use natural reinforcement opportunities – for example, if a child makes a meaningful attempt to request a stuffed animal, the reward is the stuffed animal, not a candy or other unrelated reward. While these ABA approaches are used most frequently in early childhood, the approaches continue to be integrated into ABA-based treatment of school age children.

Cognitive behavioral therapy

Cognitive behavioral therapy (CBT) 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. The key ingredient of CBT, which distinguishes it from regular behavior therapy, is working on a change in cognition or how thinking is processed. Therapists seek to reduce challenging behaviors, such as interruptions, obsessions, melt-downs 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.

CBT elements are often included in school age social skills training to help children to think more accurately about the social world and to help social skills generalize across situations.

Medication for autism

There is no medication specifically to treat autism. Rather, medications can be used to treat some symptoms of autism. These medicines are most effective when used with behavioral therapies, such as ABA. Ideally, medicines are a complement to other treatment strategies.

Medicines for treating the two core symptoms of autism – social communication/interaction and restricted and repetitive behaviors – have long been a huge area of unmet need. Unfortunately, there are no drugs on the market today that effectively relieve these symptoms.

Today, most medicines prescribed to ease the symptoms of autism are used “off label,” meaning that their FDA approval is for other sometimes-related conditions such as attention deficit hyperactivity disorder (ADHD), sleep disturbances or depression.

Speak to your child’s health care provider about medications that might help your child. Autism Speaks ATN has developed two tool kits that can help you learn more: [Autism and Medication: Safe and Careful Use](#) and a [Parents Guide to Medication and Autism](#). Both can be found at autismspeaks.org/tool-kit.



Treatment for associated conditions

Your child may need services to treat certain conditions that are related to autism but not part of the core symptoms of autism. These often are called “**related services**.” Examples include:

Speech-language therapy

Most children with ASD participate in **speech-language therapy**. SLT addresses a range of challenges often faced by people with autism. For example, some autistic people do not speak or have limited speech. Others may talk to communicate, yet have trouble having a conversation or using or understanding the nuances of language and **nonverbal cues** when talking with others.

SLT coordinates the **mechanics** of speech with the meaning and social use of language. It begins with an evaluation by a **speech-language pathologist (SLP)** to assess the individual’s verbal skills (expressive language), as well as their ability to understand verbal and nonverbal communication from others (receptive language). From this evaluation, the SLP sets goals that may include mastering spoken language and/or learning nonverbal communication skills, such as signs or gestures.

For those who have trouble communicating with speech, speech-language pathologists determine the best device and method for training on use of an **assisted communication device**. For people with more speech, therapy may focus on effectively using communication. In each case, the goal is to help the person communicate in more useful and functional ways. Speech-language pathologists can provide therapy one-on-one, in a small group or in a classroom setting.

SLPs can help a child learn to communicate through **augmentative and alternative communication (AAC) devices** or strategies. AAC refers to all forms of communication outside of verbal speech and may include:

- Speech-generating devices
- Picture cards
- Computers
- Tablets
- Apps on mobile phones

Occupational therapy

Occupational therapy (OT) addresses a combination of cognitive, physical and motor skills. Its goals include helping a person increase independence and participate more fully in life.

For a young child with autism, occupational therapy often focuses on skills related to:

- Appropriate play
- Learning
- Self-care

Therapy begins with a certified occupational therapist evaluating the person, including their:

- Developmental level
- Related learning styles
- Social abilities
- Environmental needs
- Family needs



Based on this evaluation, the therapist determines goals and selects strategies and tactics for enhancing key skills. For example, goals may include:

- Independent dressing
- Feeding
- Grooming
- Use of the toilet
- Improved social skills
- Improved fine motor skills
- Improved visual perceptual skills

OT sessions often are 30 minutes to one hour long. The number of sessions per week is based on the person's needs. Strategies and skills learned are then practiced at home and in other settings, including school.

Sensory integration therapy

Many children and adults with autism have difficulties processing sensory information, such as movement, touch, smell, sight and sound. **Sensory integration (SI)** therapy uses a variety of techniques that improve how the brain interprets and integrates this information. Occupational therapy often includes sensory integration.

Certified occupational and physical therapists provide SI therapy. They begin with an evaluation to determine a person's sensitivities. From this information, the therapist plans an individualized program that matches sensory stimulation with physical movement. This can help improve how the brain processes and organizes incoming information. The therapy often includes equipment such as swings, trampolines and slides.

SI therapy can help those with sensory issues better manage 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

Many autistic people 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. PT 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. PT sessions often run 30 minutes to one hour long. They include assisted movement, various forms of exercise and the use of orthopedic equipment. The number of sessions per week is based on the individual's needs.

Feeding therapy

Feeding issues are common in children with autism and can lead to nutrition problems. Feeding can be stressful for the child and the family. Among others, feeding issues include:

- Difficulty chewing
- Difficulty swallowing
- Challenges trying new foods or textures
- Distress at mealtimes

Feeding therapy can help people develop more effective eating routines and behaviors. Evaluations can determine the causes of feeding problems, including:

- Medical problems
- Behavioral challenges
- Sensory issues



Talk to your child's health care provider about the benefits of feeding therapy. Overcoming feeding issues can improve overall health and decrease challenging behaviors.

More information about feeding therapy, including things you can do at home to help your child with the feeding process, can be found in [Parent's Guide to Feeding Behavior in Autism](#) from the Autism Speaks Autism Treatment Network at autismspeaks.org/tool-kit.

Researchers are looking at the effects of a **gluten-free, casein-free (GFCF) diet** for people with autism. Many families have found their children's comfort level and behaviors improved with this eating plan. But it does not work for everyone. While the GFCF diet has been used in the autism community for a few decades, it has not been shown to improve autism symptoms or behaviors in controlled group studies. Talk to a dietician or your child's health care provider about the GFCF diet.

Social skills training

Individuals with autism often have a trouble with social interactions. **Social skills training** in one-on-one and peer group settings is a common treatment. Social skills training focuses on both simple skills, like making eye contact, and more difficult skills, like inviting a friend to play.

Social skills training is not an official or certified form of therapy. But social workers, speech-language pathologists and psychologists often include it when treating children and adults with autism. Parents, family members and other caregivers can learn how to include social skills training in and outside the home. There is a growing literature supporting the effectiveness of social skills therapy in improving social behavior in cognitively-able individuals with autism and additional research is underway.

How do I choose the right treatment?

You want to do everything possible to help your child. Many parents in your position are eager to try new treatments, even if they've not been proven to be effective. Your hopes for your child may make you willing to try untested treatments.

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. Speak with your child's health care provider, 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** they have tried. This may include some 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 rigorous scientific study, it has become clear that none of these "cure" claims are valid. In fact, some unproven methods have been found to be harmful for many, so it is very important to discuss all these ideas with your child's health care provider before trying them. Look for scientifically valid evidence, meaning published research studies, behind treatments you are interested in. If you conduct your own research, make sure your sources are established and reliable, such as websites that end in .gov, .edu or .org. If you want to consider a specific intervention or treatment, find out if there is scientific evidence to back it up.

Choosing a treatment for your child may feel overwhelming. Work closely with your child's health care provider and other professionals involved in their treatment to explore all the options. Your child's path likely will look different from the path of other autistic children you may know. Focus on finding the services and supports that are right for your child and your family.

Autism and insurance

While effective therapies for autism exist, these services are not consistently covered by **health insurance**. The time and energy often needed to ensure that prescribed services and supports are covered can complicate what may already be a stressful time for your family.

Since 2007, Autism Speaks has focused on improving health insurance coverage for medically necessary treatments such as applied behavior analysis (ABA). As of August 2019, all 50 states require meaningful coverage for autism therapies, including ABA, under state-regulated health insurance plans. Unfortunately, not all plans have to comply with state mandates. And many mandates exclude certain plan types or impose caps that may affect your coverage.

Your type of health insurance plan impacts how you advocate for a change in benefits, as well as how you appeal denials of coverage and to whom you file complaints if you are not satisfied with implementation of benefits. For example, if you are covered by a self-funded or employer-based plan, you would advocate at the level of your employer, while under a fully insured plan, such as Medicaid, it is usually necessary to advocate for change through state law or regulation.

Find out about what your health insurance covers and how best to advocate for autism benefits. If you don't already know what type of health insurance you have, visit our **Health Benefits Guide**. Click on the link to your plan type to find online resources that can help you find out what your plan covers for autism treatments and therapies. This can be found at autismspeaks.org/health-insurance-coverage-autism.

Families who are covered under a Medicaid plan should know about the **Early and Periodic Screening, Diagnostic, and Treatment (EPSDT)** benefit. This benefit essentially means that if your child is under the age of 21, they are entitled to receive any health care services that are medically necessary. This includes medically necessary services for autism. If a child is suspected to have autism or another developmental disability, their Medicaid plan should cover any necessary assessment and treatment services. For additional information, email advocacy@autismspeaks.org.



Section 6

Autism and the Classroom

- *Special education eligibility*
- *Individualized Education Programs (IEPs)*
- *Transition services*
- *Setting up school services*

Education plays a critical role in a child’s life and future. Your child’s autism diagnosis does not change that. Federal law ensures that children with autism and other special needs receive an education that works for them.

The **Individuals with Disabilities Education Act (IDEA)** mandates a public education for all eligible children and makes the schools responsible for providing the supports and services to allow this to happen. Under IDEA, your child is entitled to a **“free appropriate public education”** in the **“least restrictive environment.”**

A “free appropriate public education” may include:

- placement in a mainstream and/or special education classroom at a public school with appropriate modifications or accommodations to meet a child’s specific needs;
- placement at a private school (at public expense, if your school district cannot provide an appropriate placement in a public school); and/or
- the provision of related services (such as speech, occupational therapy, physical therapy, counseling services, mobility services and/or transportation).

The “least restrictive environment” requirement is to ensure that a child is not unnecessarily put in isolation or removed from his peers. Under IDEA, he must be integrated into mainstream classroom environments (with appropriate supports and accommodations) as much as possible.

Special education eligibility

It is important to note that an autism diagnosis does not mean your child will automatically qualify for special education services.

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 healthcare provider. To get an educational diagnosis

and access to services, an educational determination of disability must be made by a multidisciplinary team of school professionals.

You will need to request a school evaluation for your child after your child’s medical diagnosis so they 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 their 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 rights to the special education services that will provide them with an effective free and appropriate public education.

If it is determined that your child is eligible for special education services, a meeting will take place to develop an initial **Individualized Education Program (IEP)** that lays out what those services will be.

Individualized Education Programs

An **IEP** is a plan that determines the special education services, supports and accommodations that a student with special needs will receive to ensure the best possible education at school. Once it is determined that your child is eligible for an IEP, you will work with your school to develop a plan that best addresses your child’s unique strengths and challenges.

IDEA establishes an important team approach to education. You, as a parent, are an equal partner with the school district in defining an education plan to meet your child’s individual needs. This enables you to be a powerful advocate for your child. It also

means that you must be an informed, active participant in planning and monitoring your child's progress and legal rights. The IEP spells out your child's education needs and how these needs will be met.

An IEP will describe your child's strengths and challenges based on evaluations and set goals and objectives. It will also detail, how these can be met through services such as SLT and OT, as well as specific special education supports, counseling and social skills training. Meaningful and measurable goals make for an effective IEP and a successful IEP process. The goals will be both academic and functional.

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 their needs have changed. These re-evaluations help when modifying your child's IEP so that they have continued access to the special education services that will help achieve the best possible outcomes.

A **504 plan** is another resource that will help your child access services and supports at school. This plan outlines the accommodations your child receive so they can learn to the best of their ability in a supportive environment. Even if your child does not require specialized instruction as outlined in an IEP, the 504 plan will lay out specific services that will be provided to help support them both in and out of the classroom.



Questions to consider in developing an effective IEP

The following is an excerpt from Autism Speaks Guide to Individualized Education Programs, which can be found at autismspeaks.org/tool-kit/guide-individualized-education-programs-iep.

Placement: Where is the best place for my child to learn?

- Should my child be in a mainstream or special education class? Both?
- Should they 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?
- What type of classroom or behavioral or teaching support(s) and accommodations does my child need to be supported in the least restrictive environment?

Class content: What is and isn't appropriate for my child to learn?

- 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 supports does my child need?

- Assistive (augmentative) technology and consultative support
- Speech and language, physical or occupational therapy
- Psychological or mental health support
- Art, music or dance therapy
- After school or weekend services
- School social work services
- Recreational support
- Safety training
- Transportation

Transition services: What services/supports does my child need now to be ready to (consider if appropriate):

- Live on his own?
- Go on to higher education?
- Work?
- Participate in the community?

Transition services

As your child enters their 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 their 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 them to learn and grow. This type of planning should take place around 12 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.

Important things to consider when transition planning

1. Develop self-advocacy skills at school.

Self-advocacy is an important skill for people with autism. It means asking for what they need to help them learn and be successful. The classroom is a place to learn these skills. Ask to include self-advocacy goals in your child's IEP so that teachers will help them learn how to advocate for themselves to the best of their abilities.

2. Practice life skills at home and in the community.

Learning to do chores at home, like cooking and laundry, can help your child prepare for adulthood. At the same time, developing skills like shopping and managing money, can help them be active in the community. If your child has an IEP, you can ask for a **community skills assessment** as part of their **IEP transition plan**.

3. Encourage your child to participate in education and IEP meetings to the best of their ability.

It is important that students have a voice in their education, including at IEP or 504 plan meetings. At these meetings, make sure the IEP team works with your child to make decisions about their education. Your child can share their goals, ideas, opinions or requests for support.

4. Develop strategies for independent living.

Keys to a successful transition to independent living include being able to plan, organize and manage time. Creating and following routines can make it easier to remember and complete tasks. Try different supports to find out what works best for your child, like visual prompts, color-coded schedule or organizer, or scheduling or calendar apps.

5. Be active in the community. Being active in the community will help your child build skills they will need when they start to work. Participating in community programs can help your child meet people and make friends and other social connections. Exploring their likes, dislikes and interests through community activities can help them think about what kind of job they may want in the future.

Three great transition resources from Autism Speaks are:

Transition Tool Kit: a guide for families of children between the ages of 13 and 22 to help with the road to adulthood.

Community-based Skills Assessment: a tool 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.

Transition Roadmaps: personalized, interactive tools that provide a series of goals and resources up to age 22 to help get ready for employment, housing and postsecondary education

All of these transition resources and more can be found at autismspeaks.org.

Setting up school services

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 them to have a positive and successful educational experience.

Once your child is diagnosed, it is crucial to make sure they have 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 their teacher can provide the best and most effective education possible.

When telling your child's teachers and other school professionals about their diagnosis, be sure to provide them with helpful information. It is also important to cover both your child's strengths and weaknesses when discussing the best ways to support them 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.

The kit can be found at autismspeaks.org/tool-kit/school-community-tool-kit.



Section 7

Living with autism

- *Creating your team*
- *Managing your team*
- *Technology*
- *Talking to your child about bullying*
- *Recreation*
- *Strategies to support your child*
- *Autism and wandering*
- *Conclusion*

Raising a child with autism requires support from family members, friends and professionals. It can help to build a “team” of people who work together to be sure your child’s needs are being met and that they are making progress toward their goals. The team should be focused on helping your child overcome their challenges and build upon their strengths and abilities.

Creating your team

Your child’s team will have lots of members. Team members focus on different areas of your child’s life. And they can help you make decisions about your child’s treatment, education and health.

Medical team

Your child’s primary care provider likely is a pediatrician who understands autism and developmental issues. Depending on your child’s needs, other medical team members may include:

- **Neurologist**
- **Geneticist**
- **Developmental pediatrician**
- **Gastroenterologist**
- **Psychiatrist**
- **Nutritionist**

Behavioral intervention team

Behavioral therapists who provide ABA and other interventions play a critical role in your child’s treatment and development. Depending on the intensity of the primary intervention, there may be an intervention leader who will also structure treatment sessions that are provided by other therapists. Intensive intervention programs often start with a one- or two-day training course where individual therapists are trained by the primary intervention leader.

Related services team

Therapists and other professionals providing related services to your child should be included on your team as well. Related services your child might receive include:

- **Speech-language therapy**
- **Occupational therapy**
- **Physical therapy**
- **Sensory integration therapy**
- **Social skills instruction**

All therapists working with your child should be communicating frequently and using a consistent method of teaching.

Managing the team

Your participation on your child’s support team is critical. Understanding your child’s treatment can help you use the interventions at home. Understanding treatment goals can help you monitor your child’s progress and evaluate team members.

Team communication

Open communication between your child’s team and your family is important. It ensures that everyone is on the same page about your child’s goals and progress. Ways to maintain consistent communication include:

Shared notebook/online document. Many families use a shared notebook to foster team communication. Each therapist records information after their session with your child. Other therapists can then read the notes before their own sessions. Parents can add information, too, so that all team members are informed.

Team meetings. Another way of maintaining communication is through regular team meetings. These can happen at your home, especially if your child’s services are home-based. These meetings should include as many team members as possible. This can help ensure that your child’s therapists are up to date on every aspect of treatment and that they are all working with your child in consistent ways. At team meetings, you can discuss what is and isn’t working and make changes to your child’s program, as needed.

Making therapies work for the entire family

From Overcoming Autism

by Lynn Kern Koegel, Ph.D. and Claire LaZebnik, Ph.D., 2014.

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.

Technology and autism

Technology is a valuable tool in treatment and daily living for people with autism. Computers and devices like tablets and smart phones are helpful in many areas, including behavior tracking, scheduling and communication.

Many autistic people use technology to help with communication. Some parents worry that using a speech or communication device may prevent their child from developing speech. In fact, it's the opposite: Research shows that using technology as a communication aid can help children increase their speech skills.

Talk with your child's treatment team about how to use technology as part of your child's treatment. They can help you evaluate what method may be best for your child.

Autism Speaks has developed an **Assistive Technology for Communication Roadmap** to help you understand different types and methods of obtaining assistive technology for your child. This tool can be found at autismspeaks.org/worksheet/assistive-technology-communication-roadmap.



Strategies to support your child

There are a number of tools and strategies you can use in your daily life to help support your child. These strategies can help increase positive behaviors and limit challenging behaviors. Some of these include:

Positive behavior supports

Research has shown that the use of **Positive Behavior Supports (PBS)** is an effective way to manage challenging behavior. PBS involves identifying the function of a problem or challenging behavior and then teaching the person new skills to help correct the behavior and respond with a positive one instead. 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 their team to try to identify these causes so you can develop a plan to teach them 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 them 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 them to comprehend the sequence of events without your prompting.

Similarly, checklists can help manage your child's time and prepare them in advance of situations that may present difficulties. They 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 them 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 them 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.

Recreation

Being a part of a community is an integral component to a happy and healthy life. Autism does not change that. It is important for your child's wellbeing to try to get them involved in your community in ways that are right for them. Community activities are great opportunities for your child to learn skills that will be beneficial to them now and as they transition into adulthood.

Recreation can be particularly important for people with autism, drawing on opportunities to practice social skills, physical aptitude and increase motivation. These activities can also help increase your child's self-confidence. Some parents assume their autistic child will not enjoy or be interested in recreation activities. It may be difficult to find the right fit, but the benefits of these community programs will outweigh the challenges you might face finding an activity that works for them.

10 tips for finding the best recreation program for your child

1. Let your child take the lead. As a parent, one only wants what is best for their child. However, it is essential to consider your child's interests, abilities and strengths. Whenever possible, talk about the different sports programs that are available and include your child in the decision-making process.

2. Set realistic expectations. For your child to be able to grow in the program, it is important to set goals that are realistic and within reach. In this way, you are setting your child up for success!

3. Communication is key. When researching information about programs, communicate with the instructors or coaches. Be up front with them from the start and let them know about your child's strengths and challenges. Inform them about what works and what doesn't and see if they are a good fit for your child.

4. Try it out. Communicate with your child about trying out the program. Since many children with autism can have a tough time with transitioning, they may become anxious or nervous about going somewhere or doing something. It may help to let the child know what they will be doing to prepare them for any changes that can occur. Many parents and teachers use a visual schedule in the form of pictures, to outline their daily activities.

5. Chat with other parents. Word of mouth is one of the best tools at your disposal. Talking with the other parents is a great way to really get to know what the program is about. Asking them about their experiences can provide you with a lot of great information.

6. Class size matters. When trying out the program, whether it's a class or a team, consider the student-teacher ratio. Having only one instructor for a big group can make it difficult to provide individualized attention. Unless the program encourages parent participation, it is beneficial to have assistant instructors present, to help manage the class/practice.

7. Safety first. If the sport requires use of any equipment, examine if it is safe and in good repair. Also, consider the facilities and check to see if they are clean and hygienic. Communicate any medical conditions or allergies to the instructors beforehand and keep a first aid kit with you.

8. Be flexible. Understand that at first, your child may not be able to do everything the other children can do. Working on too many points of detail at once, or spending too much time on a task, may be overwhelming and cause frustration. Talk to the coach/instructor and see if skills and activities can be broken-down into smaller, more manageable sections, so your child can feel successful each time. If you see your child become frustrated or fatigued, have the coach allow for a short break and go with the child's pace.

9. Go the extra mile. Whenever possible, help your child with autism raise his skill level by practicing at home. Keep it fun and stress free. In the beginning, it may also help to arrange a private lesson or two with the coach. This will provide him with individualized attention and prepare him to be in a group setting.

10. Be patient and stay positive! If initially it seems like your child is not progressing as much, keep at it and use lots of encouragement. Everyone, including adults like being recognized for doing something well. Therefore, use lots of praise and high fives! Even if your child has not fully mastered the skill, reward the effort.

Bullying

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 is adapted from a Special Needs Anti-Bullying Tool Kit produced by the partnership.



Talking to your child about bullying

It is critical to help your child recognize the signs of bullying. Children may not always realize that they are being bullied. They might think it is bullying only if they are being physically hurt; they might believe the other child is joking; or they may not understand the subtle social norms and cues. Children can benefit from a definition of the differences between friendly behavior and bullying behavior.

The basic rule: Let children know if the behavior hurts or harms them, either emotionally or physically, it is bullying.

Parents can prepare themselves to talk with their children by considering how they are going to respond to their child's questions and emotions. They can also decide what information they would like to give their child about bullying. Parents should be ready to:

Listen. It is the child's story; let him or her tell it. They may be in emotional pain about the way they are being treated.

Believe. The knowledge that a child is being bullied can raise many emotions. To be an effective advocate, parents need to react in a way that encourages the child to trust.

Be supportive. Tell the child it is not his fault and that he does not deserve to be bullied. Empower the child by telling her how terrific she is. Avoid judgmental comments about the child or the child who bullies.

Be patient. Children may not be ready to open up right away. The child might be feeling insecure, withdrawn, frightened, or ashamed.

Provide information. Parents should educate their child about bullying by providing information at a level that the child can understand.

Explore options for intervention strategies. Parents can discuss options with their child to deal with bullying behavior.

Find the full article and many more bullying resources for you and your child at specialneeds.thebullyproject.com. Learn more about bullying and supporting students with autism in the [Autism Speaks School Community Tool Kit](#).

Autism and wandering

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. Safety is a critical part of everyone's life at home and in the community. Being aware of surroundings and taking precautions to stay safe are even more important for people with autism and their families. Work with your child's treatment team to create a safety plan for your child.

Wandering, or leaving a safe place alone, is a major concern in the autism community. For more information about safety and wandering, visit autismspeaks.org/safety.

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

While there are many obvious ways to help keep your child safe at home (door locks, fences, neighbor alerts, etc.), it is also critical to put in place a plan to help keep them safe at school.

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

1. **Address wandering issues in your child's 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.

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.



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? Where would they 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, be sure to voice your concerns.

6. **Introduce your child to all security staff.**

Provide the security team with more information about your child, such as how to calm them down, whether or not they respond well to touch, sound, etc.

7. **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.

Conclusion

Your child's diagnosis may leave you with many different emotions. No matter what, remember that you are not alone. Others have gone down this road before you. You are stronger than you think. You can learn how to overcome challenges and best meet your child's needs to help them live as fully and independently as possible.

You may 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 autistic people succeed. Advances are being made every day in the field of autism research, including many studies looking into new treatments and interventions.

Above all, your child will amaze you with progress both great and small. You and your child may face challenges, but you will also experience moments of great joy.

You will learn to celebrate your child's unique perspective, strengths and interests and have the privilege of guiding them as they grow into a wonderful, special human being.

We offer a number of resources and tool kits on our website to help you navigate this journey with your child.

This 100 Day Kit is only the beginning. And the Autism Response Team is ready to answer your questions and connect you with resources.

Call [888-288-4762](tel:888-288-4762) (en Español [888-772-9050](tel:888-772-9050)) or email help@autismspeaks.org. A team member is happy to help you at every step of the way.

A Week-by-Week Plan for the Next 100 Days

Getting organized

You may already have a lot of information about your child and about autism in general. Organizing paperwork and your child's records can help you manage their care and progress. Use a simple system, like a binder and dividers, to keep all the information in one place. To get started, you may need to get supplies, like:

- A binder
- Dividers
- Paper
- Pens

Your binder

If you're using a binder, you may want to organize all the paper and information by year and by subject. Here are some subjects you may want to include:

Contacts. This is information about how to contact your child's service providers and caregivers. You may want to include it in your cell phone contacts. Information can include:

- Addresses
- Phone numbers
- Email addresses

Schedules. This is information about dates and times to remember. You may want to include it in your cell phone calendar. Information can include:

- Therapy and other appointments
- Program start and end dates
- Deadlines

Diagnosis. This section includes medical documents and prescription information, if your child takes medication for any symptoms of autism or other physical or mental health conditions.

Therapy. This section can include information about therapies your child receives. You may want to have a separate section on each one, like:

- ABA
- Speech therapy
- Occupational therapy
- Sensory integration

Individualized Education Program (IEP). This section includes documents related to your child's IEP (for children age three and older).

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 also may want to summarize your child's progress in therapy and at school with cover sheets in each section.

Using your weekly planner

The weeks and action items in this planner may be different than your child's actual care. This is okay. Every child is different. Your plans depend on things like:

- Your child's age
- Your child's symptoms
- Where you live
- How long it takes to get evaluations and services

You can adjust your planner, as needed, to respond to and meet your child's needs. Follow the steps listed for each week. You also can add your own steps and notes along the way.

Start now.

Week 1

Complete evaluations.

- If your child hasn't had a complete evaluation, you might want to schedule one to learn as much as you can about your child's strengths, challenges and needs across a variety of areas. Get started right away. There may be a waiting list for evaluations and services. It's okay to put your child's name on several lists and then take the earliest appointment.

Get Special Education services.

- Contact your local school district about EI or special education services. Your school district will require that your child undergo the district's evaluations, separate from the medical evaluations, at their expense, to determine your child's eligibility for services. This can be a long and time-consuming process but may be useful in further determining the services your child needs.

Keep a record of phone calls.

- Make some time each day for phone calls to set up evaluations and begin services.
- Track your calls. Write down the day and time of each call you make.
- Make a note of when to make a follow-up call.

Start a video record.

- Take videos of your child that show a range of behavior in different settings, including at home, at school and at therapy.
- Record good and not-so-good behavior. Later, you can review your child's behavior over time.
- Make new recordings every three months. Use the video to track your child's progress and to track what therapies work or don't work for your child.

Week 2

Get support.

You can get support from:

- A parent support group
- A parent mentor
- A Special Education Parent Teacher Association (SEPTA) which may offer informational meetings and parent outreach

Get services.

- Ask for new services or follow-up on services you've already requested.
- Check to find out where your child is on waiting lists and what programs are available.
- Track your phone calls and when to make a follow-up call.

Learn about treatment options.

- Get information online from trusted sources, such as websites ending in .gov, .org or .edu. Be sure to check that the options are evidence-based.
- Speak to your child's providers. Learning about your child's treatment can help you make informed decisions for your child and your family.
- Join online groups and ask questions. Sharing experiences with others can help you feel more confident about your child's treatment and progress.
- Contact the Autism Speaks Autism Response Team. Our trained staff can answer questions and help you find local resources.

Call: 1-888-AUTISM2 (1-888-288-4762)

En Español: 1-888-772-9050

Email: help@autismspeaks.org

Week 3

Get services.

- Ask for new services or follow up on services you've already requested.
- Check to find out where your child is on waiting lists and what programs are available.
- Track your phone calls and when to make a follow-up call.

Play with your child.

Play is an important part of any child's development. For a child with autism, it's a critical part of learning social skills and how to interact with others.

Spend time with your other children.

Autism affects your whole family, including your other children. Take time alone with them to:

- Ask them how they're feeling.
- Take time to support their interests, activities and engage with their friends.

Week 4

Build your team.

Continue to add members to your child's care team, including:

- Health care providers
- Therapists and other service providers
- Teachers

Observe your child's therapy sessions to identify new team members.

Talk to other parents to help you find therapists and other providers.

Start your child's therapy even if you don't have every team member in place before.

Visit our Resource Guide to find resources and services in your area.

Create a safety plan.

- Read the section of this kit about safety.
- Look around your home for possible safety hazards.
- Identify any triggers that might lead your child to wander or exhibit other unsafe behavior. Develop strategies to eliminate these triggers as best you can.
- Contact local police and fire departments to tell them about your child's needs to help ensure your child's safety.

Visit autismspeaks.org/safety for more resources.

Plan some time away.

It's okay to spend some time away from your child. Taking care of yourself can help you better care for your family. Even if it's just going for a quick walk by yourself, taking a break can help you re-energize for the rest of the day.

Week 5

Continue building your team.

See Week 4.

Find out about your insurance.

- Contact your health insurance to find out what therapies are covered. Your health insurance may cover therapies or services not covered by your child's IEP.
- Keep track of your insurance claims. You may want to create a separate binder to keep track of insurance forms and paperwork.

Know your child's legal rights.

Familiarize yourself with your child's rights. There is a wealth of information available, including on the Autism Speaks website. Learn your rights to special education services. You may find out your child is entitled to services you weren't aware of or hadn't considered. Understanding your rights can help you ensure that your child is getting all of the services to which they are entitled.

Do something for you.

- Be proud of what you've done in the first month since your child's diagnosis. It may have been one of the most challenging months of your life. But you did it!
- Take care of yourself. Do things that you like to do, especially things you did before your child's diagnosis.
- Ask family and friends for help. They may want to help but aren't sure what to do. Be direct and tell them exactly what you need.

Week 6

Continue to learn about treatment options.

- Look for information online.
- Talk to your child's provider.
- Go to a workshop or conference about autism in your area.
- Contact our Autism Response Team.

Connect with other parents.

- Join a support group either in person or online. Being with people who know what you are going through will help you stay strong. You can learn a lot from hearing other people's stories.
- Spend time with a parent who has had experiences like yours. Your child's health care providers or therapists may be able to connect you with other parents in similar situations.

Find childcare.

- Get a babysitter who has experience caring for autistic children. Ask parents, people in your support group and your child's health care provider to help you find someone.
- Do a test run. When you find a sitter, plan a short night out.
- If you already have a babysitter, invite them to spend time with you and your child so they can learn how to care for your child.

Continue to build your team.

Continue to follow up on services and research any new possible providers.

Schedule a team meeting.

- Schedule a meeting with your child's therapists and caregivers. If you can't meet in person, ask them for help setting up a conference call. At the meeting:
 - **Set up lines of communication**, such as email or text message chains. Encourage them to communicate with each other as needed.
 - **Set up a communication schedule** so you are always on the same page with regard to your child's progress.
 - **Set measurable goals** for your child and determine how and how often you will follow up on them.

Week 7

Learn how to use your child's therapy methods.

- Use your child's therapy methods at home. This can help your child progress even between therapy sessions.
- Take parent training. Therapists often train parents on how to do therapies at home. Ask your child's providers for tips on how to best incorporate their strategies into your child's every day life.

Create a weekly schedule.

Keep a written schedule of your child's appointments. This will help you stay organized and on time. It can also help you plan for other members of your family.

- Keep the schedule in your binder or on your phone.

Continue learning about treatments and services

Consult the Autism Speaks website for contacts in your area.

Stay organized.

- Spend some time on your binder.
- Add paperwork and new tabs, as needed.
- Throw out things you don't need.

Week 8

Check your progress.

Look back through this plan. Is there anything you started that needs follow up?

Find recreational activities for your child.

- Find out about recreational activities for your child in your community, like gymnastics or swimming. Being active outside of home and school can help broaden your child's development. Some organizations have programs just for people with autism.
- Ask other parents about programs that their children enjoyed.
- Use our Resource Guide and our calendar of sensory-friendly events to find programs in your area.

Plan time with your other children.

Your other children will learn a great deal from having a sibling with autism. Maintaining as much normalcy as possible will help them reach their potential too. Help teach them that though their sibling may be different from them, they can still have an amazing relationship, it may just be different as well. Try to provide them with strategies to do so.

Stay connected with friends and family.

- Stay in touch with friends, neighbors and family. Talk to them often and make plans to see them.
- Keep up your social life as best you can.
- Be active in community events. Going out and being involved can help you feel less isolated.

Spend time alone with your partner.

- Plan a relaxing and fun activity with your partner.
- Celebrate your progress through month two!

Week 9

Continue to build your child's care team.

Continue to evaluate service providers and therapists.

Use the internet.

- Find online resources that are helpful to you. Add useful and trusted sites to your favorites in your web browser.
- Sign up for e-newsletters, list-servs and online communities where parents and professionals share information.

Continue to connect with other parents.

- Meet and spend time with other parents of autistic children. Being around other adults who share your experiences can help you build confidence and stay strong.
- Stay active with a support group, either in-person or online.

Check in on your child's sessions.

Continue to observe your child's therapy sessions. Your child should be getting used to their therapy routine by now.

Play with your child.

Continue to use the strategies you've learned from parent training sessions and other resources.

Week 10

Schedule a team meeting.

- Schedule a meeting to discuss progress and strategies.
- Stay involved with the team. Attend therapy sessions as often as you can. This can help you be better informed about your child's needs and goals for the team meetings.
- Encourage your team. Let them know you appreciate everything they are doing for your child.

Plan a family outing.

- Plan an activity that everyone in your family can do.
- Use the strategies you've learned from the care team to help your child participate.
- Ask your child's therapists to help you pick the activity and plan strategies that can help make it a success.

Learn more about the law.

Continue to learn about your child's legal rights to services.

Week 11

Check your child's progress.

- Note how long your child has been in treatment. It may be a full month by now.
- Review your binder and videos to look for improvements.
- Continue to attend therapy sessions. Take notes on what you see. Keep them in your binder and bring them to your next team meeting.

Dig deeper into treatment options.

- Set aside time to read more about treatments and therapies.
- Take notes and include them in your binder.

Week 12

Connect with your partner.

- Take some one-on-one time together.
- If you've had a hard time communicating with each other, see a counselor. A counselor can help you learn to share your feelings and help keep your relationship healthy.

Continue connecting with other parents.

Stay active in support groups. Parents are amazing resources and can give you emotional and day-to-day support.

If your group doesn't feel right to you or you need a different kind of support, look for another group. It's okay to have more than one or to feel more comfortable with one group than another.

Sign up for parent 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 their goals.

Week 13

Schedule a team meeting.

- Have a team meeting to check your child's progress. You should see progress after at least six weeks of consistent therapy.
- If you've seen little or no progress, talk with the team about adjustments to your child's therapies and routines.

Continue learning about autism and what works for your child.

Keep learning about autism. Books, seminars, movies, websites – all sorts of resources can help you deepen your understanding of autism and your child. See the Resources section of this kit for ideas.

Week 14

Do something for you.

Enjoy some "me" time. Do something nice for yourself. Celebrate your success through 100 days!

Comparing treatment methods & providers

Adapted from *Does My Child Have Autism?* by Wendy L. Stone, Ph.D. with Theresa Foy DiGeronimo, 2006.

About the program

Name of program/provider	
Method	
Location	
Phone number	
Email	
Website	
Hours per week	
Cost	
Reimbursement	

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?	

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.)	
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Personal 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?	

Parent involvement

Will I be able to participate in the treatment?	
Will you teach me how to work with my child? How?	

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?	

Service Planner

Agency & contact	Phone #	Date called	Requested services	Requested # of sessions and duration	Availability	Status	Follow-up	Other info

Service Planner

Agency & contact	Phone #	Date called	Requested services	Requested # of sessions and duration	Availability	Status	Follow-up	Other info

Contacts: Medical

Specialty	
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Name of practice	
Phone number	
Address	

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Contacts: Therapy

Specialty	
Name of contact	
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Phone number	
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Specialty	
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Contacts: Support

Specialty	
Name of contact	
Name of practice	
Phone number	
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Specialty	
Name of contact	
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Contacts: Other

Specialty	
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Phone Log

Name of contact _____

Phone number _____

Date and time

_____/_____/_____ a.m. p.m.

Summary _____

Follow-up required _____

Date and time

_____/_____/_____ a.m. p.m.

Summary _____

Follow-up required _____

Date and time

_____/_____/_____ a.m. p.m.

Summary _____

Follow-up required _____

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Summary _____

Follow-up required _____

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Phone number _____

Date and time

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Summary _____

Follow-up required _____

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Follow-up required _____

Phone Log

Name of contact _____

Phone number _____

Date and time

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Summary _____

Follow-up required _____

Date and time

_____/_____/_____ a.m. p.m.

Summary _____

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

Goal tracking: IEP

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 needed	Suggested next steps

Glossary

0-9

504 Plan

A plan that identifies accommodations (changes or adjustments) that a student with a disability needs to be successful at school. Students with a 504 plan don't generally receive an IEP or special education services. Students who don't qualify for an IEP may qualify for a 504 plan.

A

Accommodations

Changes or adjustments that help meet a person's individual needs.

Aggressive behavior

Hostile or violent behavior, including hitting others, destroying property, or throwing tantrums. Aggression is among the most common challenges reported by parents of children and adolescents with autism.

Allergy

A reaction by the immune system to something that does not bother most other people, such as certain foods, pollen or animals.

American Psychiatric Association

An organization of psychiatrists working together to ensure humane care and effective treatment for all persons with mental illness.

Americans with Disabilities Act (ADA)

U.S. law that ensures rights of persons with disabilities with regard to employment and other issues.

Angelman syndrome

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.

Antecedent

A verbal or physical stimulus, such as a command or request. The first in the three-step process used in Applied Behavior Analysis (ABA).

Anticonvulsant

A type of drug used to prevent or stop seizures or convulsions; also called antiepileptic.

Anxiety

Strong feelings of worry or fear about everyday activities. Anxiety disorder affects an estimated 30% of individuals with autism.

Applied Behavior Analysis (ABA)

A style of teaching using series of trials to shape desired behavior or response. Skills are broken into small components and taught the individual through a system of reinforcement.

Asperger syndrome

A developmental disorder, no longer used in the DSM-5, 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 DSM-5 indicates that individuals with a “well-established diagnosis” of this condition “should be given the diagnosis of autism spectrum disorder.”

Assisted communication device

A tool that helps you communicate with others. Examples include picture cards and electronic tablets that speak words that you type.

Attention deficit hyperactivity disorder (ADHD)

A disorder that affects approximately 1 in 5 children with autism. Symptoms include chronic problems with inattention, impulsivity and hyperactivity.

Audiologist

A professional who diagnoses and treats individuals with hearing loss or balance problems.

Augmentative and alternative communication (AAC)

Methods of communication for people who can't use speech (talking) to communicate; examples include sign language and using a computer for speech.

Autism Speaks Autism Treatment Network (ATN)

A collaboration of Autism Speaks and some of the finest children's hospitals and academic institutions in North America, specializing in multi-disciplinary medical care for children with autism.

Autism Spectrum Disorder (ASD)

Also called autism. A condition characterized by a broad range of challenges with social skills, repetitive behaviors, and speech and nonverbal communication.

Autism-risk genes

Specific genes that have been found to increase the risk of autism.

Autistic

A term that many people who meet the criteria for ASD have adopted to describe their differences.

B

Babbling

One of the first ways a baby communicates. Involves stringing together vowels and consonants such as “bababa” or “dadada”.

Baseline data

Measurement of a behavior before an intervention is begun. Progress is measured by comparing current behavior to baseline data.

Behavioral intervention

An intervention focused on increasing positive behavior and limiting challenging behavior, such as Applied Behavior Analysis.

Biomedical interventions

A range of treatment methods that address underlying medical conditions and biological processes, such as the gastrointestinal system, diet and nutrition, immune function and sleep.

Board-certified behavior analyst (BCBA)

A professional specialized in autism, certified and trained to write, implement and monitor a child's individualized ABA program.

Body language

Nonverbal communication through physical movements and gestures.

Brain abnormalities

Differences in typical features of the brain such as structure or functioning.

C

Casein

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

Childhood disintegrative disorder

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 DSM-5, but DSM-5 indicates that individuals with a “well-established diagnosis” of this condition “should be given the diagnosis of autism spectrum disorder.”

Chromosomal (single-gene) disorder

A disorder caused by a single gene. Examples include Fragile X syndrome, cystic fibrosis and muscular dystrophy.

Chromosome-15 duplication syndrome

A chromosome abnormality that occurs when an extra (duplicate) copy of the genetic material located on chromosome-15 is present in each cell.

Chromosome

An organized package of DNA found in the nucleus of the cell. Chromosomes are the physical carrier of genes.

Chronic constipation

An ongoing condition of having fewer than three bowel movements per week.

Cognitive behavioral therapy

A form of therapy that seeks to make changes in thoughts and perceptions of situations through a change in cognition or how thinking is processed.

Cognitive deficit

An inclusive term to describe any characteristic that acts as a barrier to mental skills such as acquiring information and knowledge.

Cognitive skills

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

Colitis

An inflammation of the large intestine.

Community skills assessment

An assessment that helps parents and professionals look at the current skill levels and abilities of students with autism related to participating in community life, such as self-advocacy, safety, transportation and leisure. The results will help you develop a unique and comprehensive plan.

Comorbid conditions

Different conditions that occur in the same person.

Complete Blood Count (CBC)

A lab test reporting number of white blood cells, red blood cells, platelets, hemoglobin, hematocrit and other values reflecting overall blood health.

Compulsions

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

Computed Axial Tomography

A medical test that examines organs by scanning with X rays and using a computer to construct series of cross-sectional scans. Called “CAT” scan.

Consequence

A result or effect of an action or condition. Consequences are used in behavioral therapy and can include positive reinforcement of the desired behavior or no reaction for incorrect responses.

Convulsions

Whole body shaking that can sometimes be caused by epilepsy or seizure disorder.

D

Daily living skills

Also called life skills or independent living skills. Skills that you need to manage your everyday life. Examples include self-care, home care, cooking and managing money and time.

Depression

A mental health condition that affects an estimated 7 percent of children and 26 percent of adults with autism. Signs can include loss of interest in once-favorite activities, a noticeable worsening in hygiene, chronic feelings of sadness, hopelessness, worthlessness and irritability.

Developmental disorder

Refers to several disorders that affect normal development. May affect single area of development (specific developmental disorders) or several areas (pervasive developmental disorders).

Developmental evaluation

A thorough assessment of current developmental concerns. It is often the first step of the autism diagnosis process.

Developmental milestones

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

Developmental pediatrician

A doctor who treats children with learning, developmental and behavior problems.

Diagnose

To find out if a person has or doesn't have a certain health or medical condition.

Diagnostic and Statistical Manual of Mental Disorders (DSM-5)

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).

Diarrhea

Loose, watery stools (bowel movements).

Dietary intervention

A change to a person's diet for health purposes such as the removal of dairy or addition of supplements. Some evidence suggests that GI issues may be helped by dietary intervention.

Digestive tract

The group of organs that food and liquids travel through when they are swallowed, digested, absorbed and leave the body as feces.

Disclosure

Telling others about your differences or disability.

Discrete Trial Training (DTT)

An ABA technique that involves teaching individual skills one at a time using several repeated teaching trials and reinforcers that may or may not be related to the skill that is being taught. DTT is the most traditional ABA technique.

E

Early and Periodic Screening, Diagnostic and Treatment (EPSDT)

A benefit that provides comprehensive and preventive health care services for children under age 21 who are enrolled in Medicaid.

Early Intervention evaluation

When an EI specialist looks at a child's skills and development to see if the child qualifies for (can get) EI services.

Early Intervention services

Services and supports for children from birth through age 3 who have developmental delays and disabilities. EI services can help children learn important skills for school and daily life. They can include programs to help a child learn physical and self-help skills and to communicate and interact with others.

Early Start Denver Model (ESDM)

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.

Electroencephalogram (EEG)

A test using electrodes on the scalp to record electrical brain activity. For diagnoses of seizure disorder or abnormal brain wave patterns.

Environmental factor

Any nongenetic influence. The role of environmental factors in the development of autism is a crucial area of study.

Epilepsy (seizure disorder)

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

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

Executive functioning

Brain processes that allow you to focus on a task, organize your ideas and solve problems.

Expressive language

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

Provided during breaks from school, such as during summer vacation, for students who experience substantial regression in skills during school vacations.

F

Feeding therapy

An intervention that helps teach people with feeding issues how to eat or eat better. This type of therapy is usually provided by a trained occupational or speech therapist.

Food intolerance

A food sensitivity that occurs when a person has difficulty digesting a particular food.

Fragile X syndrome

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

Free appropriate public education (FAPE)

Means that education must be provided to all children ages 3 to 21 at public expense.

G

Gastritis

Inflammation of the stomach.

Gastroenterologist

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

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

Gastrointestinal (GI)

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

Genetic

Pertaining to genes or heredity. We know that genetics strongly influence the risk for developing autism. However, genetics alone do not account for all instances of autism.

Geneticist

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

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

Global developmental delay

A diagnosis in children younger than 5, characterized by delay in two or more developmental domains.

Gluten

A protein present in wheat, rye and barley.

Gluten-free casein-free diet (GFCF)

A dietary invention that involves the removal of gluten and casein from a person's diet. Many families have found their children's comfort level and behaviors improved with this eating plan, though there is minimal scientific evidence that shows this diet directly improves symptoms of autism.

Grand-mal seizure

(See seizures)

H

Health insurance

Also called health coverage or a health plan. Helps pay for medical services for you and your family.

Hyperactivity

Characterized by constantly increased movement and impulsive actions.

Hyperlexia

The ability to read at an early age. To be hyperlexic, a child does not need to understand what they are reading.

Hyper-reactivity (hypersensitivity)

A tendency, outside the norm, to react negatively or with alarm to sensory input which is generally considered harmless or non-irritating to others.

Hypo-reactivity (hyposensitivity)

Lack of a behavioral response, or insufficient intensity of response, to sensory stimuli considered harmful and irritating to others.

Identity-first language

Terminology that leads with a specific part of a person's identity, such as "autistic adult". Some people with ASD prefer this type of language.

Immune system

A complex system within the human body that prevents or limits infection. Researchers are looking at the role of the immune system in increasing the risk of autism.

Impulsivity

A tendency to act with little or no consideration of the consequences. A defining symptom of ADHD.

Inattention

A lack of attention or difficulty sustaining focus. A defining symptom of ADHD.

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.

Individualized Education Program (IEP)

A plan that identifies programs, goals, services and supports to make sure a student with a disability gets a free and appropriate education at school.

Individualized Education Program (IEP) transition plan

Goals in a student's IEP that help plan for life after high school. Schools must measure and report on the goals.

Individuals with Disabilities Education Act (IDEA)

A U.S. law that makes sure that students with disabilities get free and appropriate education in public schools that meets their individual needs.

Intellectual disability

A term used when there are limits to a person's ability to learn at an expected level and function in daily life. An estimated 31% of children with ASD have an intellectual disability.

J

Joint attention

The process of sharing one's experience of observing an object or event, by following gaze or pointing gestures. Impairment in joint attention is a core deficit of ASD.

K

Kanner's autism

A term that refers to Leo Kanner, the first psychiatrist to describe autism.

L

Least restrictive environment (LRE)

Education for students with disabilities in a setting with students who aren't disabled (also known as mainstreaming), for as much time as possible and with additional services provided for success in school.

Locating device

A technological tool that can be used to follow a person's movements or to identify a person's location. Some parents and caregivers of people with autism prone to wandering use these to help keep them safe.

M

Magnetic resonance imaging (MRI)

A diagnostic technique using powerful electromagnets, radio frequency waves and a computer to produce well-defined images of the body's internal structures.

Mainstreaming

Where students are expected to participate in existing regular education 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).

Measurable outcomes

Specific results that can be clearly assessed using data and observation to evaluate the progress a person is making toward their goals.

Medicaid

A U.S. government program that provides health coverage to many Americans, including eligible low-income adults, children, pregnant women, elderly adults and people with disabilities. Medicaid is managed by each state, and each state sets its own program guidelines.

Medical identification bracelet

A bracelet that contains pertinent medical information, often worn by people who may not be able to communicate their medical needs and the appropriate responses required if they need medical attention.

Melatonin

A hormone 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.

Metabolic factor

Anything that influences a person's metabolism, the process by which the body gets energy from food and drink.

Microbiome

All the bacteria and other organisms that live on our skin and inside our digestive tract.

Modified Checklist of Autism in Toddlers (M-CHAT)

A screening tool for identifying young children who may be referred to a specialist for further evaluation and possible Autism Spectrum Disorder diagnosis.

Motivation

Wanting to do something.

Motor skills

The ability to move and control movements.

Multi-disciplinary team

A team of professionals often involved in the diagnosis or treatment of a person with autism across a variety of specialties, such as a neurologist, psychiatrist, developmental pediatrician and social worker.

N

National Institute of Mental Health (NIMH)

The largest scientific organization in the world dedicated to research focused on the understanding, treatment and prevention of mental disorders and the promotion of mental health.

Natural reinforcement

Reinforcement that occurs directly as a result of a behavior. Principles of ABA can be provided using natural reinforcement opportunities.

Neurologist

A doctor who treats children and adults who have problems with their nervous system. The nervous system includes the brain, spine, nerves and muscles.

Neuron

A specialized cell transmitting nerve impulses; a nerve cell.

Nonverbal communication

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

Nonverbal cue

(See nonverbal communication)

O

Obsession

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 snoring and gasping for breath. May cause daytime sleepiness. May increase risk of hypertension and heart problems.

Occupational therapist

Someone who helps people learn how to do daily living skills. OTs also can provide sensory integration therapy to help people process and react to sensations.

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.

P

Panic disorder

A type of anxiety disorder that causes panic attacks, which are sudden feelings of terror when there is no real danger.

Parent interview/questionnaire

Part of a diagnostic evaluation that involves speaking to the parent/asking them questions about their child, their concerns for their development and potential signs of autism.

Parent training

Programs that empower parents and provide them with strategies to help foster their child's development by increasing positive behaviors and limiting challenging behaviors. Research has proven that parent training is an effective intervention for the symptoms of autism.

Perseveration

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

Person-first language

Terminology that leads with the individual, such as "person with autism". Some people with ASD prefer this type of language.

Pervasive developmental disorders (PDD)

A 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.

Persuasive 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 a diagnosis of autism. The diagnosis is no longer used in the DSM-5, but DSM-5 indicates that individuals with a “well-established diagnosis” of these conditions “should be given the diagnosis of autism spectrum disorder.”

Petit-mal seizure (absence)

(See seizures)

Phobia

A type of anxiety disorder characterized by a strong, irrational fear of something that poses little or no real danger.

Physical therapy (PT)

A type of therapy that uses specially designed exercises and equipment to help patients regain or improve their physical abilities.

Pica

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)

A tool that helps people communicate with pictures.

Pivotal Response Treatment (PRT)

A therapeutic teaching method using incidental teaching opportunities to target and modify key behaviors related to communication, behavior and social skills.

Positive reinforcement

The introduction of something positive, such as praise or a reward, for completing a behavior or assigned task as a way of motivating the individual. An integral part of most behavioral therapy programs.

Pragmatics

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.

Predisposition

A genetic predisposition is an increased likelihood or chance of developing a particular condition due to the presence of one or more gene mutations and/or a family history.

Preoccupation

An engrossing or near obsessive interest in a topic.

Prevalence

The current number of people in a given population who have a specific diagnosis at a specified point in time. As of March 2020, the U.S. Centers for Disease Control and Prevention estimated autism prevalence as 1 in 54 children, including 1 in 34 boys and 1 in 144 girls.

Prompt

In behavioral therapy, a cue or hint meant to induce a person to perform a desired behavior.

Psychiatrist

A doctor who helps children and adults with mental health conditions, including problems with thinking, feeling and behavior.

R

Receptive language

The ability to comprehend words and sentences. It begins as early as birth and increases with each stage in development. These skills commonly emerge slightly ahead of expressive language skills.

Regression

Any loss of speech or social skills.

Respite care

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.

Restrictive and repetitive behavior

One of the first two diagnostic criteria for ASD, includes stereotyped or repetitive motor movements, insistence on sameness or inflexible adherence to routines, highly restricted, fixated interests or hyper- or hypo-reactivity to sensory input.

Rett syndrome

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.

Reward chart

A chart that lists goals and progress you make toward reaching them. When you reach a goal, you get a reward. For example, if your goal is to finish your homework each day for a week, you get a sticker or checkmark on the chart each day you finish homework. If you get a sticker or checkmark each day, you get a reward at the end of the week.

S

Seizure

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

Seizure, absence

A seizure that 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

A seizure marked by the person losing muscle tone and strength and unless supported, falling down. Atonic means lack of muscle tone and strength.

Seizure, subclinical (electrographic seizure)

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. Also called a grand mal seizure.

Seizure disorder

(See epilepsy.)

Self-advocacy

Being able to communicate your needs and preferences to others. It includes understanding your needs and legal rights, knowing what help and support you need, and communicating your needs to others.

Self-injurious behavior

A type of repetitive behavior that results in physical injury to a person's own body, often used for self-stimulating or self-soothing.

Self-regulation

Refers to both conscious and unconscious processes that have an impact on self-control.

Self-soothing behavior

(See stimming.)

Self-stimulating behavior

(See stimming.)

Sensory defensiveness

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 (sensory stimulation)

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.

Sensory integration

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 therapy

A therapy program used to improve ability to use incoming sensory information appropriately and encourage tolerance of a variety of sensory inputs

Sensory Processing Disorder (SPD)

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. SPD is not currently a medical diagnosis.

Separation anxiety

Excessive fear or worry about separation from home or an attachment figure, such as a parent or teacher.

Sign language

A complete, natural language that has the same linguistic properties as spoken languages, expressed by movements of the hands and face.

Sleep disorders

Any condition affecting sleep, such as sleep apnea, insomnia or narcolepsy.

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

Language used to interact with people.

Social communication skills

Skills needed to communicate with people. Examples include being able to have a conversation with someone; using non-verbal communication, like body language; and using language for different reasons, like to give information or to ask a question.

Social communication disorder (SCD)

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 cue

A verbal or nonverbal message communicated through ways such as body language, spoken expressions or facial expressions, that can be difficult for people with autism to interpret.

Social phobia

A mental health condition characterized by intense, persistent fear of being judged by others. Also called social anxiety disorder.

Social reciprocity

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

Social skills

Skills needed to communicate and interact with people; skills can be verbal (talking) and nonverbal (gestures, body language and appearance).

Social worker

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 Parent Teacher Association (SEPTA)

A parent-teacher organization within a school district that brings together people who are interested in special education and children with special needs.

Special education services

Instruction designed for children with disabilities. The services can include counseling and speech, physical and occupational therapy.

Speech-generative device

Unit of technology that allows a person to communicate by electronic voice generation.

Theory of mind: Refers to a person's ability to understand and identify the thoughts, feelings and intentions of others.

Speech-language pathologist

Also called a speech therapist. A trained professional who helps people with communication, language and social skills. They can do evaluations and provide treatment.

Speech-language therapy

A therapy 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 needs.

Spoken language

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

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.

Stimming (self-stimulating behaviors)

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).

T

Tactile defensiveness

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

Tuberous sclerosis

A genetic disorder that causes tumors, or growths, in the brain and other organs.

U

U.S. Centers for Disease Control and Prevention (CDC)

A government agency that protects U.S. citizens from diseases and health threats. The agency that compiles data for and releases autism prevalence numbers and other such figures.

V

Video modeling

A teaching strategy that involves an individual watching a video of someone completing a task or exhibiting a behavior and imitating the activity themselves.

Visual schedule

A support that uses pictures to show the steps needed to complete a task.

W

Wandering

Leaving a safe place alone, also called elopement.

Autism Speaks Tool Kits

Autism Speaks has developed a multitude of resources on a variety of topics to help support you and your family in every stage of life. Kits specifically geared towards families of school-age children include:

- Advocacy Tool Kit
- Autism-Friendly Youth Organizations Guide
- Challenging Behaviors Tool Kit
- Dental Guide
- Family Support Guides (for Parents, Siblings, Grandparents and Friends)
- Guide to Individualized Education Programs (IEP)
- Haircutting Training Guide
- School Community Tool Kit
- Special Needs Financial Planning Tool Kit

Autism Speaks Autism Treatment Network has also worked with medical professionals through its partnership with [Autism Intervention Research Network for Physical Health \(AIR-P\)](#) to create guides on subjects including:

- Applied Behavior Analysis
- Behavioral Health Treatments
- Blood Draws
- Electroencephalograms (EEGs)
- Feeding Behavior
- Managing Constipation in Children
- Medication Decision Aid
- Melatonin and Sleep
- Pica
- Safe and Careful Use of Medicine
- Sleep Strategies
- Toilet Training
- Vision Exams
- Visual Supports

Find all of these and more for other age groups at autismspeaks.org/tool-kit.



We're here to help.

1-888-AUTISM2 | En Español (888) 772-9050 | help@autismspeaks.org

To find resources, join a fundraising walk or make a donation, go to autismspeaks.org.

Connect with us [@autismspeaks](https://twitter.com/autismspeaks).