

# AUTISM SPEAKS™

## *100 Day Kit*

*A tool kit to assist families in getting the critical information they need in the first 100 days after an autism diagnosis.*

*Autism Speaks does not provide medical or legal advice or services. Rather, Autism Speaks provides general information about autism as a service to the community. The information provided in this kit is not a recommendation, referral or endorsement of any resource, therapeutic method, or service provider and does not replace the advice of medical, legal or educational professionals. This kit is not intended as a tool for verifying the credentials, qualifications, or abilities of any organization, product or professional. Autism Speaks has not validated and is not responsible for any information or services provided by third parties. You are urged to use independent judgment and request references when considering any resource associated with the provision of services related to autism*



# *About this Kit*

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*Autism Speaks would like to extend special thanks to the Parent Advisory Committee for the time and effort that they put into reviewing the 100 Day Kit.*

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*With gratitude, we thank the 100 Day Kit Professional Advisory Committee for generously donating their time and experience to this project.*

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*Autism Speaks thanks the following supporters whose generous  
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# *Autism Speaks™ 100 Day Kit*

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Ask for Help! Contact the Autism Response Team (ART). Our ART team members are specially trained to help families with the day-to-day challenges of living with autism. Contact ART for resources, support and information.

Call us at 888-AUTISM 2 (288-4762) or email [familyservices@autismspeaks.org](mailto:familyservices@autismspeaks.org).

More information... There is a wealth of information on the Autism Speaks web site. Visit [www.AutismSpeaks.org](http://www.AutismSpeaks.org)

*Share your comments. To share your comments on the kit - What was helpful? What additional information could be included? etc. - please email them to [100daykit@AutismSpeaks.org](mailto:100daykit@AutismSpeaks.org), with the word “feedback” in the subject line.*

## Why was My Child Diagnosed with Autism? What Does It Mean?

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

*In this kit, the umbrella term “Autism” refers to the Pervasive Developmental Disorders, also known as Autism Spectrum Disorders, including Autism, PDD, PDD-NOS, and Asperger Syndrome.*

### Why does my child need a diagnosis of Autism?



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





more subtle and are first recognized by a day-care provider or preschool teacher. Those differences, the symptoms of autism, have led thousands of parents like you to seek answers that have resulted in a diagnosis of autism. You may wonder: Why does my child need a diagnosis of autism? That's a fair question to ask - especially when right now, no one is able to offer you a cure.

*Autism Speaks* is dedicated to funding global biomedical research to find the causes and a cure, along with effective prevention and treatment methods. Great strides have been made and the current state of progress is a far cry from the time when parents were given no hope for their children. Some of the most brilliant minds of our time have turned their attention toward this disorder, and we are working at a constantly increasing pace toward a cure for autism. While we live in an age of miracles and wonders, we're not there yet. In the meantime, the best treatments available to us now – the therapies and interventions you will learn about in this handbook – are our chemotherapy, our dialysis, our insulin.

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

There are however, several reasons having a diagnosis is important for your child. A thorough and detailed diagnosis provides important information about your child's behavior and development. It can help create a road map for treatment, by identifying your child's specific strengths and challenges and providing useful information about which needs and skills should be targeted for effective intervention. A diagnosis is often required to access autism specific services through early intervention programs or your local school district.

## *How is Autism Diagnosed?*

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

From birth to at least 36 months of age, every child should be screened for developmental milestones during routine visits. The American Academy of Pediatrics recommends that all children be screened for autism at their 18- and 24-month well-baby check-ups. If concerns about a child's development are raised, his or her doctor should refer the child to Early Intervention and a specialist for a developmental evaluation. Hearing and lead exposure screenings should be performed and an autism-specific screening tool, such as the **Modified Checklist of Autism in Toddlers (M-CHAT)**, should be used. Learn more at [www.m-chat.org](http://www.m-chat.org).



The M-CHAT is a list of simple questions about your child. The answers determine whether he or she should be referred to a specialist, usually a **Developmental Pediatrician**, a **Neurologist**, a **Psychiatrist** or a **Psychologist**, for further evaluation. There are other screening tools available, some geared towards older children or specific **Autism Spectrum Disorders**. Your child may have been diagnosed by one of the professionals mentioned above. In some cases, a team of specialists may have evaluated your child and provided recommendations for treatment. The team may have included an **Audiologist**, to rule out hearing loss, a **Speech & Language Therapist**, to determine language skills and needs, and an **Occupational Therapist** to evaluate physical and **motor skills**. A multi-disciplinary evaluation is important for diagnosing autism and other challenges that often accompany autism, such as delays in motor skills. If your child has not been evaluated by a multi-disciplinary team, you will want to make sure further evaluations are conducted so that you can learn as much as possible about your child's individual strengths and needs. For more information you can visit The Autism Treatment Network at: [www.autismspeaks.org/science/programs/atn](http://www.autismspeaks.org/science/programs/atn).

## *What is Autism?*

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Autism is a general term used to describe a group of complex developmental brain disorders known as **Pervasive Developmental Disorders (PDD)**. The other pervasive developmental disorders are **PDD-NOS (Pervasive Developmental Disorder – Not Otherwise Specified)**, **Asperger Syndrome**, **Rett Syndrome** and **Childhood Disintegrative Disorder**. Many parents and professionals refer to this group as Autism Spectrum Disorders.

You may also hear the terms Classic Autism or Kanner's Autism (named after the first psychiatrist to describe autism) used to describe the most severe form of the disorder. The American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders is the main diagnostic reference used by mental health professionals and insurance providers in the United States. The current (fourth) edition, which was published in 1994, is commonly referred to as the "DSM-IV." The diagnosis of autism requires that at least six developmental and behavioral characteristics are observed, that problems are present before the age of three, and that there is no evidence for certain other conditions that are similar. The DSM-IV is currently being revised. The DSM-V will group together the subtypes of autistic disorder, PDD-NOS, and Asperger Syndrome under the umbrella term "Autism Spectrum Disorder" because research has not shown these categories to be distinct. Rather, they are part of a broad continuum of disorders that involve difficulties in social and communication skills.



## ***DSM-IV Criteria for a Diagnosis of Autism***

*I. A total of six (or more) items from heading (A), (B), and (C), with at least two from (A), and one each from (B) and (C):*

*(A) Qualitative impairment in social interaction, as manifested by at least two of the following:*

- Marked impairments in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction.*
- Failure to develop peer relationships appropriate to developmental level.*
- A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people, (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people).*
- A lack of social or emotional reciprocity.*

*(B) Qualitative impairments in communication as manifested by at least one of the following:*

- Delay in or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime).*
- In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others.*
- Stereotyped and repetitive use of language or idiosyncratic language.*
- Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level.*

*(C) Restricted repetitive and stereotyped patterns of behavior, interests and activities, as manifested by at least two of the following:*

- Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus.*
- Apparently inflexible adherence to specific, nonfunctional routines or rituals.*
- Stereotyped and repetitive motor mannerisms (e.g. Hand or finger flapping or twisting, or complex whole-body movements).*
- Persistent preoccupation with parts of objects.*

*II. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years:*

*(A) Social interaction.*

*(B) Language is used in social communication.*

*(C) Symbolic or imaginative play.*

*III. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.*

Source: Diagnostic and Statistical Manual of Mental Disorders; Fourth Edition



# How Common is Autism?

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Today, it is estimated that one in every 110 children is diagnosed with autism in the United States, making it more common than childhood cancer, juvenile diabetes and pediatric AIDS combined. An estimated 1.5 million individuals in the United States and tens of millions worldwide are affected by autism. Government statistics suggest the **prevalence** rate of autism is increasing 10-17 percent annually. There is no established explanation for this increase, although improved diagnostic methods and environmental influences are two reasons often considered. Studies suggest boys are more likely than girls to develop autism and receive the diagnosis three to four times more frequently. Current estimates are that in the United States alone, one out of 70 boys is diagnosed with autism.

## What causes Autism?

It is important to keep in mind that autism is not one disorder with one cause. Rather, it is a group of related disorders with many different causes. In most instances, autism is likely caused by a combination of genetic risk factors that interact with environmental risk factors. Several autism susceptibility genes have been identified, meaning that an individual will be more likely to develop autism if they have a specific variant of this gene, or in some cases, a rare mutation in the gene. Many genes likely contribute to autism. These specific genes are believed to interact with certain environmental factors. A great deal of research is currently focused on identifying how both genetic and environmental risk factors contribute to autism. Although some genetic factors have been identified, less is known about the specific environmental factors that contribute to autism. Exposure to environmental agents such as **infectious** agents (**maternal rubella** or **cytomegalovirus**) or chemical agents (**thalidomide** or **valproate**) during pregnancy can cause autism. About 10-15% of cases have a specific, identifiable genetic cause, such as such as **Fragile X Syndrome**, **Tuberous Sclerosis**, and **Angelman's Syndrome**.

There is a growing interest among researchers about the role of the function and regulation of the immune system, both within the body and the brain, in autism. Piecemeal evidence over the past 30 years suggests that people with autism may experience inflammation in the central nervous system. There is also emerging evidence from animal studies that illustrates how the immune system can influence behaviors related to autism. *Autism Speaks* is working to extend awareness and investigation of potential immunological issues to researchers outside the field of autism as well as those within the autism research community.

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



# *More Information about Symptoms of Autism*

Autism affects the way your child perceives the world and makes communication and social interaction difficult. He may also have repetitive behaviors or intense interests. Symptoms and their severity are different for each child in each of the affected areas (Communication, Social Interaction, and Repetitive Behaviors). Your child may not have the same symptoms and may seem very different from another child with the same diagnosis.

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

Although autism is usually a life-long condition, the symptoms of autism can change over time. The long term outcome is highly variable. Some children lose their diagnosis over time, while others remain severely affected. Many have normal cognitive skills, despite challenges in social and language abilities. Most individuals with autism develop speech and learn to communicate with others. Early intervention can make extraordinary differences in your child's development. How your child is functioning now may be very different from how he or she will function later on in life.

*The information following – about the social symptoms, communication disorders and repetitive behaviors associated with autism – is partially taken from the National Institute of Mental Health Website*

## *Social Symptoms*

From the start, typically developing infants are social beings. Early in life, they gaze at people, turn toward voices, grasp a finger and smile. By contrast, many children with autism have difficulty learning to engage in the give-and-take of everyday human interactions. Even in the first year of life, many may prefer playing with objects and may fail to initiate social interaction or engage in communicative babbling and imitative play. Eye contact may be fleeting. Most have difficulty using gestures such as pointing, waving bye-bye, and showing objects to others. Research has suggested that although children with autism are attached to their parents, their expression of this attachment is unusual and difficult to “read”. To parents, it may seem as if their child is not connected at all.

Children with autism are also slower in learning to interpret what others are thinking and feeling. Subtle social cues such as a smile, a wave, or a grimace may have little meaning to a child with autism. To a child who misses these cues, “Come here” may always mean the same thing, whether the speaker is smiling and extending her arms for a hug, or frowning and planting her fists on her hips. Without the ability to interpret gestures and facial expressions, the social world may seem bewildering. To compound the problem, people with autism have difficulty seeing things from another person's perspective. Most five-year-olds understand that other people have thoughts, feelings, and goals that are different from their own. A child with autism may lack such



understanding. This inability leaves them unable to predict or understand other people's actions.

Although not universal, it is common for people with autism to have difficulty regulating their emotions. This can take the form of "immature" behavior such as crying in class, or verbal outbursts that seem inappropriate to those around them. Sometimes they may be disruptive and physically aggressive, making social relationships even more difficult. They have a tendency to "lose control", particularly when they're in a strange or overwhelming environment, or when they are angry or frustrated. At times, they may break things, attack others, or hurt themselves. In their frustration, some bang their heads, pull their hair or bite their arms.

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

## *Communication Difficulties*

By age three, most children have passed predictable milestones on the path to learning language; one of the earliest is babbling. By the first birthday, a typical toddler says a word or two, turns and looks when he hears his name, points when he wants a toy, and when offered something distasteful, makes it clear that the answer is "no". Although a minority of people with autism doesn't use speech, the large majority develops spoken language, and all eventually learn to communicate in some way. Most infants who later show signs of autism "coo" and babble during the first few months of life, but over time, they stop. Others may be delayed, developing language as late as age five to nine. Some children may learn to use communication systems such as pictures or sign language. Children with autism who do speak often use language in unusual ways. They seem unable to combine words into meaningful sentences. Some speak only single words, while others repeat the same phrase over and over. They may repeat or "parrot" what they hear, a condition called echolalia. Although many children with autism go through a stage where they repeat what they hear, it normally passes by the time they turn three. Some children with autism who are only mildly affected may exhibit slight delays in language, or even seem to have precocious language and unusually large vocabularies, but still have great difficulty in sustaining a conversation. The "give and take" of normal conversations may be hard, but they may often carry on a monologue on a favorite subject, giving others little opportunity to comment. Another common difficulty is the inability to understand body language, tone of voice, or "phrases of speech." For example, someone with autism might interpret a sarcastic expression such as "Oh, that's just great" as meaning it really IS great. It can be challenging sometimes for others to understand what children with autism are saying, as well as what their body language means. Facial expressions, movements, and gestures may not match what they are saying. Also their tone of voice may fail to reflect their feelings. They may use a high-pitched, sing-song, or flat, robot-like voice. Some children with relatively good language skills speak like little adults, failing to pick up on the "kid-speak" that is common in their peers. Without meaningful gestures or the language to ask for things, people with autism have difficulty letting others know what they need. As a result, they may simply scream or grab what they want. Fortunately, children with autism can be taught to communicate in more appropriate way.



***Children with autism have difficulty letting others know what they want or need until they are taught how to communicate through speech, gestures, or other means.***

## ***Repetitive Behaviors***

Although children with autism usually appear physically normal, odd repetitive motions may set them apart from other children. These behaviors might be extreme and highly apparent or more subtle. Some children and older individuals with autism repeatedly flap their arms or walk on their toes. Some suddenly freeze in a position. As children, individuals with autism might spend hours lining up their cars and trains in a certain way, rather than using them for pretend play. If someone moves one of the toys, the children may become tremendously upset. Many children with autism need and demand absolute consistency in their environment. A slight change in routines, such as eating a meal, getting dressed, taking a bath, and going to school at a certain time or by the same route, can be extremely stressful. Repetitive behavior sometimes takes the form of a persistent, intense preoccupation. These strong interests may be unusual because of their content (e.g. fans or toilets) or because of the intensity of the interest (e.g. extremely detailed information about Thomas the Tank Engine). For example, a child with autism might be obsessed with learning all about vacuum cleaners, train schedules, or lighthouses. Often older children with autism have a great interest in numbers/ letters, symbols, dates or science topics.

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



# *Unique Abilities That May Accompany Autism*

Along with the challenges that autism involves, you may have noticed that your child also exhibits areas of strength. Although not all children have special talents, it is not uncommon for individuals with autism to have exceptional skills in math, music, art, and reading, among others. These areas of expertise can provide great satisfaction and pride for the child with autism. If possible, incorporate your child's areas of expertise into his everyday activities and use them whenever possible as a way for he or she to learn and excel.

*Adapted from Sally Ozonoff, Geraldine Dawson and James McPartland's, **A Parent's Guide to Asperger's Syndrome and High-Functioning Autism***

*Just as individuals with autism have a variety of difficulties, they also have some distinctive strengths. Some of the strengths that individuals with autism have may include:*

- *Ability to understand concrete concepts, rules and sequences*
- *Strong long term memory skills*
- *Math skills*
- *Computer skills*
- *Musical ability*
- *Artistic ability*
- *Ability to think in a visual way*
- *Ability to decode written language at an early age (This ability is called **Hyperlexia**. Some children with autism can decode written language earlier than they can comprehend written language.)*
- *Honesty – sometimes to a fault*
- *Ability to be extremely focused – if they are working on a preferred activity*
- *Excellent sense of direction*





***“How can my child have Autism when he seems so smart?”***

***From Does My Child Have Autism? by Wendy Stone***

*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 and DVD player 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 two-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*



# *Physical and Medical Issues That May Accompany Autism*

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## *Seizure Disorders*

■ Seizure Disorder, also called **Epilepsy**, occurs in as many as 39% of people with autism. It is more common in children who also have cognitive deficits than those who do not. Some researchers have suggested that seizure disorder is more common when the child has shown a regression or loss of skills. There are different types and subtypes of seizures and a child with autism may experience more than one type. The easiest to recognize are large “**grand mal**” (or **tonic-clonic**) **seizures**. Others include “**petit mal**” (or **absence**) **seizures** and **subclinical seizures**, which may only be apparent in an **EEG (Electroencephalogram)**. It is not clear whether subclinical seizures have effects on language, cognition, and behavior. The seizures associated with autism usually start either early in childhood or during adolescence, but may occur at any time. If you are concerned that your child may be having seizures you should see a neurologist. The neurologist may order tests which may include an EEG, an **MRI (Magnetic Resonance Imaging)**, **CT (Computed Axial Tomography)** and a **CBC (Complete Blood Count)**. Children and adults with epilepsy are typically treated with **anticonvulsant** or seizure medicines to reduce or eliminate occurrence. If your child has epilepsy, you will work closely with a neurologist to find the medicine that works the best with the fewest side effects, and to learn the best ways to ensure your child’s safety during a seizure.

*You can find more information about autism and epilepsy at the following link: <http://fiddle.readvantage.com/news/attach/DJF-EpilepsyBrochure.pdf>*

## *Genetic Disorders*

■ About 10-15% of children with autism have an identifiable neurogenetic condition such as **Fragile X Syndrome**, **Angelman’s Syndrome**, a **neurocutaneous** disorder called **Tuberous Sclerosis**, **Chromosome 15 Duplication Syndrome** or other chromosomal abnormalities. If your child has **clinical features**, such as a family history or physical symptoms, that are characteristic of one of these disorders, your pediatrician may order tests or may refer you to a developmental pediatrician, a **geneticist** and/or a child neurologist for testing. The chance of having one of these abnormalities is slightly higher if your child also has cognitive deficits or mental retardation. It is also higher if your child has certain physical features that are characteristic of a given syndrome. While none of these conditions is curable, it is important to know if your child has one of these syndromes as there may be other medical issues that go along with some of them. Having a known genetic cause for autism may also change your risk of having another child with autism.



## ***Gastrointestinal Disorders***

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

*For additional information from the Official Journal of American Academy of Pediatrics go to:*

[http://pediatrics.aappublications.org/cgi/content/full/125/Supplement\\_1/S1](http://pediatrics.aappublications.org/cgi/content/full/125/Supplement_1/S1)

*For information that can be shared with your child's doctor, go to:*

[http://www.autismspeaks.org/press/gastrointestinal\\_treatment\\_guidelines.php](http://www.autismspeaks.org/press/gastrointestinal_treatment_guidelines.php)

## ***Sleep Dysfunction***

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

## ***Sensory Integration Dysfunction***

■ Many children with autism experience unusual responses to **sensory stimuli**, or input. These responses are due to difficulty in processing and integrating sensory



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


## *Pica*

■ Pica is an eating disorder involving eating things that are not food. Children between 18 and 24 months old often eat non food items, but this is typically a normal part of development. Some children with autism and other developmental disabilities persist beyond the developmentally typical time frame and continue to eat items such as dirt, clay, chalk or paint chips. Children showing signs of persistent mouthing of fingers or objects, including toys, should be tested for elevated blood levels of lead, especially if there is a known potential for environmental exposure to lead.




# *How Will I Deal With This Diagnosis?*

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 You are never prepared for a diagnosis of autism. It is likely that you will experience a range of emotions. It is painful to love so much, to want something so much, and not quite get it. You want your child to get better so much you may feel some of the stages commonly associated with grieving. You may “revisit” these feelings from time to time in the future. Part of moving forward, is dealing with your own needs and emotions along the way.

## *Stages Associated with Grieving*


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 Elisabeth Kübler-Ross outlined five stages in the grief process. Grief does not progress in an orderly way that follows a predictable path. It is normal to move forwards and backwards among the five stages; skip a stage or be stuck in one. Her five stages are outlined below.


### *Shock*

 Immediately after the diagnosis you may feel stunned or confused. The reality of the diagnosis may be so overwhelming that you’re not ready to accept it or you initially ignore it. You may also question the diagnosis, or search for another doctor who will tell you something different.

### *Sadness or Grief*

 Many parents must mourn the loss of some of the hopes and dreams they had for their child before they can move on. There will probably be many times when you feel extremely sad. Friends may refer to this as being “depressed,” which can sound frightening. There is, however, a difference between sadness and depression. Depression often stands in the way of moving forward. Allowing yourself to feel sadness can help you grow. You have every right to feel sad and to express it in ways that are comfortable. Crying can help release some of the tension that builds up when you try to hold in sadness. A good cry can get you over one hurdle and help you face the next. If you find that your sadness is interfering with your ability to cope, or you show other symptoms of depression, such as weight loss, social withdrawal, suicidal thoughts, sleep difficulties, low self-esteem, loss of interest in daily activities, consult your family physician who can recommend treatment.

### *Anger*

 With time, your sadness may give way to anger. Although anger is a natural part of the process, you may find that it’s directed at those closest to you – your child, your spouse, your friend or at the world in general. You may also feel resentment toward parents of typical children. Your anger may come out in different ways – snapping at people, overreacting to small things, even screaming and yelling. Anger is normal. It is a healthy and expected reaction to feelings of loss and stress that come with this diagnosis. Expressing your anger releases tension. It is an attempt to tell the people around you that you hurt, and that you are outraged that this diagnosis has happened to your child.



*“I felt angry when a child at my son’s school was diagnosed with Leukemia around the time our son was diagnosed with autism. Everyone sent cards and cooked dinners for them. They didn’t know I needed that kind of help too. When I let people know I needed help they came through for me.”*

## **Denial**

■ You may go through periods of refusing to believe what is happening to your child. You don’t consciously choose this reaction; like anger, it just happens. During this time, you may not be able to hear the facts as they relate to your child’s diagnosis. Don’t be critical of yourself for reacting this way. Denial is a way of coping. It may be what gets you through a particularly difficult period. You must, however, be aware that you are in denial, so that it doesn’t cause you to lose focus on your child’s treatment. Try not to “shoot the messenger.” When someone, a professional, a therapist or a teacher, tells you something that is hard to hear about your child, consider that they are trying to help you so that you can address the problem. It is important not to alienate people who can give you helpful feedback and help monitor your child’s progress. Whether you agree or not, try to thank them for the information. If you are upset, try considering their information when you have had a chance to calm down.

*“My husband had a harder time accepting our son’s diagnosis at first. When Max began making progress in his ABA program, everything changed for the better. For a while, I was the one holding everything together for all of us.”*

## **Loneliness**

■ You may feel isolated and lonely. These feelings may have many causes. Loneliness may also come from the fact that in your new situation, you simply don’t feel like you have the time to contact friends or family for company. You may feel that if you did reach out, they wouldn’t understand or be supportive. In the pages that follow, we have some suggestions for taking care of yourself and for getting the support you need.

## **Acceptance**

■ Ultimately, you may feel a sense of acceptance. It’s helpful to distinguish between accepting that your child has been diagnosed with autism and accepting autism. Accepting the diagnosis simply means that you are ready to advocate for your child. The period following an autism diagnosis can be very challenging, even for the most harmonious families. Although the child with autism may never experience the negative emotions associated with the diagnosis, parents, siblings and extended family members may each process the diagnosis in different ways, and at different rates. Give yourself time to adjust. Be patient with yourself. It will take some time to understand your child’s disorder and the impact it has on you and your family. Difficult emotions may resurface from time to time. There may be times when you feel helpless and angry that autism has resulted in a life that is much different than you had planned. But you will also experience feelings of hope as your child begins to make progress.



# Caring for the Caregiver

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

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

Parents often fail to evaluate their own sources of strength, coping skills, or emotional attitudes. You may be so busy meeting the needs of your child that you don't allow yourself time to relax, cry, or simply think. You may wait until you are so exhausted or stressed out that you can barely carry on before you consider your own needs. Reaching this point is bad for you and for your family. You may feel that your child needs you right now, more than ever. Your "to do" list may be what is driving you forward right now. You may feel completely overwhelmed and not know where to start. There is no single way to cope. Each family is unique and deals with stressful situations differently. Getting your child started in treatment will help you feel better. Acknowledging the emotional impact of autism and taking care of yourself during this stressful period will help prepare you for the challenges ahead. Autism is a pervasive, multi-faceted disorder. It will not only change the way that you look at your child, it will change the way you look at the world. 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 what you are going through:***

- Get going. Getting your child started in treatment will help. There are many details you will be managing in an intensive treatment program, especially if it is based in your home. If you know your child is engaged in meaningful activities, you will be more able to focus on moving forward. It may also free up some of your time so you can educate yourself, advocate for your child, and take care of yourself.
- Ask for help. Asking for help can be very difficult, especially at first. Don't hesitate to use whatever support is available to you. People around you may want to help, but may not know how. Is there someone who can take your other kids somewhere for an afternoon? Or cook dinner for your family one night so that you can spend the time learning? Can they pick a few things up for you at the store or do a load of laundry? Can they let other people know you are going through a difficult time and could use a hand?
- Talk to someone. Everyone needs someone to talk to. Let someone know what you are going through and how you feel. Someone who just listens can be a great source of strength. If you can't get out of the house, use the phone to call a friend.



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

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

***You may find a listing of support groups in the Autism Speaks Resource Guide <http://www.autismspeaks.org/community/fsdb/search.php>. Another avenue is through the local SEPTA (Special Education Parent Teacher Association) in your school district. Or online through the Autism Speaks Facebook page at [www.facebook.com/autismspeaks](http://www.facebook.com/autismspeaks)***

■ Consider attending a recreational program for children with autism. This may be a good way to meet other parents just like you.





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

*“Is your son on the spectrum?”*

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

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

*“Hi, and welcome! That's my son over there, and my name is Sandy. How old is your son? Do you live in town? How long have you known your son was on the spectrum?*

*What was his diagnosis?” I really didn't want to answer her. I wasn't even sure we belonged at this class, and all I wanted to do was pay attention to my son to see how he was responding to the class. I watched the other kids as they came in – six boys and one girl – and my first instinct was that we were in the wrong place. One little boy was crying, another was spinning in circles, and another one was running in all different directions. My son's not like that, I thought to myself. This isn't us.*

*And then I looked at my Henry. I watched him hold tightly to his one-on-one helper's hand as they walked on a low balance beam, but he wouldn't look her in the eye when she talked to him. I watched him try to run away to jump into the comfort of the sensory foam blocks and become so focused on that foam pit that he couldn't move onto anything else. I listened to him babble while he swayed back and forth on the rings, and saw the terror in his face when the noise level got up too high. The tears welled up in my eyes. We did belong here. This is the right place for him. We had found a safe place for him to exercise and develop his muscles in an environment that understood his special needs. For so long we had avoided the “regular” gym classes, music classes, and playgroups because of his behavior. No one here was giving me the usual disapproving looks we get when we're out places and Henry starts to act up. I took a deep breath and turned to the mom.*

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

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

*Finally we were somewhere that felt like we belonged.*

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

*“Absolutely,” I replied.*



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

■ Consider keeping a journal. Louise DeSalvo, in *Writing as a Way of Healing*, notes that studies have shown that: "Writing that describes traumatic events and our deepest thoughts and feelings about them is linked with improved immune function, improved emotional and physical health," and positive behavioral changes. Some parents have found a journal a helpful tool for keeping track of their child's progress, what is working and what isn't. Be mindful of the time you spend on the Internet. The Internet will be one of the most important tools you have for learning what you need to know about autism and how to help your child. Unfortunately, there is more information on the web than any of us have time to read in a lifetime. There may also be a lot of misinformation.

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

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

***Is it new information?***

***Is it helpful?***

***Is it from a reliable source?***

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

***The Internet will be one of the most important tools you have for learning what you need to know about autism and how to help your child.***



# *What Should We Know About Our Younger or Future Children?*

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As discussed below, genetic risk factors contribute to autism. If you are expecting another child, or have plans to expand your family in the future, you may be concerned about the development of any younger siblings of your child with autism. Published studies have estimated that families affected with one child with autism have roughly a 5-10% percent chance of having a second child with autism.

However, statistics are changing and there are several ongoing research studies that are studying the recurrence rate, or likelihood that autism will be diagnosed in a second or third child. For the most recent findings and updated research on the rate of recurrence and susceptibility of autism in siblings, please visit [www.earlistudy.org](http://www.earlistudy.org). The EARLI study is a nationwide effort to investigate the genetic and environmental contributions to autism in a high risk group, that is, younger siblings of a child who has received a diagnosis.

More recent evidence has suggests that early signs of autism may be seen in some children as young as 8-10 months of age. For example, infants who later develop autism may be more passive, are more difficult to soothe, or fail to orient when their name is called. Some of these early signs may be noticed by parents, others may only be observed with the help of a trained clinician.

Through a joint venture between Autism Speaks and the National Institute of Child Health and Human Development, research on the early signs and symptoms of autism has been accelerated. Called the High Risk Baby Siblings Research Consortium, or BSRC, the collaboration is comprised of over 20 researchers at a dozen different sites in the US, Canada, Israel and the United Kingdom. The purpose of this collaborative effort is to help identify behavioral and biological markers for autism so that diagnosis can be made earlier than ever before, leading to improved and more specific behavioral intervention in young children and even infants. While there is a general acceptance in the scientific community that “earlier is better”, this research will provide evidence on different therapies which partner therapist time and parent training. Recently, a group of researchers within the BSRC, together with psychologists from around the US, has formed the Autism Speaks Toddler Treatment Network (TTN). The goal of the network is to determine whether intervention between the ages of 18 to 24 months of age affects developmental outcome at an age when autism can be more reliably diagnosed. A number of other projects are underway to better identify developmental paths of children *with autism, as well as potential risk factors, and common neurobiological markers.*

*If you are interested in participating in a research project studying the earliest signs of autism, visit*

[www.AutismSpeaks.org/science/research/initiatives/babysibs.php](http://www.AutismSpeaks.org/science/research/initiatives/babysibs.php)

*or find a research project in your area at*

[www.AutismSpeaks.org/participate](http://www.AutismSpeaks.org/participate).

These studies provide intense observation, documentation, and feedback by experts in



the field on the development of your child with autism, and any other children at risk for autism. If you are interested in other intervention programs that are not part these studies, visit the Family Services Resource Guide on the *Autism Speaks* website to help find an early intervention program in your area. ([www.autismspeaks.org/community/resources](http://www.autismspeaks.org/community/resources))

## *How Will This Affect Our Family?*

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Even though it is your child who has the diagnosis, it is important to acknowledge that autism affects the whole family. This section of your handbook may help you anticipate some of the emotions you and other people in your family will experience. The following article, adapted from *Does My Child Have Autism?* by Wendy L. Stone, Ph.D., provides some helpful information for talking to your parents and close family members about the diagnosis.

### *Breaking the news*

Sometimes telling your parents about your child's diagnosis can be extremely difficult, especially with your own emotions running so high. It's hard to know what to expect; I've seen that parental reactions to this news can vary dramatically. One young mother told me, "My mother-in-law told us that we shouldn't bring my son to family gatherings until he grows up. It's heartbreaking to hear her say that she would rather not see any of us for years instead of trying to understand her own grandson." But then I've also been told, "We were very touched by how our family reacted to my son's diagnosis. Everyone asked what they could do to help, and they showed us so much support. I know his grandparents read books and articles on the disorder so they could better understand him. My mother even quit her job to help me through this very difficult time." Yes, reactions vary widely. But whatever reaction you get, it will be very important to educate your parents about the nature of autism after you have told them about the diagnosis. To begin your discussion, you might talk about specific behaviors. For example: "You know those behaviors we've been confused about for so long? Well, now we have a name for them and an explanation for why they occur. Howie doesn't act the way he does because he's spoiled or because he's shy or because he doesn't like us – he acts that way because he has autism. Autism explains why he doesn't speak or use gestures and why he doesn't seem to understand what we say. It explains why he's not as interested in interacting with us as the other children in the family have been and why he plays with spoons and bottles instead of toys. I know this is upsetting news for all of us. But the good news is that the disorder has been diagnosed early, and there are a lot of things we can do to help him. He'll be starting some therapies soon, and I'll be learning about things I can do to help him at home. I know that you will need some time to think about all of this. But if you have any questions as we begin his therapy, I'll be glad to try my best to answer them. I know we're all hoping for the best outcome possible." After the initial conversation about this diagnosis, continue to keep your other children and your extended family in the information loop. Autism doesn't affect only one child. It affects the entire family.

***Autism doesn't affect only one child. It affects the entire family.***



# *Sharing Your Struggle with Family and Friends*

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

## *Telling People*



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

*Some families have downloaded the Autism Speaks 100 Day Kit and sent it to their family and close friends to provide more information about autism and what the newly diagnosed family may be going through.*

[www.autismspeaks.org/community/family\\_services/100\\_day\\_kit.php](http://www.autismspeaks.org/community/family_services/100_day_kit.php)

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## *Fifteen Tips for Your Family*

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

## *5 Tips for Parents*

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- Learn to be the best advocate you can be for your child. Be informed. Take advantage of all the services that are available to you in your community. You will meet practitioners and providers who can educate you and help you. You will gather great strength from the people you meet.
- Don't push your feelings away. Talk about them. You may feel both ambivalent and angry. Those are emotions to be expected. It's OK to feel conflicting emotions.
- Try to direct your anger towards the disorder and not towards your loved ones. When you find yourself arguing with your spouse over an autism related issue, try to remember that this topic is painful for both of you; and be careful not to get mad at each other when it really is the autism that has you so upset and angry. Try to have some semblance of an adult life. Be careful to not let autism consume every waking hour of your life. Spend quality time with your typically developing children and your spouse, and refrain from constantly talking about autism. Everyone in your family needs support, and to be happy despite the circumstances.
- Appreciate the small victories your child may achieve. Love your child and take great pride in each small 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 they should be.
- Get involved with the Autism community. Don't underestimate the power of "community". You may be the captain of your team, but you can't do everything yourself. Make friends with other parents who have children with autism. By meeting other parents you will have the support of families who understand your day to day challenges. Getting involved with autism advocacy is empowering and productive. You will be doing something for yourself as well as your child by being proactive.

*“Learning more about my child’s unique needs and abilities along with reaching out for support has enabled my husband and I to be better parents to our son and better partners for each other on this journey”*

## *5 Tips for Brothers & Sisters*

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- Remember that you are not alone! Every family is confronted with life's challenges... and yes, autism is challenging...but, if you look closely, nearly everyone has something difficult to face in their families.
- Be proud of your brother or sister. Learn to talk about autism and be open and comfortable describing the disorder to others. If you are comfortable with the topic...they will be comfortable too. If you are embarrassed by your brother or sister, your friends will sense this and it will make it awkward for them. If you talk openly to your friends about autism, they will become comfortable. But, like everyone else, sometimes you will love your brother or sister, and sometimes you will hate them. It's okay to feel your feelings. And, often it's easier when you have a professional counselor to help you understand them – someone special who is here just for you! Love your brother or sister the way they are.
- While it is OK to be sad that you have a brother or sister affected by autism it doesn't help to be upset and angry for extended periods of time. Your anger doesn't change the situation; it only makes you unhappier. Remember your Mom and Dad may have those feelings too.
- Spend time with your Mom and Dad alone. Doing things together as a family with and without your brother or sister strengthens your family bond. It's OK for you to want alone time. Having a family member with autism can often be very time consuming, and attention grabbing. You need to feel important too. Remember, even if your brother or sister didn't have autism, you would still need alone time with Mom and Dad.
- Find an activity you can do with your brother or sister. You will find it rewarding to connect with your brother or sister, even if it is just putting a simple puzzle together. No matter how impaired they may be, doing something together creates a closeness. They will look forward to these shared activities and greet you with a special smile.

*“At first I felt lost and confused about my brother but now that my Mom and Dad have helped to explain things to me, I can be a better big sister and help my brother when he needs it”*

## ***5 Tips for Grandparents and Extended Family***

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- Family members have a lot to offer. Each family member is able to offer the things they have learned to do best over time. Ask how you can be helpful to your family. Your efforts will be appreciated whether it means taking care of the child so that the parents can go out to dinner, or raising money for the special school that helps your family's child. Organize a lunch, a theatre benefit, a carnival, or a card game. It will warm your family's hearts to know that you are pitching in to create support and closeness.
- Seek out your own support. If you find yourself having a difficult time accepting and dealing with the fact that your loved one has autism, seek out your own support. Your family may not be able to provide you with that kind of support so you must be considerate and look elsewhere. In this way you can be stronger for them, helping with the many challenges they face. Be open and honest about the disorder. The more you talk about the matter, the better you will feel. Your friends and family can become your support system...but only if you share your thoughts with them. It may be hard to talk about it at first, but as time goes on it will be easier. In the end your experience with autism will end up teaching you and your family profound life lessons.
- Put judgment aside. Consider your family's feelings and be supportive. Respect the decisions they make for their child with autism. They are working very hard to explore and research all options, and are typically coming to well thought out conclusions. Try not to compare children (this goes for typically developing kids as well). Children with autism can be brought up to achieve their personal best.
- Learn more about Autism. It affects people of all social and economic standing. There is promising research, with many possibilities for the future. Share that sense of hope with your family, while educating yourself about the best ways to help manage this disorder.
- Carve out special time for each child. You can enjoy special moments with both typically developing family members and the family member with autism. Yes, they may be different, but all of the children look forward to spending time with you. Children with autism thrive on routines, so find one thing that you can do together that is structured, even if it is simply going to a park for fifteen 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.”*

## ***How Do I Get the Help My Child***

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## Needs?

The road ahead will be bumpy. There will be times when your progress stalls or takes an unexpected turn. When it does, try to remind yourself that these are speed bumps, not roadblocks. Take them one at a time. It is important that you start now. There are a variety of services available to treat and educate your child. The article below, from *Does My Child Have Autism?* by Wendy L. Stone, PhD, with Theresa Foy DiGeromino, MEd, explains why:

*There is no debate or doubt: early intervention is your child's best hope for the future. 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 four or five. A good early intervention program has at least four benefits: It will provide your child with instruction that will build on his or her strengths to teach new skills, improve behaviors, and remediate areas of weakness. It will provide you with information that will help you better understand your child's behavior and needs. It will offer resources, support, and training that will enable you to work and play with your child more effectively. It will improve the outcome for your child. For these reasons, an intervention program for your child should be implemented 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.*

*Early Intervention will improve the outcome for your child.*

## *Accessing Services: Your Child's Rights for Public Education*



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

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

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

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

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

## ***What is “Least Restrictive Environment” (LRE)?***

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




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

The participation of children with disabilities in the general education environment is often referred to as “mainstreaming” or “inclusion.” Inclusion does not mean that a child with special needs should be placed into a general education setting just like a typical learner; a variety of special education supports should be provided in order to create a successful environment and positive experience for everyone involved. Careful planning and training are essential to providing modifications or accommodations, and to successfully situating a child with a disability in the least restrictive setting. These supports might include providing a specially trained classroom or one-on-one paraprofessional, altering testing environments or expectations, adapting curriculum, providing visual supports or adaptive equipment, etc. The special education department should provide training, strategies and support for general education staff and others in the general school community who may interact with students with special needs. It is important to note that philosophies about inclusion vary considerably among school districts, staff and parents of students with and without special needs.

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

## ***Early Intervention Services (EI) – For Children under the Age of 3***

 The IDEA provides states with federal grants to institute early intervention programs. Any child younger than age three who has a developmental delay, or a physical or mental condition likely to result in a developmental delay, is eligible to



receive early intervention services through these programs. 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 or customary in your region. The document that spells out your child's needs and the services that will be provided is the **Individual Family Service Program (IFSP)**. The IFSP should be based on a comprehensive evaluation of your child. It should describe your child's current levels of functioning and the anticipated goals. It should also list the specific services that will be provided to your child and your family. EI services are aimed at minimizing the impact of disabilities on the development of your child. Services for your child may include, but are not limited to, speech and language instruction, occupational therapy, physical therapy, Applied Behavior Analysis (ABA) and psychological evaluation. Services for families may include training to help reinforce the affected child's new skills and counseling to help the family adapt.

***Information about the Legal Rights and Procedures for Early Intervention in your state can be found in the Autism Speaks Resource Guide [www.autismspeaks.org/community/fsdb/search.php](http://www.autismspeaks.org/community/fsdb/search.php).***

***Click on your state and you will find the information under Early Intervention/State Information***

In this same section of the Autism Speaks Resource Guide you will also find state specific information on the process of transitioning from Early Intervention Services to Special Education Services.

## ***Special Education Services – For Children Ages 3 - 22***

Special education services pick up where early intervention services leave off, at age 3. Your local school district provides these services through their special education department. The focus of special education is different from that of early intervention. While early intervention addresses your child's overall development, special education focuses on providing your child with an education, regardless of disabilities or special needs. The document that spells out your child's needs and how these needs will be met is the Individualized Education Program (IEP). Like the IFSP, the IEP describes your child's strengths and weaknesses, sets goals and objectives, and details how these can be met. Unlike the IFSP, the IEP is almost entirely related to how the needs of your child will be met within the context of the school district and within school walls.

***Information about the Legal Rights and Procedures for Special Education Services (both Pre-school and School Age Services) in your state can be found in the Autism Speaks Resource Guide [www.autismspeaks.org/community/fsdb/search.php](http://www.autismspeaks.org/community/fsdb/search.php).***

***Click on your state and you will find the information under Pre-School Services or School Age Services/ State Information***



You can also view the Autism Speaks School Community Toolkit at [www.autismspeaks.org/community/family\\_services/school\\_kit.php](http://www.autismspeaks.org/community/family_services/school_kit.php)

## *Extended School Year (ESY) Services*

If there is evidence that your child experiences a substantial regression in skills during school vacations, he or she may be entitled to ESY services. These services would be provided over long breaks from school (summer vacation) to prevent substantial regression, but not to acquire new skills. It is important for the family to remain involved in determining appropriate goals, communicating with the educational team about progress, and working to provide consistency between home and school.

*“I was overwhelmed in the beginning by all the evaluations and paperwork. Watching the changes in Samantha as she learns and grows, we know our efforts are paying off.”*

## *How Do I Get Services Started for My Child?*

For Early Intervention Services, if your child is under the age of three, call your local Early Intervention Agency. In most states Early Intervention is provided by the Department of Health. Contact information is included in the local resource guide of this kit. For Special Education Services, if your child is three or older, contact your local school district, and more specifically the Office of Special Education within the school district. In some cases, you may need to put the request in writing that you would like your child evaluated for special education services. Refer to “Assembling Your Team” in this kit for more information. You’ll find more information at the *Autism Speaks* web site, [www.AutismSpeaks.org/community/fsdb/search.php](http://www.AutismSpeaks.org/community/fsdb/search.php) and in the Action Plan section of this kit.

Before Service can be provided, it may be necessary to complete further assessments and evaluations. These may include:

- *An Unstructured Diagnostic Play Session*
  - *A Developmental Evaluation*
  - *A Speech - Language Assessment*
    - *A Parent Interview*
- *An Evaluation of Current Behavior*



- *An Evaluation of Adaptive or Real Life Skills*

You may find yourself spending some time in waiting rooms with your child when you are completing additional evaluations. You have probably already figured out how helpful it is to bring some snacks for your child, his or her favorite toy, or some other form of entertainment to help pass the time. Having to wait for the completion of these additional evaluations, which may be required by the school district or Early Intervention, may be frustrating. There are sometimes waiting lists, and so it is important to start the process as soon as possible. The additional evaluations will provide much more in-depth information about your child's symptoms, strengths and needs, and will be helpful for accessing and planning therapy services in the long run.

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

The purpose of the evaluations is to understand your child's challenges so that he can get the appropriate services that he needs. The Organization for Autism Research's *A Parent's Guide to Assessment* can be helpful in explaining the results of the evaluations and what they mean for your child.

*The guide can be found at*

[www.researchautism.org/resources/reading/documents/AssessmentGuide.pdf](http://www.researchautism.org/resources/reading/documents/AssessmentGuide.pdf)

If you find you are spinning your wheels waiting for the results, there are things you can be doing in the meantime. Talk to other parents about what services have been helpful for their children.

Investigate the therapies outlined in this kit. Start reading about autism. (There is a list of suggested books and web sites at the end this kit, as well as in the Autism Speaks Resource Library at [www.autismspeaks.org/community/resources/index.php#library](http://www.autismspeaks.org/community/resources/index.php#library))

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

## *How is Autism Treated?*

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. These may be based in your home with professional specialists and trained therapists or may include training for you to serve as a therapist for your child under 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 terms “treatment” and “therapy” may be used interchangeably. The word “intervention” may also be used to describe a treatment or therapy.***

We've provided an overview of many different treatment methods for autism in this section of your kit. The descriptions are meant to give you general information. Your pediatrician, developmental pediatrician, or a social worker who specializes in the treatment of children with autism, can make suggestions or help you prioritize therapies based on your child's comprehensive evaluation. Once you have narrowed down some choices of appropriate therapies for your child, you will want to explore more comprehensive information before making a commitment to one. For many children, autism is complicated by medical conditions, biological issues and symptoms that are not exclusive to autism. Children with other disorders, such as Articulation Disorder, **Apraxia, Seizures, GI problems**, etc. might require some of the same therapies.

Examples of these treatments are **Speech & Language Therapy, Occupational Therapy**, or the care of a **Neurologist** or **Gastroenterologist**. For this reason, we've included information here to explain the treatments for the core symptoms of autism and the treatments for associated symptoms and biological and medical conditions. Intensive treatments for autism's core symptoms address the social, communication and behavioral issues at the heart of autism. Treatments for associated symptoms address challenges commonly associated with autism, but not specific to the disorder. If your child has biological or medical conditions, such as allergies, food intolerances, gastrointestinal issues or sleep disturbances, these will need to be treated too. Treatment programs may combine therapies for both core symptoms and associated symptoms. Your child's treatment program will depend on his needs and strengths. Some of these therapies may be used together. For example, if medical causes for sleep disturbances are ruled out, a behavioral intervention might be used to address them. Occupational Therapy or Speech & Language Therapy are often integrated into one of the intensive therapy programs described here as core symptom therapies. Many children benefit from receiving multiple therapies provided in the same learning format. The National Research Council recommends that, during the preschool period, children with autism should receive approximately 25 hours of structured intervention per week. Intervention can include time spent in a developmental program, speech-language therapy, occupational therapy, one-on-one or small group intervention, and parent-delivered intervention.


*Therapies include a wide range of tools, services and teaching methods you may choose to use to help your child reach his or her potential. The recommended number of hours of structured intervention is 25 hours per week during the preschool period.*

*For school-age children the therapy may be provided during the school day and if necessary, there may be additional therapy provided outside of the school day. The type of services (i.e. Speech and Language Therapy), the duration of the service (i.e. 45 minutes), the frequency of the service (i.e. 3 days/week), as well as the location (in school) will be provided as part of your child's Individual Education Program*

*Many of the therapy methods described here are very complex and will require more research on your part before you get started. Whenever possible, observe the therapies in action. Talk to experienced parents and make sure you have a thorough understanding of what is involved before beginning any therapy for your child.*

## ***Treatment for the Core Symptoms of Autism***

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





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

Before we get into the types of therapies available, it is helpful to take a step back and look at the bigger picture. Although research and experience have revealed many of the mysteries surrounding autism, it remains a complex disorder that impacts each child differently. However, many children with autism have made remarkable breakthroughs with the right combination of therapies and interventions. Most parents would welcome a cure for their child, or a therapy that would alleviate all of the symptoms and challenges that make life difficult for them. Just as your child’s challenges can’t be summed up in one word, they can’t be remedied with one therapy. Each challenge must be addressed with an appropriate therapy. No single therapy works for every child. What works for one child may not work for another. What works for one child for a period of time may stop working. Some therapies are supported by research showing their efficacy, while others are not. The skill, experience, and style of the therapist are critical to the effectiveness of the intervention.

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

***For information on different treatment options, turn to the glossary in this kit, or visit [www.AutismSpeaks.org](http://www.AutismSpeaks.org) and view the National Standards Project produced by the National Autism Center at [www.nationalautismcenter.org/about.national.php](http://www.nationalautismcenter.org/about.national.php)***

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

Behavior analysis was originally described by B.F. Skinner in the 1930’s. You may have learned about Skinner and “operant conditioning” when you studied science in school. 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.

## ***What is Applied Behavioral Analysis?***

Since the early 1960’s, applied behavior analysis, or ABA, has been used by hundreds of therapists to teach communication, play, social, academic, self-care, work and community living skills, and to reduce problem behaviors in learners with autism. There is a great deal of research literature that has demonstrated that ABA is effective for improving children’s outcomes, especially their cognitive and language abilities. Over the past several decades, different models using ABA have emerged, all of which use behavioral teaching. They all use strategies that are based on Skinner’s work. ABA is often difficult to understand until you see it in action. It may be helpful to start by describing what all of the different methods of ABA have in common. ABA methods use the following three step process to teach:



- An **antecedent**, which is a verbal or physical stimulus such as a command or request. This may come from the environment or from another person, or be internal to the subject;
- A resulting **behavior**, which is the subject's (or in this case, the child's) response or lack of response to the antecedent;
- A **consequence**, which depends on the behavior. 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. Each skill is broken down into small steps, and taught using prompts, which are gradually eliminated as the steps are mastered. The child is given repeated opportunities to learn and practice each step in a variety of settings. Each time the child achieves the desired result, he receives positive reinforcement, such as verbal praise, or something else that the child finds to be highly motivating, like a small piece of candy. ABA programs often include support for the child in a school setting with a one-on-one aide to target the systemic transfer of skills to a typical school environment. Skills are broken down into manageable pieces and built upon so that a child learns how to learn in a natural environment. Facilitated play with peers is often part of the intervention. Success is measured by direct observation and data collection and analysis – all critical components of ABA. If the child isn't making satisfactory progress, adjustments are made.

One type of ABA intervention is Discrete Trial Teaching (also referred to as DTT, "traditional ABA" or the Lovaas Model, for its pioneer, Dr. Ivar Lovaas). DTT involves teaching individual skills one at a time using several repeated teaching trials and reinforcers that may or may not be intrinsically related to the skill that is being taught.

### ***Who provides traditional ABA or DTT?***

■ A board certified behavior analyst specializing in autism will write, implement and monitor the child's individualized program. Individual therapists, often called "trainers," (not necessarily board certified) will work directly with the child on a day-to-day basis.

### ***What is a typical ABA therapy session like?***

■ Sessions are typically 2 to 3 hours long, consisting of short periods of structured time devoted to a task, usually lasting 3 to 5 minutes. 10 to 15 minute breaks are often taken at the end of every hour. Free play and breaks are used for incidental teaching or practicing skills in new environments. Done correctly, ABA intervention for autism is not a "one size fits all" approach consisting of a "canned" set of programs or drills. On the contrary, every aspect of intervention is customized to each learner's skills, needs, interests, preferences, and family situation. For those reasons, an ABA program for one learner might look somewhat different than a program for another learner. An ABA program will also change as the needs and functioning of the learner change.

### ***What is the intensity of most ABA programs?***



- 25 to 40 hours per week. Families are also encouraged to use ABA principals in their daily lives.

*To find more information on ABA go to  
The Association for Behavior Analysis International  
[www.ABAinternational.org](http://www.ABAinternational.org)  
Behavior Analyst Certification Board  
[www.BACB.com](http://www.BACB.com)*

## ***What is the difference between Traditional ABA and other interventions that involve ABA, such as Verbal Behavior, Pivotal Response Treatment, and the Early Start Denver Model?***

- Verbal Behavior and Pivotal Response Treatment therapies use the methods of ABA, but with different emphasis and techniques. All of these methods use the three step process described above.

## ***What is Pivotal Response Treatment?***

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■ **Pivotal Response Treatment**, or PRT, was developed by Dr. Robert L. Koegel, Dr. Lynn Kern Koegel and Dr. Laura Shreibman, at the University of California, Santa Barbara. Pivotal Response Treatment was previously called the Natural Language Paradigm (NLP), which has been in development since the 1970s. It is a behavioral intervention model based on the principles of ABA.

PRT is used to teach language, decrease disruptive/self-stimulatory behaviors, and increase social, communication, and academic skills by focusing on critical, or “pivotal,” behaviors that affect a wide range of behaviors. The primary pivotal behaviors are motivation and initiation of communications with others. The goal of PRT is to produce positive changes in the pivotal behaviors, leading to improvement in communication skills, play skills, social behaviors and the child’s ability to monitor his or her own behavior. Unlike the Discrete Trial Teaching (DTT) method of teaching, which targets individual behaviors based on an established curriculum, PRT is child-directed. Motivational strategies are used throughout intervention as often as possible. These include varying tasks, revisiting mastered tasks to ensure the child retains acquired skills, rewarding attempts, and using direct and natural reinforcement. The child plays a crucial role in determining the activities and objects that will be used in the PRT exchange. For example, a child’s purposeful attempts at functional communication are rewarded with reinforcement related to their effort to communicate (e.g. if a child attempts a request for a stuffed animal, the child receives the animal).

### ***Who provides PRT?***

- Some psychologists, special education teachers, speech therapists and other providers specifically are trained in PRT. The Koegel Autism Center offers a PRT



Certification program.

## ***What is a typical PRT therapy session like?***

Each program is tailored to meet the goals and needs of the child, and also to fit into the family routines. A session typically involves six segments during which language, play, and social skills are targeted in structured and unstructured formats. Sessions change to accommodate more advanced goals and the changing needs as the child develops.

## ***What is the intensity of a PRT program?***

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

### ***Where can I find more information on PRT?***

***UCSB Koegel Autism Center***

***[www.Education.UCSB.edu/autism](http://www.education.ucsb.edu/autism)***

***UCSD Autism Research Program***

***<http://psy3.ucsd.edu/~autism/prtraining.html>***

## ***What is Verbal Behavior?***

Another behavioral (based on the principles of ABA) therapy method with a different approach to the acquisition and function of language is **Verbal Behavior** (VB) therapy. In his 1957 book, "Verbal Behavior," B.F. Skinner (see previous section on ABA) detailed a functional analysis of language. He described all of the parts of language as a system. Verbal Behavior uses Skinner's analysis as a basis for teaching language and shaping behavior.

Skinner theorized that all language could be grouped into a set of units, which he called operants. Each operant he identified serves a different function. He listed echoics, mands, tacts and intraverbals as the most important of these operants. The function of a "mand" is to request or obtain what is wanted. For example, the child learns to say the word "cookie" when he is interested in obtaining a cookie. When the child is given the cookie, the word is reinforced and will be used again in the same context. In a VB program, the child is taught to ask for the cookie any way he can (vocally, sign language, etc.). If the child can echo the word, he will be motivated to do so in order to obtain the desired object. The operant for labeling an object is called a "tact." For example, the child says the word "cookie" when seeing a picture and is thus labeling the item. In VB, more importance is placed on the mand than on the tact, theorizing that "using language" is different from "knowing language." An "intraverbal" describes conversational or social, language. Intraverbals allow children to discuss something that isn't present. For example, the child finishes the sentence, "I'm baking..." with the intraverbal fill-in "Cookies." Intraverbals also include responses to questions from



another person, usually answers to “wh-“questions (Who? What? When? Where? Why?). Intraverbals are strengthened with social reinforcement.

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

### ***Who provides VB?***

- VB therapy is provided by VB-trained psychologists, special education teachers, speech therapists and other providers.

### ***What is the intensity of most VB programs?***

- VB programs usually involve 30 or more hours per week of scheduled therapy.
- Families are encouraged to use VB principals in their daily lives.

*For Information on VB go to  
Cambridge Center for Behavioral Studies  
[www.behavior.org/vb](http://www.behavior.org/vb)*

## ***What is the Early Start Denver Model (ESDM)?***

■ The Early Start Denver Model (ESDM) is a developmental, relationship-based intervention approach that utilizes teaching techniques consistent with applied behavior analysis (ABA). The goals are to foster social gains – communicative, cognitive, and language – in young children with autism, and to reduce atypical behaviors associated with autism. ESDM is appropriate for children with autism or autism symptoms who are as young as 12 months of age, through preschool age. The content of intervention for each child comes from assessment using a comprehensive ESDM Curriculum Checklist which covers all domains of early development: Cognitive Skills, Language, Social Behavior, Imitation, Fine and Gross Motor Skills, Self-help Skills and Adaptive Behavior. Adults delivering ESDM focus on behaviors involved in capturing and holding children’s attention, fostering their motivation for social interaction through highly enjoyable routines, using joint play activities as the medium for treatment, developing nonverbal and verbal communication, imitation, and joint attention, and using reciprocal, turn-taking exchanges inside joint activity routines to foster social learning. Based on a NIH-funded clinical trial, ESDM has been shown to be effective for increasing IQ, language, social skills, and adaptive behavior when delivered for at least one year.

### ***Who provides ESDM?***

- ESDM can be provided by ESDM-trained behavior analysts, special education teachers, speech therapists and other providers. Parents can also be taught to use



ESDM strategies.

### ***What is the intensity of most ESDM programs?***

■ ESDM programs usually involve 20-25 or more hours per week of scheduled therapy. Families are encouraged to use ESDM strategies in their daily lives.

### ***What is a typical ESDM session like?***

■ ESDM is designed to be highly engaging and enjoyable for the child, while skills are systematically taught within a naturalistic, play-based interaction. Some skills are taught on the floor during interactive play while others are taught 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. ESDM can be delivered in the home, the clinic, or a birth-to-three or developmental preschool setting.

*To find more information on ESDM:*

***ESDM Manual: Rogers, SJ., & Dawson, G. (2009). Play and Engagement in Early Autism: The Early Start Denver Model. New York: Guilford.***

***ESDM curriculum checklist: Rogers, SJ and Dawson, G. (2009) The ESDM Curriculum Checklist.***

***Information about training in the ESDM model can be found at this website: [www.ucdmc.ucdavis.edu/edsl/esdm/training.html](http://www.ucdmc.ucdavis.edu/edsl/esdm/training.html)***

## ***What is Floortime (DIR)?***

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■ **Floortime** is a specific therapeutic technique based on the **Developmental Individual Difference Relationship Model (DIR)** developed in the 1980s by Dr. Stanley Greenspan. The premise of Floortime is that an adult can help a child expand his circles of communication by meeting him at his developmental level and building on his strengths. Therapy is often incorporated into play activities – on the floor. The goal of Floortime is to help the child reach six developmental milestones that contribute to emotional and intellectual growth:

- *Self regulation and interest in the world*
- *Intimacy or a special love for the world of human relations*
  - *Two-way communication*
  - *Complex communication*
    - *Emotional ideas*
    - *Emotional thinking*

In Floortime, the therapist or parent engages the child at a level the child currently enjoys, enters the child's activities, and follows the child's lead. From a mutually shared engagement, the parent is instructed how to move the child toward increasingly complex interactions, a process known as "opening and closing circles of communication."



Floortime does not separate and focus on speech, motor, or cognitive skills but rather addresses these areas through a synthesized emphasis on emotional development. The intervention is called Floortime because the parent gets down on the floor with the child to engage him at his level. Floortime is considered an alternative to and is sometimes delivered in combination with ABA therapies.

### ***Who provides Floortime?***

■ Parents and caregivers are trained to implement the approach. Floortime-trained psychologists, special education teachers, speech therapists, occupational therapists may also use Floortime techniques.

### ***What is a typical Floortime therapy session like?***

■ In Floortime, the parent or provider joins in the child's activities and follows the child's lead. The parent or provider then engages the child in increasingly complex interactions. During the preschool program, Floortime includes integration with typically developing peers.

### ***What is the intensity of most Floortime programs?***

■ Floortime is usually delivered in a low stimulus environment, ranging from two to five hours a day. Families are encouraged to use the principals of Floortime in their day to day lifestyle.

*To find more information on Floortime go to:*

*Floortime Foundation*

[www.Floortime.org](http://www.Floortime.org)

*Stanley Greenspan*

[www.StanleyGreenspan.com](http://www.StanleyGreenspan.com)

*Interdisciplinary Council on Developmental and Learning Disorders*

[www.ICDL.com](http://www.ICDL.com)

## ***What is Relationship Development Intervention (RDI)?***

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■ Like other therapies described in this handbook, RDI is a system of behavior modification through positive reinforcement. RDI was developed by Dr. Steven Gutstein as a parent-based treatment using dynamic intelligence. The goal of RDI is to improve the long-term quality of life of individuals with autism by helping them improve their social skills, adaptability and self-awareness. The six objectives of RDI are:

- **Emotional Referencing:** The ability to use an emotional feedback system to learn from the subjective experiences of others.
- **Social Coordination:** The ability to observe and continually regulate one's behavior in order to participate in spontaneous relationships involving collaboration and exchange of emotions.



- **Declarative Language:** The ability to use language and non-verbal communication to express curiosity, invite others to interact, share perceptions and feelings and coordinate your actions with others.
- **Flexible Thinking:** The ability to rapidly adapt, change strategies and alter plans based upon changing circumstances.
- **Relational Information Processing:** The ability to obtain meaning based upon the larger context; Solving problems that have no “right-and wrong” solutions.
- **Foresight and Hindsight:** The ability to reflect on past experiences and anticipate potential future scenarios in a productive manner.

The program involves a systematic approach to working on building motivation and teaching skills, focusing on the child’s current developmental level of functioning. Children begin work in a one-on-one setting with a parent. When they are ready, they are matched with a peer at a similar level of relationship development to form a “dyad.” Gradually, additional children are added to the group, as well as the number of settings in which children practice, in order to help the child form and maintain relationships in different contexts.

### ***Who provides RDI?***

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

### ***What is a typical RDI therapy session like?***

■ In RDI, the parent or provider uses a comprehensive set of step-by-step, developmentally appropriate objectives in everyday life situations, based on different levels, or stages, of ability. Spoken language may be limited in order to encourage eye contact and non-verbal communication. RDI may also be delivered in a specialized school setting.

### ***What is the intensity of most RDI programs?***

■ Families most often use the principles of RDI in their day to day lifestyle. Each family will make choices based on their child.

***Where can I find more information on RDI?***

***Connections Center***

**[www.RDIconnect.com](http://www.RDIconnect.com)**

## ***What is Training and Education of Autistic and Related Communication Handicapped Children (TEACCH)?***





TEACCH is a special education program, developed by Eric Schopler, PhD and his colleagues at the University of North Carolina in the early 1970s. TEACCH's intervention approach is called "Structured Teaching." Structured Teaching is based on what TEACCH calls the "Culture of Autism." The Culture of Autism refers to the relative strengths and difficulties shared by people with autism that are relevant to how they learn. Structured Teaching is designed to capitalize on the relative strengths and preferences for processing information visually, while taking into account the recognized difficulties. Children with autism are assessed in order to identify emerging skills, and work then focuses on these skills to enhance them. In Structured Teaching, an individualized plan is developed for each student. The plan creates a highly structured environment to help the individual map out activities. The physical and social environment is organized using visual supports so that the child can more easily predict and understand daily activities and as a result, respond in appropriate ways. Visual supports are also used to make individual tasks understandable.

### ***What does TEACCH look like?***

TEACCH programs are usually conducted in a classroom setting. TEACCH-based home programs are also available and are sometimes used in conjunction with a TEACCH-based classroom program. Parents work with professionals as co-therapists for their children so that TEACCH techniques can be continued in the home.

### ***Who provides TEACCH?***

TEACCH is available at the TEACCH centers in North Carolina, and through TEACCH-trained psychologists, special education teachers, speech therapists and other providers in other areas of the country.

*To find more information on TEACCH go to: [TEACCH Autism Program  
www.TEACCH.com](http://www.TEACCH.com)*

## ***What is Social Communication/ Emotional Regulation/ Transactional Support (SCERTS)?***

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

- "SC" Social Communication - Development of spontaneous, functional communication, emotional expression and secure and trusting relationships with children and adults.



- “ER” Emotional Regulation - Development of the ability to maintain a well-regulated emotional state to cope with everyday stress, and to be most available for learning and interacting.
- “TS” Transactional Support - Development and implementation of supports to help partners respond to the child’s needs and interests, modify and adapt the environment, and provide tools to enhance learning (e.g., picture communication, written schedules, and sensory supports). Specific plans are also developed to provide educational and emotional support to families, and to foster teamwork among professionals.

### ***What does a SCERTS session look like?***

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

### ***Who provides SCERTS?***

■ SCERTS is usually provided in a school setting by SCERTS-trained special education teachers or speech therapists.

*Where can I find more information on SCERTS?*

**SCERTS**

[www.SCERTS.com](http://www.SCERTS.com)

**Barry Prizant**

[www.BarryPrizant.com](http://www.BarryPrizant.com)

## ***Treatment for Biological & Medical Conditions Associated with Autism***

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

### ***Speech-Language Therapy (SLT)***

■ Speech-Language Therapy (SLT) encompasses a variety of techniques and addresses a range of challenges for children with autism. For instance, some individuals with autism are unable to speak. Others seem to love to talk. They may have difficulty understanding information, or they may struggle to express themselves. SLT is designed to coordinate the mechanics of speech and the meaning and social value of language. An SLT program begins with an individual evaluation by a speech-language pathologist. The therapy may then be conducted one-on-one, in a small group, or in a classroom setting. The therapy may have different goals for different children. Depending on the verbal aptitude of the individual, the goal might be to master spoken language or it might be to learn signs or gestures to communicate. In each case, the aim



is to help the individual learn useful and functional communication. SLT is provided by Speech-Language Pathologists who specialize in children with autism. Most intensive therapy programs address speech-language therapy as well.

## ***Occupational Therapy (OT)***

■ Occupational Therapy (OT) brings together cognitive, physical and motor skills. The aim of OT is to enable the individual to gain independence and participate more fully in life. For a child with autism, the focus may be on appropriate play, learning, and basic life skills. An occupational therapist will evaluate the child's development as well as the psychological, social and environmental factors that may be involved. The therapist will then prepare strategies and tactics for learning key tasks to practice at home, in school, and other settings. Occupational therapy is usually delivered in 30 minute to one hour sessions with the frequency determined by the needs of the child. Goals of an OT program might include independent dressing, feeding, grooming, and use of the toilet, as well as improved social, fine motor and visual perceptual skills. OT is provided by Certified Occupational Therapists.

## ***Sensory Integration (SI)***

■ Sensory Integration (SI) therapy is designed to identify disruptions in the way the individual's brain processes movement, touch, smell, sight and sound, and help he or she process these senses in a more productive way. It is sometimes used alone, but is often part of an occupational therapy program. It is believed that SI does not teach higher-level skills, but rather enhances sensory processing abilities, allowing the child to be more available to acquire higher-level skills. Sensory Integration therapy might be used to help calm your child, to help reinforce a desired behavior, or to help with transitions between activities. Therapists begin with an individual evaluation to determine your child's sensitivities. The therapist then plans an individualized program for the child, matching sensory stimulation with physical movement, to improve the way the brain processes and organizes sensory information. SI therapy often includes equipment such as swings, trampolines and slides. Certified Occupational and Physical Therapists provide Sensory Integration Therapy.

## ***Physical Therapy (PT)***

■ Physical Therapy (PT) is focused on any problems with movement that cause functional limitations. Children with autism frequently have challenges with motor skills such as sitting, walking, running or jumping. PT can address poor muscle tone, balance and coordination. A physical therapist will start by evaluating the developmental level and abilities of the child. Once they identify the individual's challenges, the physical therapists design activities that target those areas. PT might include assisted movement, various forms of exercise, and orthopedic equipment. Physical therapy is usually delivered in 30 minute to one hour sessions by a Certified Physical Therapist, with the frequency determined by the needs of the child.

## ***Social Skills***

■ Individuals with autism have a great deal of difficulty with social interactions. In recent years, social skills training, in both one-on-one and peer group settings, has become a very common treatment for facing this particular challenge. Social skills taught during training sessions range from simple skills like eye contact, to more difficult skills like inviting a peer for a play date. Studies have shown that this type of intervention



program can significantly improve social competence and social skill development. Though social skills training is not an official or certified form of therapy, professionals like social workers, speech therapists, and psychologists often focus largely on improving social skills when treating both children and adults with autism. In addition, parents, family members, and other caregivers can be taught effective ways to help improve the social skills of their loved ones with autism inside and outside the home on a regular basis.

## ***Picture Exchange Communication System***

■ Picture Exchange Communication System (PECS) is a learning system that allows children with little or no verbal ability to communicate using pictures. PECS can be used at home, in the classroom or in a variety of other settings. A therapist, teacher or parent helps the child to build a vocabulary, and to articulate desires, observations or feelings by using pictures consistently. The PECS program starts by teaching the child how to exchange a picture for an object. Eventually, the individual is shown how to distinguish between pictures and symbols and use them to form sentences. Although PECS is based on visual tools, verbal reinforcement is a major component, and verbal communication is encouraged. Standard PECS pictures can be purchased as a part of a manual, or pictures can be gathered from photos, newspapers, magazines, or other books.

## ***Auditory Integration Therapy***

■ Auditory Integration Therapy (AIT), sometimes called Sound Therapy, is sometimes used to treat children with difficulties in auditory processing or sound sensitivity. Treatment with AIT involves the patient listening to electronically modified music through headphones during multiple sessions. There are different methods of AIT, including the Tomatis and Berard methods. While some individuals have reported improvements in auditory processing as a result of AIT, there are no credible studies that demonstrate its effectiveness or support its use.

## ***Gluten Free, Casein Free Diet (GFCF)***

■ Many families of children with autism are interested in dietary and nutritional interventions that might help some of their children's symptoms. Anecdotal evidence suggests that removal of gluten (a protein found in barley, rye, and wheat, and in oats through cross contamination) and casein (a protein found in dairy products) from an individual's can be helpful for reducing some symptoms of autism. The theory behind this diet is that proteins are absorbed differently in some children. Children who benefit from the GFCF diet experience physical and behavioral symptoms when consuming gluten or casein, rather than an allergic reaction. While there have not yet been sufficient scientific studies to support the effectiveness of the GFCF diet for reducing symptoms of autism, many families report that dietary elimination of gluten and casein has helped regulate bowel habits, sleep activity, habitual behaviors, and contributed to the overall progress of their children. Because no specific laboratory tests can predict which children will benefit from dietary intervention, many families choose to try the diet with careful observation by the family and the intervention team.

Families choosing a trial of dietary restriction should make sure their child is receiving adequate nutrition by consulting their pediatrician or a nutrition specialist. Dairy products are the most common source of calcium and Vitamin D for young children in the United



States. Many young children depend on dairy products for a balanced, regular protein intake. Alternative sources of these nutrients require the substitution of other food and beverage products, with attention given to the nutritional content. Substitution of gluten free products requires attention to the overall fiber and vitamin content of a child's diet. Vitamin supplements may have both benefits and side effects. Consultation with a dietician or physician is recommended for the healthy application of a GFCF diet. This may be especially true for children who are picky eaters.

## *What about Other Medical Interventions?*

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Right now you are eager to do everything possible to help your child. Many parents in your position are eager to try new treatments, even those treatments that have not yet been scientifically proven to be effective. Your hopes for a cure for your child may make you more vulnerable to the lure of untested treatments. It is important to remember that just as each child with autism is different, so is each child's response to treatments. It may be helpful to collect information about a therapy that you are interested in trying, and speak with your pediatrician, as well as your intervention team members, in order to discuss the potential risks/benefits and establish measurable outcomes as well as baseline data. If you talk to the parents of older children with autism, they can provide you with a history of therapies and biomedical interventions that have been promised to be cures for autism over the years. Some of them may have been helpful to a small number of children. Upon further study, none of them, so far, has turned out to be a cure for the vast majority. We do know that many children get better with intensive behavioral therapy. There is a large body of scientific evidence to support this theory. It makes sense to focus on getting your child engaged in an intensive behavioral program before looking at other interventions.

## *Is There A Cure?*

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Is recovery possible? You may have heard about children who have recovered from autism. Although relatively rare, it is estimated that approximately 10% of children lose their diagnosis of autism. The factors that predict which children lose their diagnosis are unknown. Children initially diagnosed with autism who lose their diagnosis often have residual difficulties in the areas of hyperactivity, anxiety, and depressive symptoms. Recovery from autism is usually reported in connection with intensive early intervention, but it is unknown how much or which type of intervention works best, or whether the recovery can be fully credited to the intervention. You may also hear about children who reach "best outcome" status, which means they score normally on tests for IQ, language, adaptive functioning, school placement, and personality, but have mild symptoms on some personality and diagnostic tests. Recent epidemiology studies estimate that approximately 60% of children with autism have IQ's above 70 by age 8 (70 is the cut-off point for developmental delay). Presently, there is no reliable way of predicting which children will have the best outcomes. In the absence of a cure or even an accurate prognosis of your child's future, do not be afraid to believe in your child's potential. All children with autism will benefit from intervention. All will make very significant, meaningful progress.



# *How Do I Choose the Right Intervention?*

The two articles that follow may provide helpful information for you as you choose between methods of therapies for your child.

## **Alleviate Stress by Actively Pursuing the Right Intervention**

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

*It's scary to have to question your own child's potential, but the best way to relieve your fears is to take action with productive interventions.*

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

## **Understanding Your Child's Learning Style**

*From **Does My Child Have Autism?** by Wendy Stone, PhD, & Theresa Foy DiGeronimo, M.Ed*

*Finding the right intervention program begins with an understanding of your child's learning style – which is quite different from the learning style of other children. You probably realize this as you've tried to get your child with autism to wave bye-bye using the same teaching strategies you used with your other children – that is, demonstrating the action, providing a verbal prompt by saying "wave bye-bye" and even moving his or her hand to demonstrate what to do. But when that approach didn't seem to be working, you probably started to think that your child was being stubborn or uncooperative. After all, you're teaching simple skills using methods that worked very well for your other children. But the reality is that your child isn't being bad; he or she just has a different learning style from your other children. This difference in learning styles isn't apparent only when you try to teach children with autism; it's also evident in the way they learn (or don't learn) on their own. There are lots of things that children without autism seem to learn effortlessly, without being taught, but that children with autism don't pick up on as easily. For example, young children*

# *Assembling your Team*

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## *Medical Team*

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

## *Intensive Intervention Team*

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

## *Related-Services Team*

■ Speech and Language Therapy, Occupational Therapy, Physical Therapy, or Social Skills instruction are all related services. All therapists working with your child should be communicating frequently, and using a consistent method of teaching.



## *Hiring Therapists*

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

### ***Specific Things to Look for on the Resume:***

- Past experience with children with autism approximately the same age as yours.
- The amount of experience the therapist has had.
- The kind of experience the therapist has had, for example, whether they have worked in a school setting or in a private program.
- Educational background.
- Membership in professional autism organizations. If so, then they are most likely going to conferences, thus enhancing their skills in their profession.

## *Conducting Interviews*

■ Conduct a “hands on” interview, during which the potential therapist works with the child, following instructions to implement a skill acquisition program. It is important to see how the potential therapist takes direction and to see how flexible they are about changing approaches in their teaching. One would want a therapist to potentially be open to new ideas in their teaching approaches. It’s a good idea to have them bring video of a therapy session they have conducted with another child. This offers yet another view of their teaching skills. If possible, observe the therapist working with another child.

**Check references.** Be sure to talk to previous supervisors and to other parents the therapists have worked for. Previous supervisors and other parents are often good sources for finding additional therapists.

**Consider a probation period.** The therapist should be hired for a probation period, during which sessions are videotaped or observed directly until the parent and/or the home coordinator feels comfortable with the therapist and confident in their abilities.

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

## *Managing your Team*

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





## ***Establish Team Communication***

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

### ***When to Be Concerned About a Therapist***

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

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

## ***Making Therapies Work for the Entire Family***

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

*Always be sure you select interventionists who will view the family as teammates and will include you in the determination of target goals – your child needs to learn skills that will help the family function, fit into your lifestyle, and be compatible with your cultural and religious values.*

*For example, a clinician may feel that it's important to work on answering the phone, while the family may feel that toilet training is a much more pressing and immediate goal. Both goals may well be valid, but the family needs to have a say in prioritizing them. Similarly, studies show that families who are required to implement drill type interventions have greater stress than when less rigid interventions are incorporated into daily family routines. How well the family functions as a whole is just as important as how well the child with special needs is doing, and it's your responsibility to work toward both kinds of*

***How well the family functions as a whole is just as important as how well the child with special needs is doing.***

## ***Ten Things Every Child with Autism Wishes You Knew***

By Ellen Notbohm

Some days it seems the only predictable thing about it is the unpredictability. The only consistent attribute – the inconsistency. There is little argument on any level but that autism is baffling, even to those who spend their lives around it. The child who lives with autism may look “normal” but his behavior can be perplexing and downright difficult. Autism was once thought an “incurable” disorder, but that notion is crumbling in the face knowledge and understanding that is increasing even as you read this. Every day, individuals with autism are showing us that they can overcome, compensate for and otherwise manage many of autism’s most challenging characteristics. Equipping those around our children with simple understanding of autism’s most basic elements has a tremendous impact on their ability to journey towards productive, independent adulthood. Autism is an extremely complex disorder but for purposes of this one article, we can distill its myriad characteristics into four fundamental areas: sensory processing challenges, speech/language delays and impairments, the elusive social interaction skills and whole child/self-esteem issues. And though these four elements may be common to many children, keep front of-mind the fact that autism is a spectrum disorder: no two (or ten or twenty) children with autism will be completely alike. Every child will be at a different point on the spectrum. And, just as importantly – every parent, teacher and caregiver will be at a different point on the spectrum. Child or adult, each will have a unique set of needs.



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

■ I am first and foremost a child. I have autism. I am not primarily “autistic.” My autism is only one aspect of my total character. It does not define me as a person. Are you a person with thoughts, feelings and many talents, or are you just fat (overweight), myopic (wear glasses) or klutzy (uncoordinated, not good at sports)? Those may be things that I see first when I meet you, but they are not necessarily what you are all about. As an adult, you have some control over how you define yourself. If you want to single out a single characteristic, you can make that known. As a child, I am still unfolding. Neither you nor I yet know what I may be capable of. Defining me by one characteristic runs the danger of setting up an expectation that may be too low. And if I get a sense that you don’t think I “can do it,” my natural response will be: Why try?

■ My sensory perceptions are disordered. Sensory integration may be the most difficult aspect of autism to understand, but it is arguably the most critical. It means that the ordinary sights, sounds, smells, tastes and touches of everyday that you may not even notice can be downright painful for me. The very environment in which I have to live often seems hostile. I may appear withdrawn or belligerent to you but I am really just trying to defend myself. Here is why a “simple” trip to the grocery store may be hell for me: My hearing may be hyper-acute. Dozens of people are talking at once. The loudspeaker booms today’s special. Music whines from the sound system. Cash registers beep and cough, a coffee grinder is chugging. The meat cutter screeches, babies wail, carts creak, the fluorescent lighting hums. My brain can’t filter all the input and I’m in overload! My sense of smell may be highly sensitive. The fish at the meat counter isn’t quite fresh, the guy standing next to us hasn’t showered today, the deli is handing out sausage samples, the baby in line ahead of us has a poopy diaper, they’re mopping up pickles on aisle 3 with ammonia....I can’t sort it all out. I am dangerously nauseated. Because I am visually oriented (see more on this below), this may be my first sense to become over-stimulated. The fluorescent light is not only too bright, it buzzes and hums. The room seems to pulsate and it hurts my eyes. The pulsating light bounces off everything and distorts what I am seeing -- the space seems to be constantly changing. There’s glare from windows, too many items for me to be able to focus (I may compensate with “tunnel vision”), moving fans on the ceiling, so many bodies in constant motion. All this affects my vestibular and proprioceptive senses, and now I can’t even tell where my body is in space.

■ Please remember to distinguish between won’t (I choose not to) and can’t (I am not able to). Receptive and expressive language and vocabulary can be major challenges for me. It isn’t that I don’t listen to instructions. It’s that I can’t understand you. When you call to me from across the room, this is what I hear: “\*^%\$#@, Billy. #%^\*^%\$&\*.....” Instead, come speak directly to me in plain words: “Please put your book in your desk, Billy. It’s time to go to lunch.” This tells me what you want me to do and what is going to happen next. Now it is much easier for me to comply.

■ I am a concrete thinker. This means I interpret language very literally. It’s very confusing for me when you say, “Hold your horses, cowboy!” when what you really mean is “Please stop running.” Don’t tell me something is a “piece of cake” when there is no dessert in sight and what you really mean is “this will be easy for you to do.” When you say “Jamie really burned up the track,” I see a kid playing with matches. Please just tell me “Jamie ran very fast.” Idioms, puns, nuances, double entendres, inference, metaphors, allusions and sarcasm are lost on me.



■ Please be patient with my limited vocabulary. It's hard for me to tell you what I need when I don't know the words to describe my feelings. I may be hungry, frustrated, frightened or confused but right now those words are beyond my ability to express. Be alert for body language, withdrawal, agitation or other signs that something is wrong. Or, there's a flip side to this: I may sound like a "little professor" or movie star, rattling off words or whole scripts well beyond my developmental age. These are messages I have memorized from the world around me to compensate for my language deficits because I know I am expected to respond when spoken to. They may come from books, TV, the speech of other people. It is called "echolalia." I don't necessarily understand the context or the terminology I'm using. I just know that it gets me off the hook for coming up with a reply.

■ Because language is so difficult for me, I am very visually oriented. Please show me how to do something rather than just tell me. And please be prepared to show me many times. Lots of consistent repetition helps me learn. A visual schedule is extremely helpful as I move through my day. Like your day-timer, it relieves me of the stress of having to remember what comes next, makes for smooth transition between activities, and helps me manage my time and meet your expectations. I won't lose the need for a visual schedule as I get older, but my "level of representation" may change. Before I can read, I need a visual schedule with photographs or simple drawings. As I get older, a combination of words and pictures may work, and later still, just words.

■ Please focus and build on what I can do rather than what I can't do. Like any other human, I can't learn in an environment where I'm constantly made to feel that I'm not good enough and that I need "fixing." Trying anything new when I am almost sure to be met with criticism, however "constructive," becomes something to be avoided. Look for my strengths and you will find them. There is more than one "right" way to do most things.

■ Please help me with social interactions. It may look like I don't want to play with the other kids on the playground, but sometimes it's just that I simply do not know how to start a conversation or enter a play situation. If you can encourage other children to invite me to join them at kickball or shooting baskets, it may be that I'm delighted to be included. I do best in structured play activities that have a clear beginning and end. I don't know how to "read" facial expressions, body language or the emotions of others, so I appreciate ongoing coaching in proper social responses. For example, if I laugh when Emily falls off the slide, it's not that I think it's funny. It's that I don't know the proper response. Teach me to say "Are you OK?"

■ Try to identify what triggers my meltdowns. Meltdowns, blow-ups, tantrums, or whatever you want to call them, are even more horrid for me than they are for you. They occur because one or more of my senses has gone into overload. If you can figure out why my meltdowns occur, they can be prevented. Keep a log, noting times, settings, people, activities. A pattern may emerge. Try to remember that all behavior is a form of communication. It tells you, when my words cannot, how I perceive something that is happening in my environment. *Parents, keep in mind as well: persistent behavior may have an underlying medical cause. Food allergies and sensitivities, sleep disorders, and gastrointestinal problems can all have profound effects on behavior.*

■ Love me unconditionally. Banish thoughts like, "If he would just....." and "Why can't she....." You did not fulfill every last expectation your parents had for you and you



wouldn't like being constantly reminded of it. I did not choose to have autism. But remember that it is happening to me, not you. Without your support, my chances of successful, self-reliant adulthood are slim. With your support and guidance, the possibilities are broader than you might think. I promise you – I am worth it.

And finally, three words: Patience. Patience. Patience. Work to view my autism as a different ability rather than a disability. Look past what you may see as limitations and see the gifts autism has given me. It may be true that I'm not good at eye contact or conversation, but have you noticed that I don't lie, cheat at games, tattle on my classmates or pass judgment on other people? Also true that I probably won't be the next Michael Jordan. But with my attention to fine detail and capacity for extraordinary focus, I might be the next Einstein. Or Mozart. Or Van Gogh. They had autism too. The answer to Alzheimer's, the enigma of extraterrestrial life -- what future achievements from today's children with autism, children like me, lie ahead? All that I might become won't happen without you as my foundation. Be my advocate, be my friend, and we'll see just how far I can go.

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***Different Books and Websites Resonate with Different Families. Here are some that parents have recommended. For a more complete list of books and web sites, as well as magazines, products, and DVDs, please visit our Resource Library on the Autism Speaks web site, [www.AutismSpeaks.org](http://www.AutismSpeaks.org).***

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

By Veronica Zysk and Ellen Notbohm (Publisher: Future Horizons; 1 edition, 2004)

***A Parent's Guide to Asperger Syndrome & High-Functioning Autism***

By Sally Ozonoff, Ph.D., Geraldine Dawson, Ph.D., James McPartland (Publisher: The Guildford Press; 1 edition, 2002)

***Activity Schedules for Children with Autism: Teaching Independent Behavior***

By Lynn E., McClannahan, Ph.D. and Patricia J. Krantz, PhD, (Publisher: Woodbine House; 1 edition, 1999)



***The Autism Sourcebook***

By Karen Siff Exkorn (Publisher: Collins; 1 edition, 2006)

***Autism Spectrum Disorders: The Complete Guide***

By Chantal Sicile-Kira(Publisher: Vermilion, 2003)

***Changing the Course of Autism: A Scientific Approach for Parents and Physicians***

By Brian Jepson, M.D. and Jane Johnson (Publisher: Sentient Publications; 1 edition 2007)

***Children with Autism: A Parent's Guide***

By Michael D. Powers (Publisher: Woodbine House; 2 Sub edition, 2000)

***Could it be Autism? A Parent's Guide to the First Signs and Next Steps***

By Nancy Wiseman (Publisher: Broadway; 1 edition, 2006)

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

By Wendy L. Stone, Ph.D. and Theresa Foy Digeronimo, MED(Publisher: Jossey-Bass; 1 edition, 2006)

***Facing Autism: Giving Parents Reasons for Hope and Guidance for Help***

By Lynn M. Hamilton (Publisher: WaterBrook Press; 1 edition, 2000)

***Let Me Hear Your Voice***

By Catherine Maurice (Publisher: Ballantine Books, 1994)

***Look Me in the Eye: My Life with Asperger's***

By John Elder Robinson (Three Rivers Press, 2008)

***Making Peace with Autism: One Family's Story of Struggle, Discovery, and Unexpected Gifts***

By Susan Senator (Trumpeter, 2006)

***Not My Boy!: A Father, A Son, and One Family's Journey with Autism***

By Rodney Peete (Hyperion 2010)

***Nourishing Hope***

by Julie Matthews ([www.NourishingHope.com](http://www.NourishingHope.com))

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

By Lynn Kern Koegel, PhD Claire LaZebnik (Publisher: Penguin /Non-Classics, 2005)

***Playing, Laughing, and Learning with Children on the Autism Spectrum: A Practical Resource of Play Ideas for Parents and Caregivers***



By Julia Moor (Publisher: Jessica Kingsley Publishers; 1 edition, 2002)

***Play and engagement in early autism: The Early Start Denver Model***  
by Sally Rogers, PhD and Geraldine Dawson, PhD. Publisher: New York: Guilford Publishing, 2009)

***A Practical Guide to Autism: What Every Parent, Family Member, and Teacher Needs to Know***

By Fred R. Volkmar and Lisa A. Wiesner (Wiley, 2009)

***Siblings of Children with Autism: A Guide for Families***

By Sandra L. Harris, PhD and Beth A. Glasberg, Ph.D. (Publisher: Woodbine House, 1994)

***Special Diets for Special People: Understanding and Implementing a Gluten-Free and Casein-Free Diet to Aid in the Treatment of Autism and Related Developmental Disorders***

By Lisa S. Lewis (Publisher: Future Horizons, 2005)

***Strange Son***

By Portia Iverson (Riverhead Trade, 2007)

***Ten Things Every Child with Autism Wishes You***

By Ellen Notbohm (Future Horizons, 2005)

***The Complete Guide to Asperger's Syndrome***

By Tony Attwood (Jessica Kingsley Publishers, 2008)

***There's a Boy in Here***

By Judy Barron and Sean Barron (Future Horizons, 2002)

***Thinking in Pictures, Expanded Edition: My Life with Autism***

By Temple Grandin (Vintage, 2006)

***The Out-of-Sync Child***

By Carol Kranowitz (Perigee Trade, 2006)

***Understanding Autism For Dummies***

By Stephen Shore and Linda G. Rastelli (For Dummies, 2006)

***You're Going to Love This Kid!: Teaching Students With Autism in the Inclusive Classroom***

By Paula Kluth (Brookes Publishing Company, 2003)

## ***Books for Children***

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***Everybody is Different: A Book for Young People who have Brothers or Sisters with Autism***

By Fiona Bleach (Reading Level: Ages 4-8, Publisher: Autism Asperger Publishing Company, 2002)

***The Autism Acceptance Book, Being a Friend to Someone with Autism***

By Ellen Sabin (Reading Level: Ages 9-12, Publisher: Watering Can 38 Press; 1 edition, 2006)

## ***Websites***

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***Autism Research Institute***

[www.Autism.com](http://www.Autism.com)

***Autism Speaks***

[www.AutismSpeaks.org](http://www.AutismSpeaks.org)

***Autism Society of America***

[www.Autism-Society.org](http://www.Autism-Society.org)

***First Signs***

[www.FirstSigns.org](http://www.FirstSigns.org)

***Interactive Autism Network***

[www.ianproject.org](http://www.ianproject.org)

***National Autism Association***

[www.NationalAutismAssociation.org](http://www.NationalAutismAssociation.org)

***Organization for Autism Research***

[www.ResearchAutism.org](http://www.ResearchAutism.org)

***RethinkAutism***

[www.rethinkautism.com](http://www.rethinkautism.com)

***The HollyRod Foundation***

[www.hollyrod.org](http://www.hollyrod.org)

***Unlocking Autism***

[www.UnlockingAutism.org](http://www.UnlockingAutism.org)

