



100 Day Kit

For Families of Newly Diagnosed Young Children

My Autism Guide
SIGN UP



Information
based on
your needs

guide.autismspeaks.org

Table of Contents

Section 1: Introduction	1
• <i>Why was my child diagnosed with autism?</i>	2
• <i>How does an autism diagnosis benefit my child?</i>	2
• <i>How is autism diagnosed?</i>	3
Section 2: What is autism?	5
• <i>Definition</i>	6
• <i>Diagnostic criteria</i>	6
• <i>Prevalence</i>	7
• <i>Causes</i>	8
Section 3: Core signs and symptoms of autism	9
• <i>Social symptoms</i>	10
• <i>Communication difficulties</i>	11
• <i>Repetitive behaviors</i>	13
• <i>Common strengths</i>	14
• <i>Physical and mental issues that may accompany autism</i>	16
Section 4: Understanding your child's behavior	20
• <i>Developmental milestones</i>	22
Section 5: How do I respond to this diagnosis?	24
• <i>Reacting to the diagnosis</i>	25
• <i>Caring for the caregiver</i>	27
• <i>Supporting your other children</i>	30
• <i>Fifteen tips for families</i>	30
Section 6: How is autism treated?	33
• <i>Treatment options</i>	35
• <i>Applied Behavior Analysis and distinct subtypes</i>	35
• <i>Treatment for associated conditions</i>	39
Section 7: How do I get the help my child needs?	43
• <i>Benefits of early intervention</i>	44
• <i>Choosing the right treatment</i>	46
• <i>Getting services started</i>	49
• <i>Autism and insurance</i>	50
Section 8: Living with autism	51
• <i>Creating your team</i>	52
• <i>Managing your team</i>	52
• <i>Technology</i>	53
• <i>Safety</i>	53
A Week-by-Week Plan for the Next 100 Days	56
Helpful Forms	62
Glossary	79
Autism Speaks Tool Kits	95

Acknowledgments

We would like to thank the following for their review and feedback, which was critical to the development of the Autism Speaks 100 Day Kit.

*Daniel L. Coury, MD
Professor of Clinical Pediatrics and Psychiatry
The Ohio State University College of Medicine*

*Thomas Frazier, Ph.D.
Chief Science Officer
Autism Speaks
Professor, Department of Psychology
John Carroll University
Parent of child with autism*

*Amy Kurowski-Burt Ed.D., MOT, OTR/L
Associate Professor, Division of Occupational Therapy
West Virginia University School of Medicine*

*Leslie A. Markowitz, Psy.D., LP, BCBA
Pediatric Psychologist
HealthPartners/Regions Hospital*

*Donna Murray, Ph.D., CCC-SLP
Vice President, Clinical Programs
Autism Speaks*

*Valerie Paradiz, Ph.D.
Vice President, Services and Supports
Autism Speaks
Self-advocate
Parent of young adult with autism*

*Brigid Rankowski, MS
Self-advocate*

*Adrienne P. Robertiello
Special Health Care Educator
Children's Specialized Hospital
Parent of child with autism*

*Amy Rodda, Ph.D., CCC-SLP
University of Washington Department of Speech
and Hearing Sciences*

*Lydia Wayman, MA
Self-advocate*

We would also like to thank the following professionals for their contributions to the Autism Speaks 100 Day Kit:

*Lauren Elder, Ph.D., ABPP
Owner, Licensed Psychologist
Ascent Psychological Services*

*Kathryn Smerling, Ph.D., LCSW
Family Therapist*

*Stephen Shore, Ed.D.
Professor, Special Education
Adelphi University
Autism Speaks board member
Self-advocate*

We have also included contributions from the following books and websites:

*Autism Wandering Awareness Alerts Response and Education (AWAARE) Collaboration
awaare.nationalautismassociation.org*

*Does My Child Have Autism? A Parent's Guide to Early Detection and Intervention in Autism Spectrum Disorders
Wendy L. Stone, Ph.D. with Theresa Foy DiGeronimo, M.Ed.*

*Overcoming Autism: Finding the Answers, Strategy and Hope That Can Transform a Child's Life
Lynn Kern Koegel, Ph.D. and Claire LaZebnik*

*U.S. Centers for Disease Control and Prevention Learn the Signs. Act Early. Campaign
cdc.gov/ncbddd/actearly*

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 early 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 daycare provider or preschool teacher.

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.





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 or daycare provider 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 health care 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:

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 reason for 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 **early intervention programs** or your local school district.

- **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 health care 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.



Common strengths among people with autism

Along with the challenges that a person with autism may face, they also have areas of strength. It is not uncommon for autistic people to have exceptional skills in math, music, art and reading. These areas of expertise can be a point of great satisfaction and pride for people with autism. If possible, incorporate your child's areas of expertise into their everyday activities and use these skills whenever possible as a way for them to learn and excel.

Some common strengths and skills of autistic people include:

- Sharp memory, both long-term and ability to remember information
- Intense focus on task at hand
- Skills in STEM fields (science, technology, engineering and mathematics)
- Honesty
- Adherence to rules and directives
- Talents in areas of music (such as playing music from memory) and art (such as drawing or painting)
- **Hyperlexia** (ability to read at an early age)

How can my child have autism when he seems so smart?

From Does My Child Have Autism? A Parent's Guide to Early Detection and Intervention in Autism Spectrum Disorders

by Wendy L. Stone, Ph.D., with Theresa Foy DiGeronimo, M.Ed., 2006.

Right now, you might be thinking about all the things your child with autism learned at a much younger age than other children you know. And yes, you are right: there are also things that children with autism learn on their own much faster than their typically developing peers or siblings. For example, they can be very good at learning to pick out their favorite DVD from a stack, even when it's not in its case. They may learn at a very young age how to operate the remote controls to the TV so that they can rewind their videos to their favorite parts (or fast forward through the parts they don't like). They can be very creative in figuring out ways to climb up on the counter to reach a cabinet that has their favorite cereal or even how to use the key to unlock the dead bolt on the back door so they can go outside to play on the swing.

Clearly, these are not behaviors that you would even think about trying to teach a 2-year-old child. And yet some children with autism somehow manage to acquire these skills on their own. How can we understand this inconsistency between the things children with autism do and don't learn? How can a child who can't put different shapes into a shape sorter learn to turn on the TV and DVD player, put a DVD in and push the play button? How can a child who can't understand a simple direction like "get your coat" figure out how to unlock a door to get outside?

What accounts for this unique learning style? In a word: **motivation**. We all pay attention better to the things that interest us, so we become much more proficient at learning them. Understanding what is motivating to your child (all children are different) will be one of the keys to increasing their learning and their skills. Your child's special talents may be part of his unique and inherent learning style and nature.



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.

For additional information from the official journal of the American Academy of Pediatrics, on the evaluation, diagnosis and treatment of GI disorders in individuals with ASDs, go to: pediatrics.aappublications.org/cgi/content/full/125/Supplement_1/S1

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

Understanding your child's behavior

- *Developmental milestones*

As the parent or caregiver of a child with autism, it can be helpful to become familiar with developmental milestones of babies, toddlers and young children. These milestones can help you better understand your child's strengths and challenges, as well as specific areas for improvement. They can also help you see which parts of your child's development might be attributed to their autism diagnosis.

The U.S. Centers for Disease Control and Prevention (CDC) Learn the Signs. Act Early. campaign includes full lists of developmental milestones by age. Some of those lists are excerpted below. The CDC defines developmental milestones as "things most children can do by a certain age." For a more comprehensive list, visit [cdc.gov/actearly](https://www.cdc.gov/actearly).



By 6 months

- Knows familiar faces and begins to know if someone is a stranger
- Likes to play with others, especially parents
- Responds to other people's emotions and often seems happy
- Responds to sounds by making sounds
- Strings vowels together when babbling ("ah," "eh," "oh") and likes taking turns with parent while making sounds
- Makes sounds to show joy and displeasure
- Begins to say consonant sounds (jabbering with "m," "b")

By 1 year

- Is shy or nervous with strangers
- Cries when parent or caregiver leaves
- Has favorite things and people
- Shows fear in some situations
- Repeats sounds or actions to get attention
- Plays games such as "peek-a-boo" and "pat-a-cake"
- Responds to simple spoken requests
- Uses simple gestures, like shaking head "no" or waving "bye-bye"
- Says "mama" and "dada" and exclamations like "uh-oh!"

By 2 years

- Copies others, especially adults and older children
- Gets excited when with other children
- Shows more and more independence
- Plays mainly beside other children, but is beginning to include other children, such as in chase games
- Says sentences with two to four words
- Follows simple instructions
- Plays simple make-believe games

By 3 years

- Copies adults and friends
- Shows affection for friends without prompting
- Understands the idea of “mine” and “his” or “hers”
- Shows a wide range of emotions
- May get upset with major changes in routine
- Follows instructions with two or three steps
- Can name most familiar things
- Understands words like “in,” “on,” and “under”
- Says first name, age, and sex
- Names a friend
- Says words like “I,” “me,” “we,” and “you” and some plurals (cars, dogs, cats)

By 4 years

- Enjoys doing new things
- Is more and more creative with make-believe play
- Would rather play with other children than by himself
- Cooperates with other children
- Often can’t tell what’s real and what’s make-believe
- Talks about what she likes and what she is interested in
- Sings a song or says a poem from memory such as the “Itsy Bitsy Spider” or the “Wheels on the Bus”
- Tells stories
- Can say first and last name
- Remembers parts of a story

By 5 years

- Wants to please friends
- Wants to be like friends
- More likely to agree with rules
- Likes to sing, dance, and act
- Can tell what’s real and what’s make-believe
- Speaks very clearly
- Shows more independence (for example, may visit a next-door neighbor by himself [adult supervision is still needed])
- Is sometimes demanding and sometimes very cooperative
- Tells a simple story using full sentences

Section 5

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 health care 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 will not only change the way that you look at your child, it will 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.

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?

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





Telling people

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](#).

Fifteen 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.”

Section 6

How is autism treated?

- *Treatment options*
- *Applied Behavior Analysis and distinct subtypes*
- *Treatment for associated conditions, including speech, occupational and physical therapy*

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, classroom or preschool. 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 focused on decreasing bedtime resistance and anxiety 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. Experts recommend 25 hours of structured therapy per week for preschool-aged children.

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.

Below are three distinct types of ABA therapy:

1. Discrete Trial Training

Discrete Trial Training (DTT) is the most traditional ABA technique. It 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. DTT is also called the Lovaas method after its founder, Dr. Ivar Lovaas.

A **board-certified behavior analyst (BCBA)** specializing in autism writes, implements and monitors the child's individualized program. Therapists (often called trainers) will work directly with the child on a day-to-day basis. Trainers don't have to be board-certified, but they should be supervised.

DTT sessions are often two to three hours long and include short periods of structured time (three to five minutes) focused on a task. Short breaks are often taken during and at the end of therapy sessions. Free play and breaks are used for incidental teaching or practicing skills in new environments. Most DTT programs consist of 25 or more hours per week of therapy.

The principles and technologies of ABA can also be provided in a naturalistic fashion that is child-led and uses **natural reinforcement** opportunities. Two examples are Pivotal Response Treatment and Early Start Denver Model.

2. Pivotal Response Treatment

Pivotal Response Treatment (PRT) was developed by Dr. Robert L. Koegel and Dr. Lynn Kern Koegel of Stanford University. It was previously called the Natural Language Paradigm (NLP). This approach has been used since the 1970s. It is a behavioral intervention model based on the principles of ABA.

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

Rather than target individual behaviors, the PRT therapist targets "pivotal" areas of a child's development. These include

- Motivation
- Response to multiple cues
- Self-management
- Initiation of social interactions

By targeting these critical areas, PRT produces improvements across other areas of sociability, communication, behavior and academic skill building.

Motivation strategies are an important part of PRT. These emphasize "natural" reinforcement. 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.

Professionals specifically trained in PRT might include:

- Psychologists
- Special education teachers
- Board-certified behavior analysts
- Speech therapists
- Other providers

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

PRT programs usually involve 25 or more hours per week. Therapists encourage everyone involved in the child's life to use PRT methods consistently in every part of the child's life. Many families have described PRT as an adopted lifestyle for their family.



3. Early Start Denver Model

Early Start Denver Model (ESDM) is another naturalistic form of ABA. It is a behavioral early intervention approach for children with autism, ages 12 to 48 months. The program uses a curriculum that defines the skills to be taught and methods used to teach these skills. Therapy teams and/or parents can deliver both group programs and individual therapy sessions in either a clinic setting or the child's home.

ESDM was developed by psychologists Sally Rogers, Ph.D., and Geraldine Dawson, Ph.D. in 2010. The focus of ESDM is parents and therapists using play to build positive and fun relationships. Through play and joint activities, the child is encouraged to boost language, social and cognitive skills. Its core features include:

- Understanding of normal toddler learning and development
- Focus on building positive relationships
- Teaching during natural play and everyday activities
- Using play to encourage interaction and communication

ESDM is effective for autistic children with a range of learning styles and abilities. An ESDM therapist may be a:

- Psychologist
- Behavioral therapist
- Occupational therapist
- Speech and language pathologist
- Early intervention specialist
- Developmental pediatrician

What's important is that the provider has ESDM training and certification. Parents are a crucial part of ESDM programs. If your child is receiving ESDM therapy, the instructor can explain and model the strategies for you and your family to use at home.

ESDM programs usually involve 20-25 or more hours per week of scheduled therapy. ESDM is designed to be highly engaging and enjoyable for the child. Instructors teach skills within a naturalistic, play-based interaction. They teach some skills on the floor during interactive play and others at the table, focusing on more structured activities. As the child develops social skills, peers or siblings are included in the therapy session to promote peer relationships.

For other types of early intervention programs and other treatment modalities, visit autismspeaks.org/treatments.

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 *Medication Decision Aid*. 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 [Exploring Feeding Behavior in Autism: A Guide for Parents](#) 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.

Section 7

How do I get the help my child needs?

- *Benefits of early intervention*
- *Your child's rights to early intervention and special education*
- *Choosing the right treatment*
- *Getting services started*
- *Autism and insurance*

The road ahead will be bumpy. As your child grows up, you will celebrate many successes. And there may be times when progress stalls or takes an unexpected turn. When it does, remind yourself that these are speed bumps, not roadblocks. Take them one at a time.

Many services are available to treat and educate your child. After a diagnosis, start exploring services as soon as possible.

Getting services: Your child's rights

Early intervention services For children under the age of 3

The **Individuals with Disabilities Education Act (IDEA)** specifies that children with various disabilities, including autism, are entitled to **early intervention (EI)** and special education services. EI refers to services and supports for children from birth through age 3 who have developmental delays and disabilities. IDEA provides states with federal grants to offer EI programs.

EI services are designed to give children with disabilities the skills they need to adapt to and engage with the world around them. Services for your child may include, but are not limited to:

- Speech-language therapy
- Occupational therapy
- Physical therapy
- Applied Behavior Analysis (ABA)
- Psychological evaluation

Family services may include counseling and training sessions to help families understand autism and learn strategies to support their child.

EI services can vary widely from state to state and region to region. However, the services should address your child's unique needs and should not be limited to what is currently available where you live.

From Does My Child Have Autism? A Parent's Guide to Early Detection and Intervention in Autism Spectrum Disorders

*by Wendy L. Stone, Ph.D., with
Theresa Foy DiGeronimo, M.Ed., 2006.*

There is no debate or doubt: Early attention to improving the core behavioral symptoms of autism will give your child – and the rest of the family – several important benefits that you will not gain if you take a wait-and-see approach until your child enters school at age 4 or 5. A good early intervention program has at least four benefits:

1. It will provide your child with instruction that will build on his or her strengths to teach new skills, improve behaviors and support development in areas of weakness.
2. It will provide you with information that will help you better understand your child's behavior and needs.
3. It will offer resources, support and training that will enable you to work and play with your child more effectively.
4. It will improve the outcome for your child.

For these reasons, an intervention program for your child should be started as soon as possible after he or she receives a diagnosis. However, as you probably know by now, it can be very challenging to teach young children with autism. They have a unique profile of strengths and needs and require intervention services and teaching approaches that are sensitive to these needs. That's why strategies that worked for teaching your other children to remain seated at the dinner table, to play appropriately with a toy or to say words simply don't work as well for your child with autism. In the same way, intervention programs that are generic – rather than autism-specialized – are less likely to be effective for your child. That's why as you begin your exploration of early intervention, you must keep in mind that not all interventions are equal.

Your child must undergo an early intervention evaluation to determine if they qualify for services. After the evaluation, you will meet with your child's service providers to develop an **Individual Family Service Plan (IFSP)**. The IFSP is a document that spells out your child's needs and the services to be provided based on the EI evaluation. It describes your child's current levels of functioning and development goals. It also lists specific services to be provided to your child and your family.

To find EI services in your state, visit: autismspeaks.org/state-early-intervention-information.

Special education services For children ages 3 to 22

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.

It is important to note that an autism diagnosis does not mean your child will automatically qualify for special education services. Schools will need to conduct a special education evaluation to determine eligibility for services.

If your child is found to be eligible, the school will then use the evaluations to develop a plan based on your child's strengths and challenges. The law mandates that states provide eligible children with a **free appropriate public education (FAPE)** that meets their unique needs.

IDEA establishes an important team approach in 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 document that spells out your child's education needs and how these needs will be met is the **Individualized Education Program (IEP)**. You are an important member of your child's IEP team. Like the IFSP, the IEP:

- Describes your child's strengths and challenges
- Sets goals and objectives
- Details how these can be met through services such as SLT, OT, PT, as well as specific special education supports, counseling and social skills training

The IEP is focused only on your child's educational needs and how the school district plans to meet them. For more information about IEPs, visit the [Autism Speaks Guide to Individualized Education Programs](https://autismspeaks.org/tool-kit/guide-individualized-education-programs-iep) autismspeaks.org/tool-kit/guide-individualized-education-programs-iep.

A **Section 504 plan** is another resource that will help your child access services and supports at school. This plan outlines the accommodations your child will 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 the specific services that will be provided to help support them in and out of the classroom.

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.

Understanding your child's learning style

From Does My Child Have Autism? A Parent's Guide to Early Detection and Intervention in Autism Spectrum Disorders

by Wendy L. Stone, Ph.D., with Theresa Foy DiGeronimo, M.Ed., 2006.

Finding the right intervention program begins with an understanding of your child's learning style – which is quite different from the learning style of other children. You probably realize this as you've tried to get your child with autism to wave bye-bye using the same teaching strategies you used with your other children – that is, demonstrating the action, providing a verbal prompt by saying “wave bye-bye” and even moving his or her hand to demonstrate what to do. But when that approach didn't seem to be working, you probably started to think that your child was being stubborn or uncooperative. After all, you're teaching simple skills using methods that worked very well for your other children.

But the reality is that your child isn't being bad; he or she just has a different learning style from your other children. This difference in learning styles isn't apparent only when you try to teach children with autism; it's also evident in the way they learn (or don't learn) on their own. There are lots of things that children without autism seem to learn effortlessly, without being taught, but that children with autism don't pick up on as easily.

For example, young children without autism somehow learn, without explicit teaching, how

to use a pointing gesture to let you know what they want or to indicate where they want you to look. They learn to follow your point or eye gaze to figure out what you're looking at or what you're interested in. They figure out on their own how to use eye contact and facial expressions to convey their feelings—as well as to understand the meaning of your facial expressions and tone of voice. Social-communicative behaviors and skills like these just don't come as naturally to young children with autism and often need to be taught explicitly.

While autism is typically a life-long condition, children and adults benefit from treatments that help reduce symptoms and increase skills and abilities. Although it is best to begin treatment as soon as possible, its benefits can continue throughout life.

The long-term outcome for a child with autism varies. A small percentage of children might lose their diagnosis over time. Others remain severely affected. Many have typical learning and thinking skills but challenges with social and language skills. Most develop speech and learn to communicate with others. Early intervention can make huge differences in your child's development. How your child functions now may be very different than later in life.

Evaluating early interventions

by Lauren Elder, Ph.D.

Once their children begin receiving early intervention for autism, many parents wonder how to evaluate these services. I frequently get questions such as, “How do I know whether the intervention is right for my child? How do I know if my child is making as much progress as possible?”

It can be difficult to say how much progress any one child “should” be making. Keep in mind that all children learn at different rates, and children may go through periods of time when they are learning more slowly or quickly. What’s most important is that your child is learning, and that you can see new skills developing over time.

That said, it’s important to trust your instinct if your concerns persist. In my experience, parents are usually right when they say their child could be making more progress!

To help ensure that your child is receiving the highest-quality treatment, I suggest posing these questions:

What research supports this intervention? Programs and techniques should have the backing of scientific studies demonstrating clear benefits. Ask for references to published studies on the method the program uses.

What training has the staff received? The intervention providers should be happy to describe their training and educational background. If the team includes paraprofessionals (individuals without advanced degrees), inquire about the team leader’s training and how closely he or she supervises all those working with your child.

What are the intervention’s goals – both in general and for my child in particular? Your child’s providers should clearly describe the skill areas that the intervention addresses, as well as their specific goals for your child.



How is the intervention individualized for my child? The providers should describe clearly how the intervention builds on your child’s personal strengths and motivations.

How do you assess my child’s progress? Providers should regularly collect information on your child’s progress and challenges. And they should regularly use this information to adapt the program to your child’s needs to ensure continued progress. These regular reviews should include at least one standardized developmental assessment - a test performed by a qualified professional - of your child’s skills.

How will we work together as a team? Children do better when their parents actively participate in their treatment. You know your child best. Use this knowledge to help the intervention team understand how your child learns. Also ask to be trained in the program’s intervention strategies. In this way, you can apply them at home to maximize your child’s learning. As part of the team, you should also expect regular updates on the program and your child’s progress.

What to do if your child is not making progress

Typically children need time to adjust to new intervention programs. So, allow your child to settle in before evaluating progress. If you still don't see that progress – or don't think your child is making as much progress as possible – consider the following:

What's the team's opinion? As they get to know your child, the members of the intervention team can help you determine whether he or she could be learning more. Ask them for ideas about adjusting your child's program to maximize progress. There may even be more than one model of early intervention offered in your area.

Is my child healthy? Several medical problems such as sleep difficulties and seizures are relatively common among those with autism. Clearly, they can interfere with learning. If you are concerned about possible medical issues, consult your child's doctor and ask for evaluations that can help identify underlying conditions so they can be treated. Autism Speaks Autism Treatment Network (ATN) is dedicated to this "whole-child" approach to treating autism and related medical issues.

How do I get services started for my child?

Before EI or special education services can be provided, your child will need other assessments and evaluations. These may include:

- An observation of your child playing
- A **developmental evaluation**
- A speech-language assessment
- A **parent interview/questionnaire**
- An evaluation of current behavior, including classroom observation if your child is in school
- An evaluation of **daily living skills**

If your child is younger than 3, call your local EI agency. In most states, the Department of Health provides EI services.

If your child is 3 or older, contact your school district's special education office. You may need to request an evaluation for your child in writing.

The purpose of these evaluations is to understand your child's challenges to determine appropriate services. [A Parent's Guide to Assessment](#) from the Organization for Autism Research can be helpful in explaining results and what they mean for your child.

Waiting for all of these evaluations may be frustrating. There may be waiting lists, so start the process as soon as possible. These evaluations provide more in-depth information about your child's symptoms, strengths and needs. They will be helpful in accessing and planning services for your child.

You can do a lot while you wait for results, including:

- Talk to other parents about what services have been helpful for their children.
- Investigate the therapies outlined in this kit and on the Autism Speaks website.
- Learn about how you can support your child by reading books, blogs and other resources online.
- You may want to check out books or blogs written by autistic people to hear their experiences.

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 8

Living with autism

- *Creating your team*
- *Managing your team*
- *Technology*
- *Safety*

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.

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 information about safety and wandering, visit autismspeaks.org/safety.



Tips to help prevent and respond to wandering

The information below is adapted from the Autism Wandering Awareness Alerts Response and Education Coalition (AWAARE).

Secure your home.

Contact a professional locksmith, security company or home improvement professional to help you make your home safe and prevent wandering. Ask about using various safety tools, such as:

- Secure dead bolt locks that require keys on both sides
- A home security alarm system
- Inexpensive battery-operated alarms on doors
- Hook and eye locks on all doors above your child's reach
- A fence around your yard
- Printable stop signs on doors, windows and other exits

Use a locating device.

Check with local law enforcement to see if they offer any type of safety program or resources for children and adults prone to wandering, such as Project Lifesaver. These **locating devices** are worn on the wrist or ankle and can help find an individual through radio frequency. Global positioning system (GPS) tracking systems are also available.

Have your child wear an identification bracelet.

A **medical identification (ID) bracelet** can include your name and telephone number as well as medical information, like that a child has autism and is nonverbal. If your child will not wear a bracelet or necklace, think about using a temporary tattoo with your contact information.

Teach your child to swim.

The leading cause of death for autistic people who wander is drowning. It is critical to teach your child to swim and to understand the importance of water safety. Many community organizations such as YMCAs offer swimming lessons for children with special needs. The final lesson should be with clothes on. Teaching your child to swim does not mean your child is safe in water. If you own a pool, put a fence around it. Remove all toys or items of interest from the pool when it's not in use. If your neighbors have pools, tell them about your child's tendency to wander and ask them to use similar safety measures to help keep your child safe.

Autism Speaks offers grants to organizations that offer swimming and water safety lessons to autistic people who may not be able to afford them. Learn more at autismspeaks.org/grants-service-providers.

Tell your neighbors.

Making sure your neighbors know your child can help reduce the risks associated with wandering. Introduce your child to your neighbors. Or show them a photo of your child. Create an information sheet about your child and share it with neighbors as well as family, friends and coworkers.

Alert first responders in your area.

Giving first responders information about your child before wandering happens may help improve their response. Share the information sheet about your child with local first responders.

Always make sure to work with your child's team to express any concerns about safety issues, so that you can work together on a safety plan best suited for your child. For more information, visit awaare.org or download the **Big Red Safety Toolkit** from the National Autism Association.

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 Family Service Plan (IFSP). This section is for documents related to your child's IFSP (for children under three years).

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 Early Intervention services.

- **If your child is younger than three:** Contact your state health department to find out about EI services.
- **If your child is three or older:** Contact your local school district about EI or special education services. EI or your school district may want to do their own 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.

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 IFSP or 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 Early Intervention and 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	
Recommended by	

Program content

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

Measuring progress

How will I know if my child is making progress?	
How long will it be before I see changes?	
What types of improvements should I expect?	
How often will you assess progress and how is it measured?	
What will happen if my child doesn't make progress with this treatment?	

Therapist qualifications

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

Scientific evidence of effectiveness

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

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?	
How often will you see my child personally?	

Parent involvement

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

Compatibility with other treatments

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

Contacts: Medical

Specialty	
Name of contact	
Name of practice	
Phone number	
Address	
Email address/Website	

Specialty	
Name of contact	
Name of practice	
Phone number	
Address	
Email address/Website	

Specialty	
Name of contact	
Name of practice	
Phone number	
Address	
Email address/Website	

Specialty	
Name of contact	
Name of practice	
Phone number	
Address	
Email address/Website	

Specialty	
Name of contact	
Name of practice	
Phone number	
Address	
Email address/Website	

Specialty	
Name of contact	
Name of practice	
Phone number	
Address	
Email address/Website	

Contacts: Therapy

Specialty	
Name of contact	
Name of practice	
Phone number	
Address	
Email address/Website	

Specialty	
Name of contact	
Name of practice	
Phone number	
Address	
Email address/Website	

Specialty	
Name of contact	
Name of practice	
Phone number	
Address	
Email address/Website	

Specialty	
Name of contact	
Name of practice	
Phone number	
Address	
Email address/Website	

Specialty	
Name of contact	
Name of practice	
Phone number	
Address	
Email address/Website	

Specialty	
Name of contact	
Name of practice	
Phone number	
Address	
Email address/Website	

Contacts: Support

Specialty	
Name of contact	
Name of practice	
Phone number	
Address	
Email address/Website	

Specialty	
Name of contact	
Name of practice	
Phone number	
Address	
Email address/Website	

Specialty	
Name of contact	
Name of practice	
Phone number	
Address	
Email address/Website	

Specialty	
Name of contact	
Name of practice	
Phone number	
Address	
Email address/Website	

Specialty	
Name of contact	
Name of practice	
Phone number	
Address	
Email address/Website	

Specialty	
Name of contact	
Name of practice	
Phone number	
Address	
Email address/Website	

Contacts: Other

Specialty	
Name of contact	
Name of practice	
Phone number	
Address	
Email address/Website	

Specialty	
Name of contact	
Name of practice	
Phone number	
Address	
Email address/Website	

Specialty	
Name of contact	
Name of practice	
Phone number	
Address	
Email address/Website	

Specialty	
Name of contact	
Name of practice	
Phone number	
Address	
Email address/Website	

Specialty	
Name of contact	
Name of practice	
Phone number	
Address	
Email address/Website	

Specialty	
Name of contact	
Name of practice	
Phone number	
Address	
Email address/Website	

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 _____

Date and time

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

Summary _____

Follow-up required _____

Date and time

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

Summary _____

Follow-up required _____

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

Date and time

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

Summary

Follow-up required

Date and time

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

Summary

Follow-up required

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 _____

Date and time

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

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: IFSP goals

Date	Comments	Goals mastered	Goals making progress	Goals just started	Goals not started

Goal tracking: IEP vs. IFSP goals

Date	Comments	Goals mastered	Goals making progress	Goals just started	Goals not started

Safety log

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

Date	Location	Description	Possible triggers	Changes 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 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.

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.

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.

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.

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.

Individual Family Services Plan (IFSP)

A plan developed by a multidisciplinary team including family as primary participant. Describes child's level of development in all areas; family's resources, priorities and concerns, services to be received and the frequency, intensity and method of delivery. Must state natural environments in which services will occur.

Individualized Education 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.

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-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-emotional reciprocity

The back-and-forth flow of social communication.

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.

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 gooey 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

Verbal Behavior

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

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 young 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).