



# First 100 Days 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*

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# About this Kit...

*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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# Contact Us...

## Ask for Help

Contact the

### Autism Response Team

Autism Response Team (ART) members are specially trained to help families with the day-to-day challenges of living with autism. Contact ART with your questions about resources, support and information.

Call us at 888-AUTISM 2 (288-4762) or email:

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[westART@autismspeaks.org](mailto:westART@autismspeaks.org)

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## 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 [1oodaykit@AutismSpeaks.org](mailto:1oodaykit@AutismSpeaks.org), with the word "feedback" in the subject line.








# Autism Speaks.™ 100 Day Kit.

## Section

	<b>About Autism.....</b>	<b>1</b>
	Why was my child diagnosed with Autism? And what does it mean?.....	1
	Why does my child need a diagnosis of Autism?.....	1
	How is Autism Diagnosed?.....	2
	What is Autism?.....	3
	More information on the Symptoms of Autism.....	5,6,7
	Unique Abilities that may Accompany Autism.....	8
	Physical & Medical Issues that may Accompany Autism.....	9,10
	<b>You, Your Family &amp; Autism.....</b>	<b>2</b>
	How will I deal with the diagnosis?.....	11,12,13
	Tips from Experienced Parents.....	13,14
	What should we know about our younger and future children?.....	14
	How will this effect our Family?.....	15
	Sharing Your Struggle.....	16
	Fifteen Tips for your Family.....	17,18
	<b>Getting Your Child Services.....</b>	<b>3</b>
	How do I get help my child get the help he needs?.....	19
	Accessing Services.....	20
	Your Child's Rights.....	20,21
	<b>Treating Autism.....</b>	<b>4</b>
	How is Autism Treated?.....	23
	Treatments for Core Symptoms.....	24-30
	Applied Behavioral Analysis (ABA).....	25, 26
	Pivotal Response Treatment (PRT).....	26
	VerbalBehavior(VB).....	26,27
	Floortime (DIR).....	27, 28
	Relationship Development Intervention (RDI).....	28
	Training & Education of Autistic & Related Communication Handicapped Children (TEACCH).....	29
	Social Communication/Emotional Regulation/Transactional Support (SCERTS).....	29, 30
	Treatment for Associated, Medical & Biological Symptoms.....	31-33
	Is there a Cure?.....	33
	Choosing the Right Intervention.....	34
	<b>Making it Happen.....</b>	<b>5</b>
	Assembling Your Team.....	35
	Hiring Therapists.....	36
	Managing Your Team.....	36
	Including Your Family in Your Child's Therapy.....	37
	Suggested Books & Websites.....	38,39,40,41

Section

	Action Plan for the next 100 Days.....	6
	Autism Safety Kit .....	7
	Useful Forms.....	8
	Glossary.....	9
	Your Local Resources.....	10

# Why was my child diagnosed with Autism? And what does it mean?

Your child has been diagnosed with autism and you have asked for help. This is an important turning point in a long journey. For some families, it may be the point where, 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’s 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 are 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, prevention, treatment and a cure for autism. Great strides have been made and the 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 work at a constantly increasing pace toward a cure for autism. While indeed, 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, your child is the same unique, lovable, wonderful person he or she was before the diagnosis. There are however, several reasons why having a diagnosis is important for

# *Autism Speaks*



“Now we know Nicky has Autism. Everyone told me I was worrying about nothing; that he was a late bloomer and would ‘grow out of it.’ I didn’t want to wait and see if he got better. Now that we know, we can help him.”

your child. A thorough and detailed diagnosis provides important information about your child’s behavior and development. It can provide a road map for treatment, by identifying your child’s specific strengths and challenges, providing useful information about which needs and skills to target for intervention. A diagnosis is often required to access autism specific services through early intervention programs or your local school district.

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 (MCHAT)** should be used.

The MCHAT, 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. If this was not the case for your child, you will want to make sure further evaluations are conducted so that you can learn as much as possible about your child’s strengths and needs.

## 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 yourself. 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 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 well visits. If concerns about a child’s development are raised, their doctor should

More information on terms that are printed in **bold** is available in the glossary at the end of this handbook and in the Video Glossary at [www.AutismSpeaks.org](http://www.AutismSpeaks.org)



# What is Autism?

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’s 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 at least six developmental and behavioral characteristics are observed, that problems are present before age three, and there is no evidence for certain other conditions that are similar.

## 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?

Today, it is estimated that one in every 150 children is diagnosed with autism, making it more common than childhood cancer, juvenile diabetes and pediatric AIDS combined. An estimated 1.5 million individuals in the U.S. 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 not established explanation for this increase, although improved diagnosis 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 94 boys is diagnosed with autism.

## What causes Autism?

The simple answer is we don't know. The vast majority of cases of autism are idiopathic, which means the cause is unknown.

The more complex answer is that just as there are different levels of severity and combinations of symptoms in autism, there are probably multiple causes. The best scientific evidence available to us today points toward a potential for various combinations of factors causing autism – multiple genetic components that may cause autism on their own or possibly when combined with exposure to as yet undetermined environmental factors. Timing of exposure during the child's development (before, during or after birth) may also play a role in the development or final presentation of the disorder.

A small number of cases can be linked to genetic disorders such as Fragile X, Tuberous Sclerosis, and Angelman's Syndrome, as well as exposure to environmental agents such as infectious ones (maternal rubella or cytomegalovirus) or chemical ones (thalidomide or valproate) during pregnancy.

There is a growing interest among researchers about the role of the functions 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 involve 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 definitive cause (or causes) of autism is not yet clear, 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 not caused by cold parents but rather is a biological disorder.

The best scientific evidence available to us today points toward a potential for various combinations of factors causing autism.



# 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 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.

The symptoms of autism typically last throughout a person's lifetime. A mildly affected person might seem merely quirky and lead a typical life. A severely affected person might be unable to speak or care for himself. 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 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 even smile.

By contrast, most children with autism seem to have tremendous difficulty learning to engage in the give-and-take of everyday human interactions. Even in the first year of life, many do not interact and avoid eye contact in a normal way. They may seem indifferent to other people, and prefer being alone. They may resist attention or passively accept hugs and cuddling. Later, they may fail to seek comfort or

respond to parents' displays of anger or affection in a typical way. 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. Parents who looked forward to the joys of cuddling, teaching and playing with their child may feel crushed by this lack of the expected and typical attachment behavior.

Children with autism also are 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 different thoughts, feelings, and goals than they have. 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 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.

# 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”.

Some people with autism remain mute throughout their lives; although the majority develops spoken language and all eventually learn to communicate in some way. Some infants who later show signs of autism “coo” and babble during the first few months of life, but 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 of 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 are 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 have great difficulty in sustaining a conversation. The “give and take” of normal conversations may be hard, although 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.

While it can be challenging for others to understand what children with autism are less able to say, their body language may also be difficult to understand. 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 are less able to let others know what they need. As a result, they may simply scream or grab what they want. Until they are taught better ways to express their needs, children with autism do whatever they can to get through to others. As they grow up, they can become increasingly aware of their difficulties in understanding others and in being understood. As a result, they are at greater risk of becoming anxious or depressed.

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# 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 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 be tremendously upset. Many children with autism need, and demand, absolute consistency in their environment. A slight change in routines, such as mealtimes, dressing, 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. Being interested in fans or toilets) or because of the intensity of the interest (e.g. knowing much more detailed information about Thomas the Tank Engine than peers). 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

You may have recognized that your child with autism has some unusual skills and abilities. The information that follows, adapted from Sally Ozonoff, Geraldine Dawson and James McPartland's book, *A Parent's Guide to Asperger's Syndrome and High-Functioning Autism*, and the article, "How can my child have Autism when he seems so smart?" From *Does My Child Have Autism?* By Wendy Stone, highlight some of them.

Consider incorporating some of these abilities into your child's treatment plan, where possible and appropriate, to take advantage of them.

## From A Parent's Guide to Asperger Syndrome and High-Functioning Autism

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

**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.

# Physical and Medical Issues

that may Accompany Autism

## 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 without. Some researchers have suggested that it 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.

## Genetic Disorders

A small number of children with autism may also have an identifiable neurogenetic condition such as **Fragile X Syndrome**, **Angelman’s Syndrome**, a neurocutaneous disorder called **Tuberous Sclerosis**, **Chromosome 15 Duplication Syndrome** or another chromosomal abnormality.

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 a little

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 because 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 number of children with both gastrointestinal issues such as gastritis, chronic constipation, colitis, celiac disease and esophagitis and autism is unknown. Surveys have suggested that between 46 and 85% of children with autism have problems such as chronic constipation or diarrhea.

One recent 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, compared with 42% of children with other developmental disabilities and 28% of children without developmental disabilities.

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 such as rocking or outbursts of aggression or self-injury. Bear in mind that your child may not have the language skills to communicate pain caused by GI issues. Treating GI problems may result in improvement in your child’s behavior.

A popular dietary intervention for GI issues includes 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 February 2007, Autism Speaks initiated a campaign to inform pediatricians about the diagnosis and treatment of GI problems associated with autism. For additional information that can be



shared with your child's doctor, go to the following link on the *Autism Speaks* website: [www.AutismSpeaks.org/docs/Autism\\_Speaks\\_GI\\_Statement\\_1-07.pdf](http://www.AutismSpeaks.org/docs/Autism_Speaks_GI_Statement_1-07.pdf)

## 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 study 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 the 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 of 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?

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

### 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 some of the hopes and dreams they held 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.

### 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 at 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’s an attempt to tell the people around you that you hurt, 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 related 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 of that you may be experiencing 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 monitoring of 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 you have the time to contact friends or family for company or 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 affected by 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

Changing the course of your child's life 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. Or, 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 so that you can keep going.

### 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.

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!

**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 for 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.

## 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 it will help you to be 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 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 journaling a helpful tool for keeping track of their children's progress, what's 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?

Although autism is believed to have a strong environmental component, there is little doubt that autism is a disorder with a strong genetic basis. 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.

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. This risk increases if two or more children in the family are already affected.

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 and Israel, with a similar effort in 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 Family Services at [www.AutismSpeak.org/participate/index.php](http://www.AutismSpeak.org/participate/index.php) to find a project in your area. 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, contact Family Services at *Autism Speaks* to help identify an early intervention program in your area.

## How will this affect our Family?

Even though it is your child who has the diagnosis, it is important to acknowledge that autism “happens” to the whole family. It affects every member of the household. 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 & friends

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.

Our friends and families rallied around us in amazing ways and have continued to cheer Andrew's progress.

**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.



# Fifteen Tips for Your Family

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

## 5 Tips for Parents

**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.

## 5 Tips for Brothers & Sisters

**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.

## 5 Tips for Grandparents and Extended Family

**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 both 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 that you are making.

# How do I get the help my child 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:

## Early Intervention is Your Child's Best Hope for the Future

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

Your special needs child has the right to a free and appropriate education. The Individuals with Disabilities Education Act (IDEA), which was first enacted in 1975 and most recently revised in 2004, mandates that each state provide all eligible children with a public education that meets their individual needs.

The Individuals with Disabilities Act (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 all eligible children with a free and appropriate public education that meets their unique individual needs.

IDEA specifies that children with various disabilities, including autism, are entitled to early intervention services and special education. If your child has been diagnosed with a form of autism, the diagnosis is generally sufficient to gain access to the rights afforded by IDEA. The IDEA legislation has established an important role for parents in their children's education. 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 and his or her individual needs. This enables you to be a powerful advocate for your child. It also means that you must be an informed, active participant in planning and monitoring your child's unique program and legal rights.

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 or optimal program and services, the school district is not required to provide the best or optimal but rather 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 that may involve considerable negotiation to secure the services from the school.

## What is "Least Restrictive Environment" (LRE)?

As specified in the IDEA, your child is also entitled to experience the "least restrictive environment." This means that your child should be placed in the environment in which he or she has the greatest possible opportunity to interact with children who do not have a disability and to participate in the general education curriculum. This is commonly referred to as mainstreaming or inclusion. In the general education setting, providing the least restrictive environment can sometimes be accomplished with accommodations, such as using a one-on-one aide who is trained to work with children with autism. While it may be true that seeking the least restrictive environment is beneficial for children with autism, it's important to consider whether or not an option such as inclusion is right for your child. It may or may not be more appropriate for your child to be placed in a special education program, in a school for children with special needs, or in a home instruction program.



# Early Intervention Services (EI)

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. If your child is determined to be eligible, these early intervention services must be provided to you at no cost.

EI services can vary widely from state to state and region to region. However, the services should address your child's unique needs rather than being limited to what is currently available or customary in your area. The document that spells out your child's needs and the services that will be provided is the Individual Family Service Plan (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.

# Special Education Services

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.

# 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. Contact information is included in the local resources guide of this kit.

For Special Education Services, if your child is three or older, contact your local school district. 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. Often, they 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.

If you find you are spinning your wheels, waiting for them, there are things you can be doing to 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 in this kit.)

“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 your being trained 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. You may find it is helpful to see the different methods in action so that you can better understand them. The ASD Video Glossary on the *Autism Speaks* web site, [www.AutismSpeaks.org](http://www.AutismSpeaks.org), is a great place to start.

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. Before beginning any therapy, please read the information in this handbook about "Choosing Providers."

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 Apraxia, Cerebral Palsy or Celiac Disease, might require some of the same therapies. Examples of these treatments are Speech & Language Therapy, Occupational Therapy, or the care of a

Gastroenterologist. For this reason, we've included information here to explain treatments for the Core Symptoms of autism & the treatments for Associated Symptoms and Biological and Medical Conditions Associated with autism.

Intensive treatments for autism's Core Symptoms address the Social, Communication & Cognitive 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.

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.

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

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’s helpful to take a step back and look at the bigger picture. Although research and experience have revealed many of the mysteries surrounding autism, it remains a complex disorder that impacts each child differently. However, many children with autism have made remarkable breakthroughs with the right combinations of therapies and interventions.

Most parents would welcome a 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, 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.

Turn to the glossary in this kit, [www.AutismSpeaks.org](http://www.AutismSpeaks.org) and your pediatrician for more information so that you can be confident you are making informed choices as you begin to narrow down your options.

# Applied Behavioral Analysis (ABA)

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 ABA?

There is a lot of confusion and disagreement surrounding the use of the term Applied Behavioral Analysis, or ABA. Since the early 1960's, hundreds of behavior analysts have used positive reinforcement in a repetitive manner to teach communication, play, social, academic, self-care, work and community living skills and to reduce problem behaviors in learners with autism. During this time, different models using ABA have emerged, all of which use behavioral teaching. They are all based on Skinner's work. Many of them use the research and techniques of other experts in the field of using behavioral analysis to teach children with autism.

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;
- And a consequence, which depends on the behavior. The consequence can include positive reinforcement of the desired behavior or no response for incorrect response.

ABA is sometimes referred to as the Lovaas Model, for its pioneer, Dr. Ivar Lovaas, or Discrete Trial Teaching (DTT), for its primary teaching technique. 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 that the child finds to be highly motivating.

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.

## What is the difference between ABA and Verbal Behavior and Pivotal Response Treatment?

Verbal Behavior and Pivotal Response Treatment therapies are different forms of ABA with different emphasis and techniques. All of these methods use the three step process described previously.

## Who provides ABA?

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 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 taken at the end of every hour. Free play and breaks are used for incidental teaching or practicing skills in new environments.

## What is the intensity of most ABA programs?

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

## Where can I find more information on ABA?

*The Association for Behavior Analysis International*

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

*Behavior Analyst Certification Board*

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

## Pivotal Response Treatment

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.

### What is PRT?

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 child’s initiations 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 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 the variation of tasks, revisiting mastered tasks to ensure the child retains acquired skills, rewarding attempts, and the use of 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 (for example, if a child attempts a request for a stuffed animal, the child receives the animal).

## Who provides PRT?

Psychologists, special education teachers, speech therapists and other providers specifically 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 as well as 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>

## 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.

### What is VB?

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 identified by Skinner serves a different function. The most important of these operants, or units, he named echoics, mands, tacts and intraverbals:

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 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 anyway he can (vocally, sign language, etc.). If the child can echo the word he will be motivated to do so 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 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.

## Where can I find more information on VB?

Cambridge Center for Behavioral Studies  
[www.behavior.org/vb/](http://www.behavior.org/vb/)

# Floortime (DIR)

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 more 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 behavioral 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.

## Where can I find more information on Floortime?

*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)

# Relationship Development Intervention (RDI)

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 individual's long-term quality of life 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:** Using 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 and 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 use the principles of RDI in their day to day lifestyle.

## Where can I find more information on RDI?

*Connections Center*

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

# Training and Education of Autistic and Related Handicapped Children (TEACCH)

TEACCH is a special education program, developed by Eric Schopler, PhD and 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 strength and preference for processing information visually, while taking into account the recognized difficulties.

Children with autism are assessed to identify emerging skills and work then focuses on these to enhance them. In Structured Teaching, an individualized plan is developed for each student rather than using a standard curriculum. 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 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 techniques can be continued at home.

## Who provides TEACCH?

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

## Where can I find more information on TEACCH?

TEACCH Autism Program

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

## 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 children who provide good social and language models in inclusive settings as much as possible. SCERTS is implemented using transactional supports implemented by a team, such as environmental accommodations, learning supports (schedules or visual organizers).

## Who provides SCERTS?

SCERTS is usually provided in a school setting by SCERTS-trained special education teachers, speech therapist.

## 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 Associated, 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 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.

Speech-language therapy 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 a half hour to one hour session 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 and improved social, fine motor and visual perceptual skills.

OT is provided by Certified Occupational Therapists.

## Sensory Integration Therapy (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 them 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 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, reinforce a desired behavior or to help with transitions between activities.

Therapists begin with an individual evaluation to determine what your child’s sensitivities are. The therapist then plans an individualized program for the child matching sensory stimulation with physical movement to improve how the brain processes and organizes sensory information. The 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 focuses on any problems with movement that cause functional limitations. Children with autism frequently have challenges with motor skills such as sitting, walking, running and jumping. PT can also address poor muscle tone, balance and coordination.

A physical therapist will start by evaluating the abilities and developmental level of the child. Once they identify where the individual's challenges are, they design activities that target those areas. PT might include assisted movement, various forms of exercise and orthopedic equipment.

Physical therapy is usually delivered in a half hour to one hour session by a Certified Physical Therapist, with the frequency determined by the needs of the child.

# Picture Exchange Communication System (PECS)

Picture Exchange Communication System (PECS) is a learning system that allows children with little or not verbal ability to communicate using pictures. PECS can be used at home, in the classroom or a variety of settings. A therapist, teacher or parent helps the child build a vocabulary and 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 Tomatis and Berard.

While some individuals have reported improvements in auditory processing resulting from 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. 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), is a popular dietary treatment for symptoms of autism.

The theory behind this diet is that proteins are absorbed differently in some children. Rather than having an allergic reaction, children who benefit from the GFCF diet experience physical and behavioral symptoms. While there have not yet been sufficient scientific studies to support this theory, 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 in their individual child.

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 intervention team.

Families choosing a trial of dietary restriction should make sure their child is receiving adequate nutrition. Dairy products are the most common source of calcium and vitamin D in young children in the U.S. Many young children depend on dairy products for a balanced protein intake. Alternative sources of these nutrients require the substitution of other food and

beverage products with attention to the nutritional content.

Substitution of gluten free products requires attention to the overall fiber and vitamin content of a child's diet. Vitamin supplement use may have both positive effects and side effects. Consultation with a dietician or physician should be considered and can be helpful to families in the determination of healthy application of a GFCF diet. This may be especially true for children who are picky eaters.

## What about other medical interventions?

Right now you are eager to do everything possible to help your child. Many parents in your position are eager to try new treatments, even those 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's important to remember that just as each child with autism presents differently, so is their 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, so that you can 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 a history of therapies and biomedical interventions that have been promised as a cure for autism over the years. Some of them may have been meaningful for a small number of children. Upon further study, none of them, so far, has turned out to be a cure for many.

We do know that many children get better with intensive behavioral therapy. There is a large body of scientific evidence to support it. For this reason, it makes sense to focus on getting your child engaged in an intensive program before looking at other interventions.

## Is there a Cure? Is recovery possible?

You may have heard about children who have recovered from autism. Experts disagree about whether or not this is possible.

Growing evidence suggests that a small minority of children with autism have progressed to the point where they no longer meet the criteria for a diagnosis. The theories behind the recovery of some children range from the assertion that the child was misdiagnosed to the belief that the child had a form of autism that may resolve as he matures to the opinion that the child benefited from successful treatment. 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.

Some children who no longer meet the criteria for an autism diagnosis are later diagnosed as having ADHD, Anxiety or even Asperger Syndrome.

We don't yet know what percentage of children with autism will recover, or what genetic, physiological or developmental factors can predict which ones will. Recovery from autism is usually reported in connection with intensive early intervention, but we do not know how much or which type of intervention works best, or whether the recovery can be fully credited to the intervention. Presently, there is no 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. Most children with autism will benefit from intervention. Many, if not most, will make very significant, meaningful progress.

# How do I choose the right intervention?

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

## Alleviate Stress by Actively Pursuing the Right Intervention

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

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

## Understanding Your Child's Learning Style

From: *Does My Child Have Autism?*  
By Wendy Stone, PhD, & 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 by-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 with autism seem to learn effortlessly, without being taught, but that children with autism don't pick up on as easily. For example, young children without autism somehow learn, without explicit teaching, how to use a pointing gesture to let you know what they want or to indicate where they want you to look. They learn to follow your point or eye gaze to figure out what you're looking at or what you're interested in. They figure out on their own how to use eye contact and facial expressions to convey their feelings—as well as to understand the meaning of your facial expressions and tone of voice. Social-communicative behaviors and skills like these just don't come as naturally to young children with autism and often need to be taught explicitly.



# Assembling your Team

## Medical Team

Your child should be supported by a pediatrician who understands developmental issues, 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, 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, Occupational Therapy, Physical Therapy, or Social Skills instruction are all related services. All therapists working with your child should be communicating frequently, and use 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 in the resume:

- Past experience with children with autism approximately the same age as yours.
- The amount of experience the therapist has.
- 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 this profession.

## Conduct interviews

Conduct a portion of the interview as 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. It 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 video taped 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 in 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 your therapists are up to date on every aspect of the program and are all working with your child in a consistent way. At team meetings, you will discuss what is working, as well as where there has not been progress so that you can determine whether to make changes and what those changes will 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 looking for another therapist or agency.



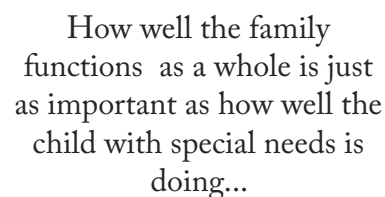
# Including your family in your child's program

## Making Therapies Work for the Entire Family


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

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

How well the family functions as a whole is just as important as how well the child with special needs is doing, and it's your responsibility to work toward both kinds of success.



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



# Suggested Reading

Different books and web sites 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, 2005)

*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)

*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)

*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)

## Books for Children

*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 Press; 1 edition, 2006)



## Websites

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)

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

National Autism Association  
[www.NationalAutismAssociation.org](http://www.NationalAutismAssociation.org)

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

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

# Ten Things Every Child with Autism Wishes You Knew

From *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 of 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:

## 1. 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?

## 2. 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. Musak 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 overstimulated. 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.

## 3. 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. #\$\$%^\*&c^%\$&\*.....” 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.

## 4. 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.

## 5. 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.



**6. Because language is so difficult for me, I am very visually oriented.** Please show me how to do something rather than just telling 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, 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.

**7. 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.

**8. 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?"

**9. 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.*

**10. 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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# A Week by Week Plan for the Next 100 Days

## Getting Organized

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

### The Binders

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

#### Contacts

A section for service providers, caregivers and others

#### Schedules

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

#### Diagnosis

A section for medical documents and any prescriptions

#### Therapy

A section for Speech, Occupational Therapy, SI, and so on (Multiple or sub sections may be necessary)

#### Individual Family Service Plan (IFSP)

A section for your child's IFSP and related documents (For children under three years of age)

#### Individualized Education Plan (IEP)

A section for your child's IEP and related documents (For children older than three years)

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

### Using your Weekly Planner

The time frame and action items will vary depending on your child's symptoms, your child's age, where you live and what you have already accomplished.

Even if you are very on top of this, it may take a while to be able to access additional evaluations and the services that your child needs.

# Start now.

# Week 1

## Complete Evaluations

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

## Getting Services

If your child is younger than three, you'll start with Early Intervention (EI) often through your state department of health. If your child is three or older, you'll start with your local school district. Call to begin the process of getting services. EI or your school district may want to conduct evaluations of your child (at their expense). This can be a long and time consuming process, but may be useful in further determining the services that are needed.

## Keep a Phone Log

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

## Start a Video Record

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

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# Week 2

## Getting Support

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

## Getting Services (Follow Up)

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

## Research Treatment Options

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

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# Week 3

## Getting Services (Continue to Follow Up)

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

## Play with Your Child

Play with your child. Play is an important part of any child's development, and is a critical part of learning socialization for a child with autism. We've included a very helpful article, Ideas for Purposeful Play, from the University of Washington's Autism Center that illustrates how to include useful play activities, which will help your child learn.



# Week 5

Continue Building Your Team  
See Week 4.

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

Get to know Your Child's  
Legal Rights

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

Do Something for You

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

## Set Aside Sibling Time

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

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# Week 4

Build Your Team

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

Create a safety plan

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

Plan some Time Away

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

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

# Week 6

## Continue to Research Treatment Options

Continue to research treatment options. If possible, go to a workshop or look for additional information online.

## Connect with Other Parents

Go to a support group or spend some time with a parent who can help you along your journey. You'll learn a lot and being around people who know what you are going through will help you stay strong.

## Find Childcare

Get a baby-sitter. Look into qualified baby-sitting services and respite care. Don't wait until you're desperate—find someone you're comfortable with and plan a night out. If you already have a great baby-sitter, invite her or him to spend some time with you and your child so they can adjust to the new techniques your family is using at home.

## Build your Team

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

## Schedule a Team Meeting

If you've built a team of therapists, you may want to call a meeting to establish procedures and goals and open lines of communication. You'll also want to continue observing therapy sessions and using what you learn at home. If it's difficult to schedule a time for the service providers to meet in person, you may want to schedule a conference call instead.

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

# Week 7

## Become Competent in the Intervention Methods you have Chosen for Your Child

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

## Create a Schedule

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

## Continue Learning about Treatments & Services

Continue research on treatments and services. Consult the *Autism Speaks* web site for contacts in your area.

## Spend some time organizing your paperwork

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

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

# Week 8

## Check your Progress

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





## Investigate Recreational Activities for Your Child

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

## Plan more Sibling Time

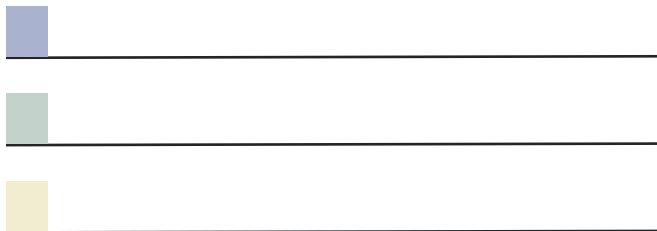
Your typically-developing children will no doubt be richer for having a sibling with Autism. But maintaining as much normalcy as possible will help them reach their potential too.

## Make Contact with Friends and Family

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

## Spend Time Alone with Your Spouse

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



# Week 9

## Round out Your Team

Continue to evaluate service providers and therapists.

## Use the Internet

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

## Continue to Connect with Other Parents

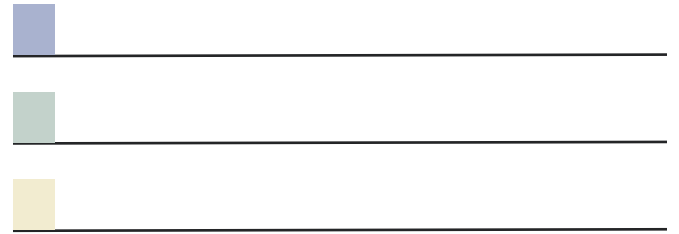
Stay active with a support group or, if possible, socialize with other parents of children with Autism. Being around other adults who understand what your family is going through will help you stay strong.

## Check in on Your Child's Sessions

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

## Play with Your Child

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



# Week 10

## Schedule a Team Meeting

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

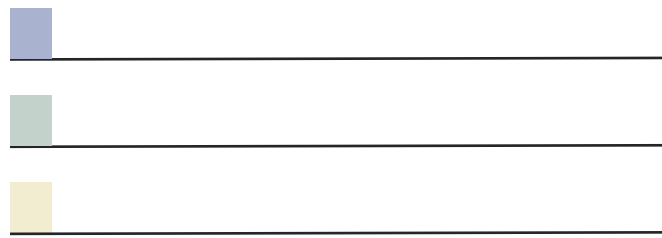
## Rally the Troops

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


## Plan a Family Outing

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

 **Brush up on the Law**  
Continue to learn about your child's legal rights.

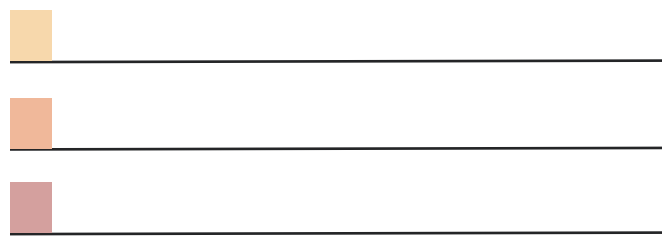


## Week 11


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

 **Dig deeper into Treatment Options**

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




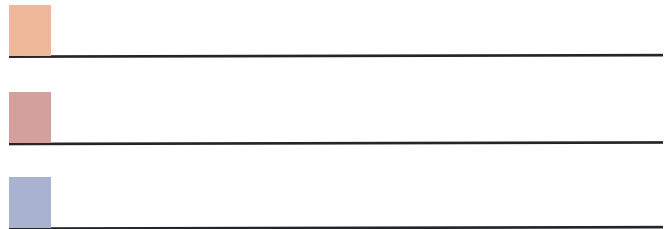
## Week 12

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


 **Continue Connecting with Other Parents**


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


 **Sign up for More Training**  
Using the methods you are learning from your child's therapists will help create a productive environment at home, so your child will have the best chance of obtaining their goals.

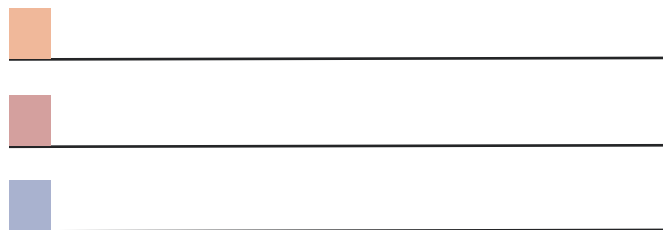


## Week 13

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

 **Continue Learning**  
Keep learning about autism. Books, seminars, movies, Web sites—all sorts of sources can help you deepen your understanding of autism and your child. See the Suggested Reading List in this kit for ideas.

 **Do Something for You**  
Enjoy some "me" time. Do something nice for yourself—you've made it through 100 days!



# Ideas for Purposeful Play

*From the University of Washington Autism Center Parent Care Book*

## Imitation: Object and Motor

- Sing finger play songs such as the Itsy Bitsy Spider, 5 Little Monkeys, Zoom down the Freeway
- Utilize musical instruments: “Let’s make music”, play Simon Says, have a musical parade, slow down, speed up, “Follow Me Song”
- Figurines: know on barn door, follow the leader to the schoolhouse
- Block play: make identical block structures
- Painting and drawing similar pictures, strokes, circles, lines, dot art
- Dramatic play: feeding babies, pouring tea, driving cars or trains on tracks, hammering nails, stirring

## Receptive and Expressive Labeling

Embed labeling into activities such as:

- House (cup, spoon, plate, door)
- Grocery store (orange, apple, banana)
- Dolls (body parts, brush, clothing)
- Barn (animals, tractor)
- Art: Colors, scissors, glue, markers, big crayons, little crayons
- Books: pointing and labeling objects, letters, numbers, shapes, etc.
- Sensory Table: put different colors of animals, shapes, sizes, common objects
- Park/Playground: slide, swing, ball
- Play Dough: use different colored play dough, animal shaped cookie cutters

## Receptive Instructions


- Songs: “Simon Says” clap hands, tap legs, etc.
- Clean up time: put in garbage, put on shelf
- During activities request items, “Give me \_\_\_\_”
- Ask child to get their coat/backpack on the way outside or at the end of the day

## Matching

- Lotto matching game
- Puzzles with pictures underneath
- Picture to object matching can be done as activity during play (have the child match the picture of a cow while playing with the barn)

## Requesting

- Utilize motivating items (i.e. bubbles, juice, trains) to address requesting/communication
- Swing: wait to push until child makes the request
- Door: wait to open until child makes a request
- Lunch/Snack withhold until child makes request
- Art: child can request glitter, glue, stickers, paint, etc.



# How can I keep my child Safe?

Autism presents a unique set of safety concerns for parents. The advocacy and awareness groups, Unlocking Autism (UA) and the National Autism Association (NAA), have teamed up to provide the following safety information for parents. Not all suggestions listed below are right for every family in every neighborhood. You should carefully consider the best safety options for your individual child.

“We had no idea Louis was out of the house, when we received a call from a neighbor. Thankfully, they were familiar with Lou and knew how to reach us.”

## Are You Prepared for an Autism Emergency?

A leading cause of concern for parents with a child with autism is children who run or wander away. In a recent online survey conducted by NAA, an incredible 92% of the parents who responded reported their children were at risk of wandering. This is a problem that must be addressed in every city and town across America. Please review the following information and contact your local first responders to get a plan in place for your child and others who may be at risk in your community.

Wandering can occur anywhere at anytime. The first time is often the worst time. Another concern is preparation in the event that you become incapacitated or injured while caring for a person with autism at home or in the community. If you are concerned that your child may wander, now is the time to get to know your local law enforcement, fire and ambulance agencies. Ask your local 911 call center to “red flag” this information in their 911 computer data base. Should you need help in the future, dispatchers can alert patrol officers about your concerns before they arrive. By providing law enforcement with key information before an incident occurs, you can expect better responses.

Make sure any alterations you make to your home not delay or prevent fire, police, ambulance or rescue personnel from getting to her or him immediately in an emergency.

# An ounce of prevention...

You know the expression, “an ounce of prevention is worth a pound of cure.” Following are some tools and ideas to help you plan for and prevent emergencies.

## Survey and secure your home

Are there changes you can make to help ensure your child’s safety? If wandering is an issue for your family, consider contacting a professional locksmith, security company or home improvement professional to prepare your home. You may find it is necessary to prevent your child from slipping away unnoticed by:

- Installing secure dead bolt locks that require keys on both sides.
- Installing a home security alarm system.
- Installing inexpensive battery-operated alarms on doors and windows to alert you when they are opened. These are available at stores like WalMart and Radio Shack.
- Placing hook and eye locks on all doors, above your child’s reach.
- Fencing your yard.



# Create an informational handout about your child.

Having a description of and information about your child could be an incredibly valuable tool in ensuring his or her safety. It should be copied and carried with you at all times, at home, in your car, purse or wallet. Include a photo of your child and any important information. Be sure to include your name, address and phone number. Circulate this handout to family members, trusted neighbors, friends and co-workers. The handout will also come in handy if you are in an area other than your neighborhood and need the help of or are approached by the police. This is one item it is important to have before you actually need it.

# Alert your neighbors

The behaviors and characteristics of a child with autism have the potential to attract attention from the public. Law enforcement professionals suggest that you reach out and get to know your neighbors.

Decide what information to present to neighbors:

- Does your child have a fear of cars and animals or is he drawn to them?
- Is your child a wanderer or runner?
- Does he respond to his name or would a stranger think he is deaf?





Plan a brief visit to your neighbors:

- Introduce your child or provide a photograph.
- If a neighbor spots your child outside of your yard, what is the best way for them to get your child back to you?
- Are there sensory issues your neighbors should know about?

Give your neighbor a simple handout with your name, address, and phone number. Ask them to call you immediately if they see your child outside the home. This approach may be a good way to avoid problems down the road and will let your neighbors:

- Know the reason for unusual behaviors
- Know that you are approachable
- Have the opportunity to call you before they call 911

Knowing your neighbors and making them comfortable with your child's differences can lead to better social interactions for your child.

## Consider a personal tracking device.

Some use a small unit that is put in a child's pocket or backpack and work with your computer or mobile phone so that you can monitor your child's location. Others involve a handheld unit for the parent which tracks the location of the child's wristband. Some units work with local law enforcement and rescue personnel. The tracking distance for the devices varies considerably and ranges from 300 feet for parent monitored units to one mile on the ground and 5-7 miles from the air for those monitored by rescue personnel. Some systems include waterproof tracking devices. Prices range from around \$200 for some parent monitoring units to around \$7,000 for units tied into local rescue personnel. Many local law enforcement agencies have purchased units for tracking residents with autism, Alzheimer's and Down's Syndrome.

## Teach your child to swim.

Too often, children with autism are often attracted to water sources such as pools, ponds, and lakes. Drowning is a leading cause of death for a child or adult who has Autism. Be sure your child knows how to swim unassisted. Swimming lessons for children with special needs are available at many YMCA locations. The final lesson should be with clothes on.

## Consider a Medical ID Bracelet for your child.

You may want to purchase an ID Bracelet for your child, especially if your child is non-verbal. Include your name and telephone number. State that your child has autism and is non-verbal if applicable.

If your child will not wear a bracelet or necklace, consider a temporary tattoo with your contact information.

# Child with Autism Emergency Information

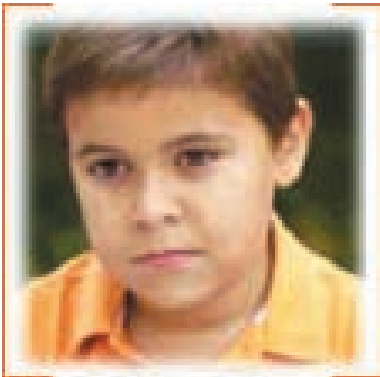


Photo taken: 11/1/2007

## Sean O'Donnell

### Physical Description

Date of Birth: 6/21/2002

Height: 3' 6"

Weight: 54 lbs.

Eye Color: brown

Hair Color: brown

Scars: small scar above right eyebrow

Identifying Marks: birthmark on left shoulder blade

### Responds to:

Sean loves SpongeBob Square Pants. He may be carrying a stuffed Sponge Bob toy. He loves to hear about Sponge Bob and the Sponge Bob song. He will answer yes or no questions about Sponge Bob characters like Squidward and Patrick from the Sponge Bob Show

### Please be aware that:

Sean currently takes medication for seizures. Check MED ID bracelet. He does not like to have his head touched. He will tolerate being taken by the hand.

### Child may:

Sean likes to climb and may often be found playing on climbing equipment at playgrounds or climbing trees or fences. Sean flaps his arms up and down and rocks from foot to foot when he is excited or afraid.

### Favorite places:

South Marlboro Elementary School Playground  
Marlboro Haven Mall – Water Fountain

### May be frightened by:

Sean is very afraid of dogs and may hide to avoid them or scream and run away. He is very sensitive to loud noises.

### Best way to communicate:

Sean has a limited vocabulary but can understand "Let's go see Mom" or "Let's go home." He will respond if asked his name. He can give yes or no answers but may answer yes or no without understanding the question.

### Identification:

Sean wears a MED ID bracelet for EPILEPSY

### Contact Immediately:

Name	Peggy O'Donnell
Home phone	508-555-7238
Mobile phone	508-550-7239
Relationship	Mother

Name	Robert O'Donnell
Home Phone	508-555-7238
Mobile phone	508-550-7240
Relationship	Father

Home Address	465 Canterbury Way South Marlboro, MA 01000
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**PLEASE REFER TO ATTACHED MAP FOR  
LOCATION OF PLAYGROUNDS AND HOME.**

# Comparing Treatment Methods & Providers

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

PROGRAM	
Name of Program/Provider	
Method	
Location Phone Number Email Website	
Hours per Week	
Cost	
Reimbursement	
Recommended by	
PROGRAM CONTENT	
Areas of development focused on: (language, communication, toy play, imitation, peer play, social interactions, behavior, pre-academic skills, work skills, parent training)	
How specific goals are identified for each child:	
How behaviors and skills are prioritized:	
What kind of teaching is used:	
How behaviors are managed:	
MEASURING PROGRESS	
How will I know if my child is making progress?	
How long will it be before I see changes?	
What types of improvements should I expect?	
How often will you assess progress & how is it measured?	

What will happen if my child doesn't make progress with this treatment?

### THERAPIST QUALIFICATIONS

How many children with Autism have you worked with?  
What ages?

Do you serve children over three years old?

What are your qualifications?  
What type of training do you have?

Do you have a professional degree or certificate  
(Ask for details)

Are you affiliated with a professional organization?  
(Ask for details)

What do you see as your strongest skills in working with children with Autism?

Are there issues or problems you consider to be outside of your realm of expertise?

### SCIENTIFIC EVIDENCE OF EFFECTIVENESS

Is there research to support the effectiveness of this type of treatment?  
(Ask for details as well as copies of published articles)

Has research shown this treatment to be better than other types of treatment?

### PROFESSIONAL INVOLVEMENT

Who will be providing the direct intervention with my child?

What type of training do they have?

Who will be supervising them and how?

How often will you see my child personally?

**PARENT INVOLVEMENT**

Will I be able to participate in the treatment?

Will you teach me to work with my child? How?

What skills will you teach me?  
(Ask for examples)

**COMPATIBILITY WITH OTHER TREATMENTS**

How many hours per week of your treatment will my child need?

Is your treatment compatible with other interventions my child is participating in?

How do you collaborate with other therapy providers on my child's team?  
(get examples)







# CONTACTS - Medical

Specialty	Neurology
Name of Contact	Dr. Sample Doctor
Name of Practice	Children's Hospital
Phone Number	(508)555-1000
Address	2000 Summit Drive Anytown, MA 01000
Email Address/ Website	sample.doctor@childrens.edu
Specialty	
Name of Contact	
Name of Practice	
Phone Number	
Address	
Email Address/ Website	
Specialty	
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Email Address/ Website	

# CONTACTS - Therapy

Specialty	Neurology
Name of Contact	Dr. Sample Doctor
Name of Practice	Children's Hospital
Phone Number	(508)555-1000
Address	2000 Summit Drive Anytown, MA 01000
Email Address/ Website	sample.doctor@childrens.edu
Specialty	
Name of Contact	
Name of Practice	
Phone Number	
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# CONTACTS - Support

Specialty	Neurology
Name of Contact	Dr. Sample Doctor
Name of Practice	Children's Hospital
Phone Number	(508)555-1000
Address	2000 Summit Drive Anytown, MA 01000
Email Address/ Website	sample.doctor@childrens.edu
Specialty	
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# CONTACTS - Other

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# Phone Log

Name of Contact	
Phone Number	
Date/Time	
Summary of Call	
Follow up Required	
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Summary of Call	
Follow up Required	
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Follow up Required	
Date/Time	
Summary of Call	
Follow up Required	



# Assessment Tracking

Type of Therapy: \_\_\_\_\_

Date	Test Administered	Evaluator	Standard Score	Age Equivalent	Change in Standard Score	Change in Age Equivalent
1/12/07	Oral & Written Language Scales	Ms. Smith				
	(Subtest) Oral Expression		49	3.4		
	(Subtest) Listening Comprehension		48	3.5		
2/8/08	Oral & Written Language Scales	Ms. Jones				
	(Subtest) Oral Expression		50	3.8	1	4 months
	(Subtest) Listening Comprehension		57	4.1	9	8 months
	Team Meeting/Review		10	2	1	











# Glossary

Visit the Autism Speaks Video Glossary at [www.AutismSpeaks.org](http://www.AutismSpeaks.org) to see video of the items in blue.

## A

*Absence Seizure*, see Seizures

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

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

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

*Aphasia* is the complete or partial loss of ability to use or understand language.

*Apraxia* is a disorder consisting of partial or total incapacity to execute purposeful movements, without impairment of muscular power and coordination. The person has difficulty sequencing movements. Apraxia may be specific to speech.

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

*Asperger Syndrome* is a developmental disorder on the Autism spectrum defined by impairments in communication and social development and by repetitive interests and behaviors, without a significant delay in language and cognitive development.

*Astatic Seizure*, see Seizures

*Atonic Seizure*, see Seizures

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

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

**Autism Spectrum Disorders** encompasses the following disorders listed in DSM-IV: Autistic Disorder,

Asperger's Disorder, PDD – Not Otherwise Specified, Childhood Disintegrative Disorder, and Retts Disorder.

## B

## C

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

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

*Cerebral Palsy (CP)* is an abnormality of motor function (as opposed to mental function) that is acquired at an early age, usually in utero or at less than a year of age, and is due to a brain lesion that is non-progressive.

*Childhood Disintegrative Disorder* is a disorder in which development begins normally in all areas, physical and mental. At some point between 2 and 10 years of age, the child loses previously developed skills. The child may lose social and language skills and other functions, including bowel and bladder control.

*Chromosome 15 Duplication Syndrome* is a rare chromosomal disorder. Symptoms may be similar to Prader-Willi and Angelman syndromes and range from asymptomatic cases to variable combinations of skeletal, neurological, gastrointestinal, psychological, and other abnormalities in association with developmental delay.

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

*Clinical Features* are directly observed during examination; based on or characterized by observable and diagnosable symptoms of disease.

*Cognition* is mental process of knowing, including aspects such as awareness, perception, reasoning and judgment.

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

*Colitis* is inflammation of the large intestine .

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

**Compulsions** are deliberate repetitive behaviors that follow specific rules, such as pertaining to cleaning, checking, or

counting. In young children, restricted patterns of interest may be early sign of compulsions.

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

*Cytomegalovirus (CMV)* common virus of herpes family. May be asymptomatic in healthy people. May be serious in patient with impaired immune system. Infection in utero may cause serious developmental disorders.

## D

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

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

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

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

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

**Diagnostic and Statistical Manual** the official system for classification of psychological and psychiatric disorders published by the American Psychiatric Association.

*Discrete Trial Teaching (DTT)*, is technique incorporating principles of ABA, including positive reinforcement. Not in itself ABA. Used to teach behaviors in one-to-one setting. Concepts are broken down into small parts.

*Dyspraxia* is brain's inability to plan muscle movements and carry them out. In Speech, this term may be used to describe Apraxia.

## E

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

**Echolalia** is repeating words or phrases heard previously,

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

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

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

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

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

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

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

## F

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

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

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

## G

*Gastritis* is inflammation of the stomach.

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

*Gastroesophageal Reflux* return of stomach contents back up into the esophagus which frequently causes

heartburn due to irritation of the esophagus by stomach acid.

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

*General Education* is a pattern of courses in multiple subjects taught to the same grade level to deliver a well-balanced education.

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

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

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

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

*Grand mal Seizure*, see Seizures

## H

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

*Hyperresponsiveness*, *Hypersensitivity*, see Sensory Defensiveness

*Hyposensitivity*, *Hyporesponsiveness*, is abnormal insensitivity to sensory input. Child who appears to be deaf, whose hearing is normal, is under reactive. Child who is under reactive to sensory input may have a high tolerance to pain, may be clumsy, sensation-seeking, and may act aggressively.

*Hypotonia* is a term that means low muscle tone.

## I

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

*Individual Family Service Plan (IFSP)* is developed by a multidisciplinary team including family as primary participant. Describes child’s level of development

in all areas; family’s resources, priorities, & concerns, services to be received and the frequency, intensity, and method of delivery. Must state natural environments in which services will occur.

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

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

*Infectious agents* are organisms that cause infection; can be viruses, bacteria, fungi, or parasites.

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

## J

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

## K

## L

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

## M

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

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



within regular school, or participate in regular gym and lunch only).

*Maternal Rubella* is a mild, highly contagious virus, also known as “German measles” that crosses the placenta from infected mothers and leads to major developmental defects in developing fetus.

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

*Mental Retardation* describes person with limitations in mental functioning that cause them to develop more slowly than typical child. They may take longer to learn to speak, walk, and take care of personal needs such as dressing or eating, and are likely to have trouble learning in school. May be mild or severe.

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

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

*Motor function (or Motor Skills)* is the ability to move and control movements.

## N

*Neurocutaneous Disorders* are genetic disorders leading to abnormal growth of tumors. Usually first appearing as skin lesions like birthmarks; may eventually lead to tumors affecting central nervous system and other parts of the body.

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

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

## O

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

*Obstructive Sleep Apnea* breathing disorder interrupting breathing during sleep when air flow cannot flow through the nose or mouth although

efforts to breathe continue. Throat collapses during sleep causing snorting and gasping for breath. May cause daytime sleepiness. May increase risk of hypertension and heart problems.

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

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

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

## P

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

**Pervasive Developmental Disorders (PDD)** group of conditions involving delays in development of many basic skills, including ability to socialize with others, to communicate and use imagination. Includes Autism, Asperger Syndrome, Childhood Disintegrative Disorder, Rett Syndrome and Pervasive Development Disorder - Not Otherwise Specified.

*Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS)* a category of PDD referring to children having significant problems with communication & play, and some difficulty interacting with others, but are too social for diagnosis of autism.

*Petit Mal Seizure*, see Seizures

*Phenylketonuria (PKU)* a metabolic disorder involving deficiency of enzyme phenylalanine hydroxylase which leads to harmful buildup of phenylalanine in body. Symptoms range from mild to severe. May cause mental retardation.

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

*Physical Therapists* design and implement physical therapy programs and may work within a hospital or clinic, in a school, or as an independent practitioner.

*Pica* is persistent eating or mouthing of non nutritive

substances for at least 1 month when behavior is developmentally inappropriate (older than 18-24 months). Substances may include items such as clay, dirt, sand, stones, pebbles, hair, feces, lead, laundry starch, vinyl gloves, plastic, erasers, ice, fingernails, paper, paint chips, coal, chalk, wood, plaster, light bulbs, needles, string, cigarette butts, wire, and burnt matches.

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

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

*Prevalence* is the current number of people in a given population who have a specific diagnosis at a specified point in time.

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

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

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

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

## Q

## R

*Receptive Labeling*, see receptive language

*Receptive Language* the ability to comprehend words and sentences. Begins as early as birth and increases with each stage in development. By 12 months a child

begins to understand words and responds to his name and may respond to familiar words in context. By 18 to 20 months a child identifies familiar people by looking when named (e.g., Where’s mommy?), gives familiar objects when named (e.g., Where’s the ball?), and points to a few body parts (e.g., Where’s your nose?). These skills commonly emerge slightly ahead of expressive language skills.

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

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

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

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

## S

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

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

*Seizure, Atonic*, seizure where person loses muscle tone & strength &, unless supported, falls down. Atonic means lack of muscle tone & strength.

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

*Seizure, Tonic-clonic*, Seizures involving two phases – tonic phase when body becomes rigid, & clonic phase of uncontrolled jerking. May be preceded by aura & are often followed by headache, confusion, & sleep. May last for seconds, or continue for several minutes.

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

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

**Sensory Input**, see sensory stimuli

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

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

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

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

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

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

*Social Stories*, developed by Carol Gray, are simple stories that describe social events & situations that are difficult for a child with a PDD to understand. For ex-

ample, a social story might be written about birthday parties if the child appears to have a difficult time understanding what is expected of him or how he is supposed to behave at a birthday party.

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

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

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

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

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

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

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

*Stim*, or "self-stimulation" behaviors that stimulate one's senses. Some "stims" may serve a regulatory function (calming, increasing concentration, or shutting out an overwhelming sound).

*Subclinical Seizure*, see Seizures

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

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

X  
Y  
Z

## T

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

*Thalidomide* is a sedative & hypnotic drug that has been the cause of malformation of infants born to mothers using it during pregnancy. Thalidomide acts as an angiogenesis inhibitor & can inhibit bone formation. Currently used to treat certain types of cancer.

*Training and Education of Autistic and Related Communication Handicapped Children (TEACCH)* is a therapeutic approach broadly based on the idea that individuals with autism more effectively use & understand visual cues.

*Tonic-clonic seizure*, see Seizures

*Tuberous Sclerosis* is a neurocutaneous disorder characterized by mental retardation, seizures, skin lesions & intracranial lesions. An autosomal dominant disorder that occurs in 1 in 7,000 births.

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

## U

## V

*Valproate, or Valproic Acid*, is an antiepileptic drug used to treat epilepsy, migraines & bipolar disorder. Given orally or by injection. Associated with high rate of serious adverse events, including major congenital abnormalities & fetal death with in utero exposure.

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

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

## W

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



# The pages that follow contain information from the *Autism Speaks* Family Services Resource Guide.

We have provided information on resources and services in your area that may be helpful to you and your family.

The Family Services Resource Guide can be found on the Autism Speaks website, [www.AutismSpeaks.org/community/fsdb/index.php](http://www.AutismSpeaks.org/community/fsdb/index.php).

*Autism Speaks* maintains the Family Services Resource Guide as a service to families as a reference tool. Every effort is made to ensure listings are up-to-date. *Autism Speaks* does not endorse or claim to have personal knowledge of the abilities of those listed. The resources listed in these pages are not intended as a recommendation, referral, or endorsement of any resource or as a tool for verifying the credentials, qualifications, or abilities of any organization, product or professional. Users are urged to use independent judgment and request references when considering any resource associated with diagnosis or treatment of autism, or the provision of services related to autism.