

# AUTISM SPEAKS™

## *Asperger Syndrome and High Functioning Autism Tool Kit*

*A tool kit to assist families in getting the  
critical information they need in the first 100  
days after an Asperger Syndrome or High Functioning Autism  
diagnosis.*

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



# *About this Kit*

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*Autism Speaks would like to extend special thanks to the Advisory Committee for the time and effort that they put into reviewing the Asperger Syndrome and High Functioning Autism Tool Kit.*

## *Asperger Syndrome and High Functioning Autism Tool Kit Advisory Committee*

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*Ann Brendel*

*Geraldine Dawson, Ph.D.*

Chief Science Officer, *Autism Speaks*  
Research Professor, University of North Carolina, Chapel Hill

*Peter F. Gerhardt, Ed.D.*

President, Organization for Autism Research (OAR)

*Kerry Magro*

*Valerie Paradiz, PhD*

*Patricia R Schissel, LMSW*

President, Asperger Syndrome and High Functioning Autism Association (AHA), Inc.

*Stephen M. Shore, Ed.D*

Assistant Professor of Education  
Adelphi University

## *Family Services Committee Members*

---

*Liz Bell*

Parent

*Sallie Bernard*

Parent, Executive Director, SafeMinds

*Michele Pierce Burns*

Parent

*Farah Chapes*

Chief Administrative Officer, The Marcus Autism Center



*Peter F. Gerhardt, Ed.D*

President, Organization for Autism Research (OAR)

*T. Michael Glenn\**

Parent

*Susan Hyman, M.D.*

Strong Center for Developmental Disabilities

*Brian Kelly \* \*\**

Parent

*Artie Kempner\**

Parent

*Gary S. Mayerson\**

Founding Attorney, Mayerson & Associates

*Kevin Murray\**

Parent

*Linda Meyer, Ed.D*

Executive Director, Autism New Jersey

*Denise D. Resnik*

Parent, Co-Founder Southwest Autism Research and Resource Center (SARRC)

*Stuart Savitz*

Parent

*Michelle Smigel*

Parent

*Kim Wolf*

Parent

\*Autism Speaks board member

\*\*Chairperson – Family Services Committee

Parent – indicates a parent of a child with autism



# *Autism Speaks.™ Asperger Syndrome and High Functioning Autism Tool Kit*

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*Your child has normal cognitive abilities and has experienced normal language development, but has been diagnosed with Asperger Syndrome or High Functioning Autism, and you have asked for help. This is an important turning point in your journey. For some families, this may be the point when, after a long search for answers, you now have a name for something you didn't know what to call, but you knew existed. 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 had for your child are valid. Whatever you feel, you should know that thousands of parents share this journey. You are not alone. There is help and reason to hope.*

*Now that you have the diagnosis, the question is: Where do you go from here? This handbook, part of Autism Speaks™ 100 Day Kit, focuses specifically on Asperger Syndrome (AS) and High Functioning Autism (HFA). It 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 Asperger Syndrome /HFA and parents just like you.*

## Contact Us...

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

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

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

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



# *What is Asperger Syndrome/HFA?*

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 The National Institute of Neurological Disorders and Stroke (NINDS), part of the National Institute of Health, defines Asperger Syndrome as:

A developmental disorder that is characterized by:

- repetitive routines or rituals,
- peculiarities in speech and language, such as speaking in an overly formal manner or in a monotone, or taking figures of speech literally,
- socially and emotionally inappropriate behavior and the inability to interact successfully with peers,
- problems with non-verbal communication, including the restricted use of gestures, limited or inappropriate facial expressions or a peculiar, stiff gaze,
- clumsiness and uncoordinated motor movements.


Below is the NINDS history of Asperger Syndrome, which we hope will help you to understand more about the disorder and what the diagnosis means for your child and your family:

In 1944, an Austrian pediatrician named Hans Asperger observed four children in his practice who had difficulty integrating socially. Although their intelligence appeared normal, the children lacked nonverbal communication skills, failed to demonstrate empathy with their peers, and were physically clumsy. Their way of speaking was either disjointed or overly formal, and their all-absorbing interest in a single topic dominated their conversations.

Asperger's observations, published in German, were not widely known until 1981, when an English doctor named Lorna Wing published a series of case studies of children showing similar symptoms, which she called "Asperger" syndrome. Wing's writings were widely published and popularized. AS became a distinct condition and diagnosis in 1992, when it was included in the tenth published edition of the World Health Organization's diagnostic manual, *International Classification of Diseases (ICD-10)*, and in 1994, it was added to the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)*, the American Psychiatric Association's diagnostic reference book.

Individuals who are diagnosed with autism or autism spectrum disorder who have normal cognitive abilities, and experienced no significant delay in acquiring language skills, are very similar to individuals with Asperger Syndrome. High Functioning Autism Spectrum Disorder (HFA) and Asperger Syndrome share similar symptoms and are helped by similar treatment approaches.

## *What are the Symptoms of Asperger Syndrome/HFA?*

 Oftentimes, Asperger Syndrome is not diagnosed until a child is school age. Unlike autism, AS can generally only be determined based on a child's social interactions. Children with Asperger Syndrome show typical language development and often an above average vocabulary. However, you may have noticed that when your child interacts with others, he or she might use language skills inappropriately or awkwardly. Because of regularly developing language skills, in the early stages, symptoms of AS may be hard to differentiate from those of other behavioral issues like attention deficit



hyperactivity disorder (ADHD). As a result, your child may have first been diagnosed with disorders such as ADHD, until the issues appear to be caused by more of an inability to socialize than an inability to focus.

The following is a list of symptoms that may present themselves in children with Asperger Syndrome:

- improper or very few social interactions
- "robotic" or repetitive speech
- average or below average nonverbal communication skills, yet average or above average verbal communication skills
- tendency to discuss self rather than others
- inability to understand issues or phrases that are considered "common sense"
- lack of eye contact or reciprocal conversation
- obsession with specific unique topics
- one-sided conversations
- awkward movements and/or mannerisms

A very obvious and distinct indicator of Asperger Syndrome is preoccupation with one particular issue, from simple things like refrigerators or weather, to complex topics like President Franklin D. Roosevelt during the Great Depression. They become so attentive to these topics that they strive to learn every possible fact and detail, and as a result become incredible experts. Children with AS might initiate one-way conversations with others by speaking only about the facts related to their particular topic of interest. They may not like the idea of discussing anything else, or may be unable to listen to and understand the responses of others. Your child may not be aware that his or her audience may no longer be listening, or may not be in the topic of discussion.

Another symptom of Asperger Syndrome is an inability to understand the actions, words or behaviors of other people. Individuals with AS very often don't understand humor or the implications of particular phrases or actions of other people. Subtle gestures or expressions such as a smile, a frown or a "come here" motion may not phase children with AS because they are unable to see the relationship between these nonverbal communication methods, and verbal methods like speech and language. Because they are often incapable of understanding these nonverbal cues, the social world can seem very confusing and overwhelming to these individuals. To compound the problem, people with Asperger Syndrome have difficulty seeing things from another person's perspective. This inability leaves them unable to predict or understand other people's actions. Although not universal, it is common for people with AS to have difficulty regulating their emotions.

Individuals with Asperger Syndrome may have an awkward or peculiar way of speaking. They might speak extremely loudly, constantly in a monotone, or with a particular accent. These individuals lack understanding of social interactions, and as a result, are unaware that their topics of discussion or method of speaking might be inappropriate or awkward, particularly in specific situations. For example, children who speak very loudly might enter a church and not understand that they can no longer speak at the same volume.





Another typical sign of Asperger Syndrome may be awkward movements, or a delay in motor skills. They may have an abnormal walk or a poor sense of coordination. Though these individuals might be very intelligent and might display expert language skills, they may not be able to catch a ball or understand how to bounce on a trampoline, despite the many attempts of others to teach them.

It is important to note that not all individuals with Asperger Syndrome display each of these symptoms, and that the presence and severity of each symptom is likely to vary between individuals with the same diagnosis. While displaying some or all of these symptoms, each child with autism also possesses many unique gifts.

### *What Causes Asperger Syndrome/HFA?*

■ It is important to keep in mind that autism spectrum disorders are not one disorder with one cause. Rather, the term represents a group of related disorders with many different causes. In most instances, AS/HFA is caused by a combination of genetic risk factors that may interact with environmental risk factors. Many genes likely contribute to Asperger Syndrome/HFA. These genes are believed to interact with environmental factors. A great deal of research is currently focused on identifying how both genetic and environmental risk factors contribute to autism.

There may be some common misconceptions about people with Asperger Syndrome/HFA. AS/HFA cannot be caused by the way a person was brought up, bad parenting, or emotional issues a child may have experienced at some point early on. Asperger Syndrome/HFA is a neurobiological disorder, and not the result of issues stemming from the child's life experiences.



## *Strengths and Challenges*

Created by Stephen Shore

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

<i>Strengths</i>	<i>Challenges</i>
Attention to detail	Grasping the "big" picture
Often highly skilled in a particular area	Uneven set of skills
Deep study resulting in encyclopedic knowledge on areas of interest	Difficulty in developing motivation to study areas not of interest
Tendency to be logical (helpful in decision-making where emotions may interfere)	Difficulty perceiving emotional states of other
Less concern for what others may think of them (can be a strength and a challenge). Also known as independent thinking. Often results in novel "big picture" insights due to different ways of looking at things, ideas, and concepts.	Perceiving unwritten rules of social interaction. But can learn these rules through direct instruction and social narratives social as Power Cards (Gagnon, 2004)
Usually visual processing (thinking in pictures or video)	Difficulty processing in non-favorite modalities such as aural, kinesthetic, etc.
Often very verbal (Propensity of giving detailed descriptions may be useful in providing directions to lost persons)	Difficulty parsing out and summarizing important information for a conversation
Direct communication	Sensory integration problems where input may register unevenly, distorted, and difficulty in screening out background noise
Loyalty	Generalization of skills and concepts
Honesty	Difficulty expressing empathy in ways that others expect or understand
Nonjudgemental listening	
Average to above average intelligence	Executive functioning resulting in difficulties planning long-term tasks



# *Executive Functioning and Theory of Mind*

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

Difficulties in the area of Executive Functioning can manifest themselves in many different ways. Some individuals pay attention to minor details, but fail to see how these details fit into a bigger picture. Others have difficulty with complex thinking that requires holding more than one train of thought simultaneously. Others have difficulty maintaining their attention, or organizing their thoughts and actions. Executive Functioning difficulties can also be associated with poor impulse control. Temple Grandin once said: "I cannot hold one piece of information in my mind while I manipulate the next step in the sequence." Individuals with AS often lack the ability to use skills related to executive functioning like planning, sequencing and self-regulation.

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

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

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



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

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



# Diagnostic Overview

Asperger Syndrome and HFA are terms applied to the high functioning end of what is known as the spectrum of pervasive developmental disorders, or the autism spectrum. Asperger Syndrome is a relatively new category, as it was officially recognized in the Diagnostic and Statistical Manual of Mental Disorders (DSM) for the first time in 1994. In the future, it is possible that the DSM may combine AS and HFA into one category, as they are very similar and the treatment approaches for each are the same. Since AS/HFA shows a range or spectrum of symptom severity, many individuals who might meet criteria for that diagnosis are viewed as "unusual" or "awkward," or are misdiagnosed with other conditions such as Attention Deficit Disorder.

## *.DSM-IV Criteria for a Diagnosis of Asperger Syndrome*

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

- 1. marked impairments in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction*
- 2. failure to develop peer relationships appropriate to developmental level*
- 3. 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)*
- 4. lack of social or emotional reciprocity*

*B. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:*

- 1. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus*
- 2. apparently inflexible adherence to specific, nonfunctional routines or rituals*
- 3. stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)*
- 4. persistent preoccupation with parts of objects*

*C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning*

*D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years)*


*E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than social interaction), and curiosity about the environment in childhood*

*F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia (DSM IV, p. 77)*



# Diagnosing Asperger Syndrome/HFA

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 Presently, there is no medical test for Asperger Syndrome/HFA. A diagnosis is based on observed behavior and educational and psychological testing. As the symptoms of AS/HFA 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 or AS and may already receive some Early Intervention or Special Education services. Unfortunately, parents' concerns are sometimes not taken seriously by their doctor and an accurate diagnosis is delayed. *Autism Speaks* and other autism-related organizations are working hard to educate parents and physicians so that children with autism spectrum disorders are identified as early as possible.

Many issues can commonly arise when trying to diagnose a child with Asperger Syndrome/HFA. These difficulties can occur since children with AS/HFA are usually able to function very well in many aspects of their lives, and exhibit only a few peculiar or different behaviors. You may have noticed that your child has advanced skills in certain areas and may be very smart. These observations can make it more challenging to get an early diagnosis for your child and as a result, may delay the process of getting the help and assistance you need. As you continue to take steps toward helping your child receive the proper diagnosis, it is important to explore different options and reach out for support.

Your role as the parent is crucial in helping to diagnose your child with Asperger Syndrome/HFA, since you are the one observing your child's growth and development on a daily basis. If certain behaviors develop, such as preoccupations, unusual habits, favorite activities, it may be a good time to visit your child's pediatrician. If your child's pediatrician is concerned, you will be referred to a specialist who will evaluate your child. The specialist will usually take a very detailed history of your child, including his or her development, language skills and various aspects of their social behavior.

When a doctor is trying to assess your child and investigate the possibility that your child may be on the autism spectrum, he or she will take the time to ask about social issues and development. It is important for the doctor to know if there have been problems in school, issues with making friends, or struggles with general social interactions. This evaluation will show areas where your child may struggle, but also areas where your child exhibits numerous strengths.

*"This experience comes with many challenges that we must surmount in order to lovingly support our children and to assimilate their acute sensory sensitivities into a world that is oftentimes overwhelmingly intolerant of diversity. But it also comes with a myriad of gifts if you can be open to seeing this perspective. Your child requires you in their life; and indeed, dozens of parents have told me they are better people than they would've been had they not been blessed to raise this child. Rest assured, given the proper respect, appreciation, and opportunity, your child will change the world in ways that are right and true and good and kind."*

– William Stillman, *Empowered Autism Parenting*



# *How are Asperger Syndrome and High Functioning Autism Different?*

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Once your child receives a diagnosis, you will have many questions and be looking for the answers. One question that you may have is how is AS different and similar to other autism spectrum disorders? Asperger Syndrome exists as part of the autism spectrum but differs in early development of language from classic autism and other pervasive developmental disorders. After the diagnosis of an autism spectrum disorder, it is important to explain and understand both similarities and differences between disorders on the spectrum.

Asperger Syndrome and high functioning autism (HFA) are often referred to as the same diagnosis. While they currently exist as two separate diagnoses, there is an ongoing debate about whether that is necessary. It is possible that, in the future, they may be combined into one category. Individuals with HFA and AS have average or above average intelligence but may struggle with issues related to social interaction and communication. The diagnosis of either High Functioning Autism or Asperger Syndrome can oftentimes feel frustrating to a parent and the child as it may seem that the terms are not clearly defined. It is essential to remember that both AS and HFA do present themselves largely the same way, and as a result may be treated in a similar way. The primary difference is that a diagnosis of HFA requires that, early in development, the child had delayed language whereas in AS, the child did not show a significant delay in language development.

## *How Asperger Syndrome is Similar to Classic Autism*

According to the National Institute of Neurological Disorders and Stroke (NINDS), children with Asperger Syndrome find it difficult to identify and express their feelings, just like those with HFA. They find it challenging to connect with others, often don't hold eye contact and have trouble reading other people's faces and gestures. Many children with AS flap their hands, a behavior often associated with classic autism; speak without much emotion (or have otherwise unusual speech patterns), need to follow schedules rigidly, and are intensely, even obsessively, interested in one specific subject, so much that they become veritable experts in that field. They also exhibit sensitivities to various stimuli, from sounds to clothing to food items.

## *How do AS/HFA Diagnoses differ from Classic Autism?*

Compared with classic autism, children with Asperger Syndrome/HFA have IQs that fall in the normal or even superior range. To many, they may seem just like other children but not quite: children with AS are socially awkward in a manner that's not easily understood.

This explains why healthcare providers may miss seeing Asperger Syndrome/HFA symptoms in their young patients, or may misdiagnose it completely. The late onset of complex social skills, such as peer interaction, also explains why some parents don't seek help until much later compared to those whose kids display a more profound or more obvious set of symptoms from a very young age.





# *How Will I Deal with the Diagnosis? How Will this Affect My Family?*

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

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





## *Explaining the Diagnosis to Your Child*

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

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

## *Telling Family Members*

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

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



## Telling Others

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

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

## Telling Peers

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

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



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

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

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

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

## ***Join a Support Group***

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



# Interventions and Treatment Options

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*“A treatment method or an educational method that will work for one child may not work for another child. The one common denominator for all of the young children is that early intervention does work, and it seems to improve the prognosis.” – Temple Grandin*

Just like the case with autism, early intervention is crucial for Asperger Syndrome/HFA. It is very important to remember that one method or intervention may not work for every child. Remember that your child is unique, and work with their strengths to help them in the best way possible. Treatment of AS/HFA can help your child navigate through social challenges, capitalize on his or her strengths, and be successful. Before we get into the types of therapies available, it is helpful to take a step back and look at the bigger picture. Although research and experience have revealed many of the mysteries surrounding Asperger Syndrome/HFA, it remains a complex disorder that impacts each child differently. However, many children with AS/HFA have made remarkable breakthroughs with the right combinations of therapies and interventions. Most parents would welcome a therapy that would alleviate all of the challenges that make life difficult for their child. Just as your child's challenges can't be summed up in one word, they can't be remedied with one therapy. Each challenge must be addressed with an appropriate therapy. No single therapy works for every child. What works for one child may not work for another. What works for one child for a period of time may stop working. Some therapies are supported by research showing their efficacy, while others are not. The skill, experience, and style of the therapist are critical to the effectiveness of the intervention.

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

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

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

In order to determine what treatments and interventions will be most effective for an individual with AS, a thorough assessment of all symptoms must be done. The evaluation must examine a wide variety of factors including behavioral history, current symptoms, communication patterns, social competence and neuropsychological



functioning. It is crucial to look at the strengths and weaknesses of the child in each of these areas in order to paint a full and clear picture. An individual with AS/HFA may have completely different strengths and weaknesses than another individual with the same diagnosis. One treatment that is the most significant and most effective for one child may be completely unnecessary and ineffective for another. As a result, treatments and interventions must be very individualized based on the information gathered from the thorough assessment.

The factor that has proved to be the most critical in terms of improvements in these children is early intervention. If behavior management and social skills training begin at a young age, the chances of progress are significantly greater.

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

## *Options for Treatment Include:*

### *Parent Education and Training*

■ Parent training can be especially beneficial to the improvement of children with AS/HFA. If caregivers such as parents, grandparents, siblings, babysitters, etc. are fully aware of and understand the strengths and deficits of the child, they will be able to incorporate aspects of successful treatment options like social skills training into the child's life at home. The more children with AS are exposed to social skills and behavior training, the more likely they are to improve their behavior. Parents and other caregivers can learn how to effectively implement treatment mechanisms into the child's everyday life. Treatment then becomes consistent and routine for children with AS.

### *Social Skills Training and Speech-Language Therapy*

■ Children with Asperger Syndrome/HFA can expand and improve their social skills through training and therapy. Though children with AS may have strong language skills, it is important that they learn how to express their thoughts and feelings appropriately. Their ability to interact with others can improve with lots of practice and explicit teaching. Therapists often teach social skills to children with AS/HFA using visual techniques such as social stories, or using exercises that involve the children in various social situations. Social skills groups have proved to be very beneficial to children with AS in teaching them how to interact with their peers. Speech and language therapy may also help these children to communicate better. This therapy could correct awkward methods of speaking such as monotone, and help children to better understand and interpret the speech and communication signals of others such as humor, eye contact, and hand gestures.



## *Cognitive Behavior Therapy*

■ Cognitive Behavioral Therapy (CBT) is used primarily to help individuals with AS regulate their emotions, develop impulse control, and improve their behavior as a result. In addition, some individuals with AS/HFA struggle with fears and anxiety, or may become depressed. Cognitive behavior therapy has been shown to be helpful for reducing anxious and depressed feelings and behavior by making changes in thoughts and perceptions of situations through a change in cognition. The key ingredient of CBT, which distinguishes it from regular behavior therapy is working on this change in cognition or how thinking is processed. Therapists seek to reduce challenging behaviors, such as interruptions, obsessions, meltdowns or angry outbursts, while also teaching individuals how to become familiar with and manage certain feelings that may arise. Cognitive behavioral therapy can be individualized for each patient, and as a result, is very effective at improving very specific behaviors and challenges in each child or young adult. Stabilizing emotions and improving behavior allows those with AS to prepare for and respond more appropriately in specific situations.

## *Applied Behavioral Analysis (ABA)*

■ Since the early 1960's, Applied Behavior Analysis, or ABA, has been used by hundreds of therapists to teach communication, play, social, academic, self-care, work, and community living skills, and to reduce problem behaviors in learners with autism. There now is a great deal of research literature that demonstrates that ABA is effective for improving children's outcomes, especially their cognitive and language abilities. Over the past several decades, different treatment models using ABA have emerged, all of which use behavioral teaching. They all use strategies that are based on the work of B.F. Skinner. 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 reaction for the incorrect response.

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.





### *Sensory Integration/Occupational Therapy*

■ Many children with AS/HFA have problems with motor skills or issues with their senses. In sensory integration therapy, occupational therapists work with children to stabilize their senses and their reactions to external stimuli. This therapy can help children gain better control over their bodies, and thus can reduce clumsiness, instability and hand-eye coordination. SI therapy can also reduce anxiety in children with AS/HFA by improving their responses to particular sounds or touches. When children have better control of their senses, they are better able to control their movements, sounds, and emotions. This leads to reduced awkwardness and improved social skills.

### *Medication*

■ No medications specifically treat Asperger Syndrome. However, some children with AS experience symptoms that can be controlled by medication: depression, anxiety, attention deficits, or hyperactivity. Though the symptoms of Asperger Syndrome can only be improved through treatments and interventions, it is important to also assess and treat associated conditions such as depression, anxiety, and attention problems as these symptoms can often be more debilitating than AS/HFA itself.



# *Asperger Syndrome/HFA and the Classroom*

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## *Accessing Services: Your Child's Right to Public Education*

■ The Individuals with Disabilities Education Act (IDEA), first enacted in 1975, mandates that each state provide all eligible children with a free and appropriate public education that meets their unique, individual needs. 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).

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

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

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

Once your child is diagnosed, it is crucial to make sure they have the proper supports in school. As you work with your school system, it is important to remember that your child's program should be designed individually, as each child has unique needs, even if the diagnosis is the same as that of another child. Acquiring these services will help your child and will also ensure that his or her teacher can provide the best and most effective education possible.





In the classroom, the student and the teacher will face different challenges. The Organization for Autism Research (OAR) offers the following six step plan, which is included in their comprehensive kit entitled, [\*An Educator's Guide to Asperger Syndrome\*](#), to help your child enter a classroom, and throughout their education:

### *Step 1: Educate Yourself*

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

- **Operate on “Asperger time.”** “Asperger time” means “Twice as much time, half as much done.” Students with Asperger Syndrome/HFA often need additional time to complete assignments, gather materials, and orient themselves during transitions.
- **Manage the environment.** Any change can increase anxiety in a student with Asperger Syndrome/HFA. Strive to provide consistency in the schedule and avoid sudden changes.
- **Create a balanced agenda.** Make a visual schedule that includes daily activities for students with Asperger Syndrome/HFA. Some parts of the daily schedule or certain classes or activities should be monitored or restructured, as needed.
- **Simplify language.** Keep your language simple and concise, and speak at a slow, deliberate pace. Students with Asperger Syndrome/HFA have difficulty “reading between the lines,” understanding abstract concepts like sarcasm, or interpreting facial expressions. Be clear and specific when providing instructions.
- **Manage change of plans.** Make sure the student with Asperger Syndrome understands that sometimes planned activities can be changed, canceled, or rescheduled. Have backup plans and share them with the child with Asperger Syndrome/HFA.
- **Be generous with praise.** Find opportunities throughout the day to tell the student with Asperger Syndrome what he or she did right. Compliment attempts as well as successes. Be specific to ensure that the student with Asperger Syndrome knows why you are providing praise.

### *Step 2: Reach Out to the Parents*

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

### *Step 3: Prepare the Classroom*

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



about specific approaches for structuring the academic and physical environment to address the needs of your student with Asperger Syndrome.

#### *Step 4: Educate Peers and Promote Social Goals*

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

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

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

#### *Step 5: Collaborate on the Educational Program Development.*


#### *Step 6: Manage Behavioral Challenges*

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

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

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





## *Individualized Education Program (IEP)*

Throughout your child's education, it will be essential for both you and your child's various educators to continue learning more about AS. You will need to collaborate during each school year and stay motivated to make certain that your child is excelling and feels comfortable in their learning environment. It is vital that your child's needs continue to be assessed and that you work with the team at school to set goals and objectives in your child's Individualized Education Program (IEP).

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

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

*You may also find useful information in the Autism Speaks School Community Tool Kit at*  
[www.autismspeaks.org/community/family\\_services/school\\_kit](http://www.autismspeaks.org/community/family_services/school_kit)



# Transitioning Into Adulthood

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

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

In 2004, the Individuals with Disabilities Education Act (IDEA) was revised and now defines "transition services" as a coordinated set of activities for a child with a disability that:

- *is designed to be within a results-oriented process that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child's movement from school to post-school activities, including post-secondary education, vocational education, integrated employment (including supported employment); continuing and adult education, adult services, independent living, or community participation,*
- *is based on the individual child's needs, taking into account the child's strengths, preferences, and interests; and*
- *includes instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and, if appropriate, acquisition of daily living skills and functional vocational evaluation.*

A successful transition will lead your child with AS/HFA on the path to a fulfilling life that enables him or her to learn and grow. This type of planning should take place around 16 years of age. The transition plan will begin with individuals assessing their own skills and interests with their families. This will allow them the time and space to reflect on the best way to hone their skills on things that interest and excite them. With your family and educational team, your child may look into options such as college, employment, vocational training, life skills training, and residential opportunities.




As you move forward in your planning, it is essential to remember that young adults are protected by the Americans with Disabilities Act (ADA). The ADA notes that a child with ASD/AS cannot be discriminated against in school and beyond. The law also provides protections for young adults while in college, noting that supportive services should be available and that all programs should be accessible, including extracurricular activities. The ADA also prohibits qualified individuals from being discriminated against in the workforce.

Some individuals with AS/HFA may decide to move on to college as part of their transition plan. Making this decision will require research to find out which institutions of higher learning offer the best supports for individuals with AS/HFA. Since each individual's needs are unique, it will be important for these young adults to see what their strengths are and what type of environment they will thrive in. Some students choose to go to a traditional college setting, while others may look to go into a non-degree program, or an associate's degree program. It is important that individuals with AS/HFA choose colleges that will help them meet their future goals, but that will also be able to support their specific needs. There is a place for each individual, and before making any decisions, it is essential to find the best match for your child based on his or her strengths, desires, and challenges.

For young adults who go directly into the employment world, it will also be critical for them to focus on their strengths and what brings them the greatest joy. They will want to explore different areas of the job market. Different work environments may help different individuals to excel. There are many opportunities for supported employment, where the employer offers supports to a worker with different challenges. Other individuals will require less support and may do better independently. Each individual has unique skills that will lend themselves to certain jobs, so it is important for your child with AS/HFA to be open to all options throughout the transition to adulthood.

*"You should know what you want to do, what you can do, what your interests are, what your capacity for multitasking is. There can be challenges sometimes associated with the diagnosis of AS. But there are potential gifts, and the ability to bury yourself in deep interests and passions is the greatest one we know of. Cultivate this; it is a gift to yourself, and to others."*

*-Adapted from Asperger's from the Inside Out, by Michael John Carley*

 The experience of having your child diagnosed with Asperger Syndrome/HFA can be overwhelming and difficult. Staying positive and focusing on the things that make your child with AS/HFA special will help you immensely on this journey with your family. Individuals with AS/HFA can make huge strides with the right treatments and just like other children, can go on to accomplish great things. We hope this kit has helped ease your fears and answer your questions. We have many other valuable resources for your child and your family on our website, [www.autismspeaks.org](http://www.autismspeaks.org). If you have any additional questions or would like to talk to someone, please contact our Autism Response Team at 888-AUTISM2, or [contactus@autismspeaks.org](mailto:contactus@autismspeaks.org).



# Resources by Topic Area

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## *What is Asperger Syndrome?*

- National Institute of Neurological Disorders and Stroke – Asperger Syndrome Information Page [www.ninds.nih.gov/disorders/asperger/asperger.htm](http://www.ninds.nih.gov/disorders/asperger/asperger.htm)
- *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV)

## *What are the Symptoms of Asperger Syndrome/HFA?*

- National Institute of Mental Health – What are the Autism Spectrum Disorders? [www.nimh.nih.gov/health/publications/autism/what-are-the-autism-spectrum-disorders.shtml](http://www.nimh.nih.gov/health/publications/autism/what-are-the-autism-spectrum-disorders.shtml)
- Kids Health – An Autism Spectrum Disorder <http://kidshealth.org/parent/medical/brain/asperger.html>
- Ozonoff, S., Dawson, G., and McPartland, J. (2002) A Parent's Guide to Asperger Syndrome and High-Functioning Autism: How to Meet the Challenges and Help your Child Thrive. NY: Guilford Publications.

## *Executive Functioning and Theory of Mind*

- Blair, J; Mitchel D; Blair K (2005). *Psychopathy, emotion and the brain*. Wiley-Blackwell. pp. 25–27
- Sacramento Asperger Syndrome Information and Support [www.sacramentoasis.com](http://www.sacramentoasis.com)
- Pinkham, Amy E., Penn, David L., Perkins, Diana O., Lieberman, Jeffrey Implications for the Neural Basis of Social Cognition for the Study of Schizophrenia American Journal of Psychiatry 2003 160: 815-824
- Winner, M. (2002). Assessment of social skills for students with Asperger syndrome and high-functioning autism. *Assessment for Effective Intervention*, 27, 73–80
- Baron-Cohen, S. (2001). Theory of mind in normal development and autism. *Prisme*, 34, pp. 174-183

## *What Causes Asperger Syndrome?*

- Kids Health – An Autism Spectrum Disorder <http://kidshealth.org/parent/medical/brain/asperger.html>

## *Diagnostic Overview*

- *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV)

## *Diagnosing Asperger Syndrome*

- Kids Health – An Autism Spectrum Disorder [www.kidshealth.org/parent/medical/brain/asperger.html](http://www.kidshealth.org/parent/medical/brain/asperger.html)
- Asperger's Syndrome: Guidelines for Assessment and Diagnosis - by Ami Klin, Ph.D., and Fred R. Volkmar, M.D., Yale Child Study Center, New Haven, Ct [www.med.yale.edu/chldstudy/autism/asdiagnosis.html](http://www.med.yale.edu/chldstudy/autism/asdiagnosis.html)





### *How is it Different from Autism and Other Disorders?*

- Autism Speaks – Asperger Syndrome  
[www.autismspeaks.org/navigating/index.php](http://www.autismspeaks.org/navigating/index.php)
- National Autism Society – UK  
[www.nas.org.uk/](http://www.nas.org.uk/)
- OASIS @ MAAP - The Online Asperger Syndrome Information and Support  
[www.aspergersyndrome.org](http://www.aspergersyndrome.org)

### *How Will I Deal With the Diagnosis? How Will This Affect My Family?*

- Asperger Syndrome – Mayo Clinic  
[www.mayoclinic.com/health/aspergers-syndrome/DS00551](http://www.mayoclinic.com/health/aspergers-syndrome/DS00551)
- Attwood, Tony. Ph.D. Should You Explain the Diagnosis to the Child?  
[www.ahany.org/ShouldYouExplainTheDiagnosis.htm](http://www.ahany.org/ShouldYouExplainTheDiagnosis.htm)
- Ozonoff, S., Dawson, G., and McPartland, J. (2002) A Parent's Guide to Asperger Syndrome and High-Functioning Autism: How to Meet the Challenges and Help your Child Thrive. NY: Guilford Publications.

### *Interventions and Treatment Options*

- National Institute of Neurological Disorders and Stroke – Asperger Syndrome Information Page  
[www.ninds.nih.gov/disorders/asperger/detail\\_asperger.htm](http://www.ninds.nih.gov/disorders/asperger/detail_asperger.htm)
- Asperger Syndrome – Mayo Clinic  
[www.mayoclinic.com/health/aspergers-syndrome/DS00551/DSECTION=treatments-and-drugs](http://www.mayoclinic.com/health/aspergers-syndrome/DS00551/DSECTION=treatments-and-drugs)
- Ozonoff, S., Dawson, G., and McPartland, J. (2002) A Parent's Guide to Asperger Syndrome and High-Functioning Autism: How to Meet the Challenges and Help your Child Thrive. NY: Guilford Publications.

### *Asperger Syndrome/HFA and the Classroom*

- Washington University (2007) What are typical challenges and accommodations for students with Asperger's Disorder and high-functioning Autism? [www.washington.edu/doit/Faculty/print.html?ID=247](http://www.washington.edu/doit/Faculty/print.html?ID=247)
- Autism Society (2010) Working with Individuals with Asperger's Disorder  
[http://www.autism-society.org/site/PageServer?pagename=life\\_aspergers\\_working](http://www.autism-society.org/site/PageServer?pagename=life_aspergers_working)
- Organization for Autism Research  
[www.researchautism.org](http://www.researchautism.org)
- Understanding Asperger Syndrome: A Professor's Guide  
<http://www.researchautism.org/resources/AspergerDVDSeries.asp>

### *Transitioning Into Adulthood*

- US Department of Education (2007) Free Appropriate Education for Students with Disabilities: Requirements under Section 504 of the *Rehabilitation Act of 1973* [www.ed.gov/about/offices/list/ocr/docs/edlite-FAPE504.html](http://www.ed.gov/about/offices/list/ocr/docs/edlite-FAPE504.html)
- Wright, Peter and Pamela (2008). Key Differences Between Section 504, the ADA, and the IDEA  
[www.wrightslaw.com/info/sec504.summ.rights.htm](http://www.wrightslaw.com/info/sec504.summ.rights.htm)
- Office for Civil Rights - Questions and Answers on Disability Discrimination under Section 504 and Title II  
[www.ed.gov/about/offices/list/ocr/qa-disability.html](http://www.ed.gov/about/offices/list/ocr/qa-disability.html)




- Office for Civil Rights - Frequently Asked Questions About Section 504 and the Education of Children with Disabilities  
[www.ed.gov/about/offices/list/ocr/504faq.html](http://www.ed.gov/about/offices/list/ocr/504faq.html)
- U.S. Department of Education, Office of Special Education Programs (2007)  
<http://idea.ed.gov/explore/view/p/%2Croot%2Cdynamic%2CTopicalBrief%2C17%2C>
- Asperger Center for Education and Training  
[www.aspergercenter.com](http://www.aspergercenter.com)
- U.S. Department of Justice, Civil Rights Division, *Disability Rights Section* (2005). *A Guide to Disability Rights Laws*  
[www.ada.gov/cguide.htm](http://www.ada.gov/cguide.htm)





# *Autism and Safety – How can I keep my child Safe?*


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 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?*

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 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*


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 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*

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 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*

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 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.*

## *Some Things to Consider...*

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### *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.

### *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.

### *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.

*For more information on safety you can visit:*

*Autism Safety Toolkit*

[www.nationalautismassociation.org/safetytoolkit.php](http://www.nationalautismassociation.org/safetytoolkit.php) or

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

and

*The Autism Safety Project*

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



# *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 three or older, you'll start with your local school district. Call to begin the process of getting services. You may want to put this in writing. EI (Early Intervention) 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.

## Week 2

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

***Getting Services (Follow Up)*** Follow up on services. Continue to check status on waiting lists and available programs.

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

## Week 3

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

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



## Week 4

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

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

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

## Week 5

***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.





## 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.

***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 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.

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

## 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.





## 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!



## 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)	



# Service Provider Planner

Agency & Contact	Phone #	Date Called	Requested Services	Requested # of Sessions & Duration	Availability	Status	Follow-Up	Other Info
Kid's Agency Mary Jones	555-555-555	1/7/08	Speech	4 sessions - 30 min each	Jane Smith - 2 sessions	Will call me back can start 1/15/08	can start 2/1/08	Jane's #555-2222 email: jane@speechtherapy.com





Agency & Contact	Phone #	Date Called	Requested Services	Requested # of Sessions & Duration	Availability	Status	Follow-Up	Other Info
Kid's Agency Mary Jones	555-555-555	1/7/08	Speech	4 sessions - 30 min each	Jane Smith - 2 sessions	Will call me back can start 1/15/08	Can start 2/1/08	Jane's #555-2222 email: jane@speechtherapy.com



# 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	
Name of Contact	
Name of Practice	
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# 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	
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Specialty	
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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	
Name of Contact	
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# CONTACTS - Other

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# Phone Log

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# Phone Log

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

# Assessment Tracking

Type of Therapy:

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







11

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# Useful Books and Websites

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## Websites

*Answer – Aspergers Network Support*

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

*Autism Asperger Publishing Company*

[www.asperger.net](http://www.asperger.net)

*ASPEN – Asperger Syndrome Education Network*

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

*Asperger Association of New England*

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

*Asperger Friends Support*

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

*Aspie Land*

[www.aspieland.com/directory/](http://www.aspieland.com/directory/)

*Asperger Support Group*

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

*Asperger Syndrome and High Functioning Autism Association*

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

*Asperger Syndrome Parents Support Group*

<http://myweb.lmu.edu/jdevine/as>

*Coulter Videos*

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

*Daily Strength*

[www.dailystrength.org/c/Asperger-Syndrome/support-group](http://www.dailystrength.org/c/Asperger-Syndrome/support-group)

*A Directory for Asperger Syndrome*

[www.kandi.org/aspergers/Support Groups and Organizations/index2.html](http://www.kandi.org/aspergers/Support_Groups_and_Organizations/index2.html)

*Disability Scoop*

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



*Facebook Page for Asperger Syndrome Support Group*  
[www.facebook.com/pages/Aspergers-Syndrome-Support-Group/27019793856](http://www.facebook.com/pages/Aspergers-Syndrome-Support-Group/27019793856)

*Families of Adults Affected by Asperger Syndrome*  
[www.faaas.org](http://www.faaas.org)

*GRASP – The Global and Regional Asperger Syndrome Partnership*  
[www.grasp.org](http://www.grasp.org)

*I Can Do It – A Special Place for Special Kids*  
[www.camelotforchildren.org/default.aspx?pageid=316](http://www.camelotforchildren.org/default.aspx?pageid=316)

*Interactive Autism Network*  
[www.ianproject.org](http://www.ianproject.org)

*MDJunction – People helping People*  
[www.mdjunction.com/asperger-syndrome](http://www.mdjunction.com/asperger-syndrome)

*The Online Asperger Syndrome Information and Support Center*  
[www.aspergersyndrome.org](http://www.aspergersyndrome.org)

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

*Sacramento Asperger Syndrome Information and Support*  
[www.sacramentoasis.com](http://www.sacramentoasis.com)

*Understanding Asperger Syndrome: A Professors Guide*  
[www.researchautism.org/resources/AspergerDVDSeries.asp](http://www.researchautism.org/resources/AspergerDVDSeries.asp)

*The Website of James Williams*  
[www.jamesmw.com](http://www.jamesmw.com)

## *Books*

### *Parenting and Family Books*

*Asperger Syndrome and Difficult Moments: Practical Solutions for Tantrums, Rage, and Meltdowns*  
By Brenda Smith Myles, Jack Southwick

*Asperger's Syndrome in Young Children: A Developmental Guide for Parents and Professionals*  
By Laurie Leventhal-Belfer, Cassandra Coe



*Asperger Syndrome and Adolescence: Helping Preteens and Teens Get Ready for the Real World*  
By Teresa Bolick

*Can I Tell You About Asperger Syndrome?: A Guide for Friends and Family*  
By Jude Welton, Jane Telford

*Finding a Different Kind of Normal: Misadventures with Asperger Syndrome*  
By Jeanette Purkis

*Freaks, Geeks and Asperger Syndrome: A User Guide to Adolescence*  
By Luke Jackson, Tony Attwood

*Help for the Child with Asperger's Syndrome: A Parent's Guide to Negotiating*  
By Gretchen Mertz

*I Am Utterly Unique: Celebrating the Strengths of Children with Asperger Syndrome and High-Functioning Autism*  
By Elaine Marie Larson

*A Parent's Guide to Asperger Syndrome and High-Functioning Autism: How to Meet the Challenges and Help Your Child Thrive*  
By Sally Ozonoff, Geraldine Dawson, James McPartland

*The Everything Parent's Guide to Children with Asperger's Syndrome*  
By William Stillman

*Talking Teenagers: Information and Inspiration for Parents of Teenagers with Autism or Asperger's Syndrome*  
By Ann Boushéy

### *Education Books*

*Asperger's Syndrome: Intervening in Schools, Clinics, and Communities*  
By Linda J. Baker, Lawrence A. Welkowitz

*Autism: Asserting Your Child's Right to A Special Education*  
By David A Sherman



*Inclusive Programming for High School Students with Autism or Asperger's Syndrome*

By Sheila Wagner

*Navigating the Social World: A Curriculum for Individuals with Asperger's Syndrome, High Functioning Autism and Related Disorders*

By Jeanette L. McAfee

*Realizing the College Dream with Autism or Asperger Syndrome: A Parent's Guide*

By Ann Palmer

*The Hidden Curriculum: Practical Solutions for Understanding Unstated Rules in Social Situations*

By Brenda Smith Myles, Melissa L. Trautman and Ronda L. Schelvan

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

By Paula Kluth

*General Asperger Syndrome Books*

*Asperger's Disorder*

By Jeffrey L. Rausch, Maria E. Johnson, Manuel F. Casanova

*Asperger's from the Inside Out*

By Michael John Carley

*Beyond the Wall*

By Stephen Shore

*Bye Bye Balloon: An Introductory Guide to Asperger Syndrome*

By Carlene Inge

*Coming Out Asperger: Diagnosis, Disclosure and Self-Confidence*

By Dinah Murray

*A Guide to Asperger Syndrome*

By Christopher Gillberg

*Elijah's Cup*

By Valerie Paradiz

*The Asperger's Answer Book: The Top 300 Questions Parents Ask*

By Susan Ashley



*The Complete Guide to Asperger's Syndrome*  
By Tony Attwood

*The OASIS Guide to Asperger Syndrome: Completely Revised and Updated:  
Advice, Support, Insight, and Inspiration*  
By Patricia Romanowski, Barbara L. Kirby, Simon Baron-Cohen and Tony Attwood





*Useful information can be found in 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.*

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*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.*

