



Children's National
Medical Center



ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES
RESEARCH, EDUCATION, SERVICE

Autism Spectrum Disorders: *Selected Readings and Resources*

Written and Compiled by

Kelly Register Brown, MD

and the Staff of The Center for Autism Spectrum Disorders
at Children's National Medical Center



AUTISM SPECTRUM DISORDERS: SELECTED READINGS AND RESOURCES

**Written and Compiled by
Kelly Register Brown, MD; Jenifer Walkowiak, PhD; Laura
Anthony, PhD; and Lauren Kenworthy, PhD**

***15245 Shady Grove Road, Suite 350 (South Building), Rockville, MD 20850; 301-765-5430
www.childrensnational.org***

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This book is designed to be a resource for parents as they navigate the journey of raising a child with special needs. We have found that well-informed parents are their children’s best advocates and teachers. We ourselves have learned many things from parents as they have advocated for their special children in their schools and communities. We hope this book will provide help in this process.

This book is dedicated to the families and children who have enriched our lives at the Center for Autism Spectrum Disorders.

This book can be found online at the website of the Center for Autism Spectrum Disorders at Children’s National Medical Center (go to www.childrensnational.org, click “Departments and Programs,” click "Center for Autism Spectrum Disorders,” and click “Resources for Families”).

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Before undertaking a course of action discussed herein, Users are advised to seek professional counsel on the issues raised by consulting with the appropriate medical professionals.

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SERVICES PROVIDED BY THE *CENTER FOR AUTISM SPECTRUM DISORDERS* AT CHILDREN'S NATIONAL MEDICAL CENTER

15245 Shady Grove Road, Suite 350 (South Building), Rockville, MD 20850; 301-765-5430

Children's National Medical Center, Center for Autism Spectrum Disorders (CASD) provides evaluation and treatment services for children with atypical or complicated developmental disorders. It addresses the needs of all children with autism spectrum disorders (ASD) and specializes in the diagnosis and evaluation of children with primary deficits in social cognition, communication, and executive functioning (including planning/organization skills, mental flexibility skills, inhibition skills, working memory skills, and self-monitoring skills). CASD has four major activities: clinical services, research, professional training, and community education and advocacy.

CLINICAL SERVICES

Children with ASD, including full autistic disorder (autism), Asperger syndrome, and other social development disorders, benefit from our multidisciplinary team that includes specialists in developmental/clinical psychology, neuropsychology, developmental neuropsychology, psychiatry, and speech and language pathology. Services from other Children's divisions are integrated as needed, including developmental pediatrics, genetics, Metabolics and Genetics, and neurology. Depending on the individual child's needs, services may include a range of assessments and interventions, described below.

Multidisciplinary Evaluation – Our Multidisciplinary Evaluation incorporates state-of-the-art tests to assess the complex needs of children and families. Drawing on the skills of our entire team, this evaluation includes:

- Review of medical and developmental histories
- Complete neuropsychological or developmental evaluation of cognitive, social, and adaptive functioning
- Comprehensive speech/language assessment of verbal and nonverbal communication skills
- Standardized diagnostic play/interview session

Based on our findings, team members meet with the child's parents/guardians to discuss diagnosis, prognosis, and recommendations for school placement and programming, treatment plans, specialized therapies, behavioral intervention, and additional services. In addition to a meeting with parents, we provide a written report with recommendations for academic and therapeutic interventions. Based on parents' preferences, we can consult with the child's treatment team or school by attending school meetings and assisting with the development and implementation of educational plans.

Neuropsychological Evaluation – This service is available as a part of the Multidisciplinary Evaluation or as a stand-alone evaluation. We assess children, ages 4-18, who are high-functioning and have developmental disorders. A neuropsychological evaluation includes measures of intellectual functioning, language, visual-spatial skills, attention, executive function, memory, social problem solving, and fine motor abilities. We provide a written report describing the child's cognitive strengths and weaknesses, areas of greatest risk, and detailed recommendations, and can consult with the child's school and treatment team when parents request we do so.

Developmental Evaluation – This service is available as a part of the Multidisciplinary Evaluations or as a stand-alone evaluation. We assess children younger than 5 years old who have age appropriate cognitive development but who may be experiencing developmental delays. We also assess children younger than 7 years old who are suspected of having cognitive impairments. A developmental evaluation provides information on intellectual functioning, language, visual-spatial skills, fine motor abilities, daily living skills, and general development. We provide a written report of our findings and recommendations, and can consult with the child's school when parents request we do so.

Speech and Language Evaluation – This service is available as a part of the Multidisciplinary Evaluations or as a stand-alone evaluation. We assess children, age birth to 18, to determine their speech and language abilities including the development of the mechanics of speech (e.g., articulation), the perception of language (e.g., phonological processing), the comprehension of language, expressive language, higher order language functioning, and the social use of language (e.g., pragmatics). We provide a written report of our findings and recommendations, and can consult with the child's school when parents request we do so.

Social Skills Training Groups – We offer training groups for children who have been diagnosed with high functioning autism, pervasive developmental disorder – not otherwise specified (PDD-NOS), Asperger syndrome, or a social learning disorder. Topics covered in groups are tailored to each family’s needs, and may include identifying and responding to emotions, handling teasing and bullying, developing strategies for making and maintaining friendships, and developing nonverbal communication. The format of these groups includes both direct instruction and role-playing activities, which allow children to develop and practice skills in a controlled setting. Parents are provided with home lesson plans and background materials so they can help their child continue practicing these new skills at home and/or school.

Psychiatric Services – We offer patients psychiatric evaluation and consultation in order to help identify conditions that may compound developmental delays. We can develop a complete treatment plan that may include the use of medications and psychological counseling. Our team’s child and adolescent psychiatrist provides ongoing monitoring of medications along with psychological counseling, if needed.

Additional Consultation and Support Services – In addition to the services outlined here, we also offer consulting and support for patients, siblings, and whole families whose lives may be disrupted by the challenges of raising a child with developmental delays and/or autism spectrum disorders. We offer individual therapy (talk therapy), family therapy (talk therapy), behavior management consultation, speech and language therapy, psychopharmacological (medication) management, school consultation, and educational advocacy.

RESEARCH

CASD conducts research to investigate cognitive, neurological, or genetic differences in children with autism, as compared to their typically developing peers. One of CASD’s main targets of interest is studying executive function (EF), which can help to better understand repetitive, inflexible and disorganized behaviors in ASD and underlying, biologically based brain abnormalities in ASD.

The Center for Autism Spectrum Disorders offers four main avenues for researching executive function, social development, and the treatment of ASD symptoms:

- **Neuropsychological/behavioral research**, which uses established state-of-the-art diagnostic and cognitive tests that characterize the strengths and weaknesses of individuals with autism spectrum disorders, as well as new measures that help us investigate the development of children with ASD. This type of research may involve participating in paper-and-pencil tasks, computer tasks, and an intelligence test.
- **Functional and structural imaging research**, which examines the brain areas that are involved in cognitive abilities, such as shifting tasks, learning, and social perception. This type of research may involve participating in MRI (magnetic resonance imaging) scans.
- **Genetics research** that explores the causes of autism. This type of research can involve providing saliva and/or blood samples.
- **Intervention research** to develop effective treatments aimed at improving executive function skills that directly impede academic performance on a daily basis.

We are always seeking children and adolescents with autism spectrum disorders, their parents, and their siblings who are interested in becoming research participants. To contact us about our research, call 301-765-5425 or e-mail autism@cnmc.org.

PROFESSIONAL TRAINING

CASD is a multidisciplinary program including neuropsychology, developmental psychology, speech/language pathology, and psychiatry. Trainees include medical residents, postdoctoral neuropsychology fellows, speech/language therapists, predoctoral psychology interns and externs, and other health professionals.

COMMUNITY EDUCATION AND ADVOCACY

CASD disseminates up-to-date information to families, patients, school personnel, physicians and other health providers, and community agency personnel through seminars, workshops, in-services, and consultations. The CASD team offers talks and workshops in the community, distributes newsletters with research updates, and supports a parent advisory committee.



THE DISTRICT OF COLUMBIA LEADERSHIP EDUCATION IN NEURODEVELOPMENTAL DISABILITIES (DC LEND) PROGRAM AT CHILDREN'S NATIONAL MEDICAL CENTER

OVERVIEW

The District of Columbia Leadership Education in Neurodevelopmental and Related Disabilities (DC LEND) Training Program provides an interdisciplinary model of learning that stresses an intensive sharing of expertise and progressive interdependence among practitioners, administrators, policymakers, and parents.

The DC LEND Program aims to prepare future leaders in the field of neurodevelopmental and related disabilities. We encourage individuals in the DC LEND Program to contribute by sharing their insights about working with and caring for children with neurodevelopmental and related disabilities.

FAMILY INVOLVEMENT IN DC LEND

The experience of being a family member or parent of an individual with a developmental disability cannot be learned in any university course. The DC LEND program actively seeks families of children with neurodevelopmental disabilities, including autism spectrum disorders, to participate in our Family Connections Program. Family Connections families are matched with one or two LEND trainees, with whom they share their personal experiences and invaluable perspective. Family members of children with neurodevelopmental disabilities are encouraged to apply to become LEND trainees.

FOR FURTHER INFORMATION

For information regarding the program please contact Joseph Knight, Program Manager (jknight@cnmc.org; 202-476-5811) or Lorraine Berko, Program Associate (lberko@cnmc.org; 202-476-5828). See also the website of the Association of University Centers on Disabilities (www.aucd.org; click on "LENDs," then "Family").



Autism Research at the NICHD

Autism Overview: What We Know

The *Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)*, part of the National Institutes of Health (NIH), within the U.S. Department of Health and Human Services, is one of many federal agencies working to understand autism. The NICHD supports and conducts research on what causes autism, how many people have autism, how best to treat the symptoms of autism, and other topics.

Even though autism was first described in the 1940s, little was really known about the disorder until the 1990s. Even today, there is a great deal that researchers, scientists, and health care providers don't know about autism.

But there are things that we do know about autism. This fact sheet offers broad information about autism and answers some of the more common questions that parents and families often have about the disorder. You can get more detailed information on these topics from the sources listed in the *References* section. Keep in mind that the articles listed are geared toward scientists and researchers, so the information is more technical than what is presented here.

Knowledge of autism is always growing as research examines more and different sides of the disorder. The NICHD joins other federal agencies, organizations, and support groups in helping those with autism achieve their full potential to live healthy, productive lives.

What is autism?

Autism is a complex neurobiological disorder of development that lasts throughout a person’s life. It is sometimes called a *developmental disability* because it usually starts before age three, in the developmental period, and because it causes delays or problems in many different skills that arise from infancy to adulthood.

Check the Glossary on pages 14-15 to learn how to say the **bolded** words and what they mean.

The main signs and symptoms of autism involve¹ language, social behavior, and behaviors concerning objects and routines:

- Communication—both verbal (spoken) and non-verbal (unspoken, such as pointing, eye contact, or smiling)
- Social interactions—such as sharing emotions, understanding how others think and feel (sometimes called empathy), and holding a conversation, as well as the amount of time a person spends interacting with others
- Routines or repetitive behaviors—often called **stereotyped behaviors**, such as repeating words or actions, obsessively following routines or schedules, playing with toys or objects in repetitive and sometimes inappropriate ways, or having very specific and inflexible ways of arranging items

People with autism might have problems talking with you, or they might not look you in the eye when you talk to them. They may have to line up their pencils before they can pay attention, or they may say the same sentence again and again

to calm themselves down. They may flap their arms to tell you they are happy, or they might hurt themselves to tell you they are not. Some people with autism never learn how to talk. These behaviors not only make life challenging for people who have autism, but also take a toll on their families, their health care providers, their teachers, and anyone who comes in contact with them.

Because different people with autism can have very different features or symptoms, health care providers think of autism as a “*spectrum*” disorder—a group of disorders with a range of similar features. Based on their specific strengths and weaknesses, people with autism spectrum disorders (ASDs) may have mild symptoms or more serious symptoms, but they all have an ASD. This fact sheet uses the terms “*ASD*” and “*autism*” to mean the same thing.

What conditions are in the ASD category?

Currently, the ASD category includes:

- Autistic disorder (also called “classic” autism)
- Asperger syndrome
- Pervasive Developmental Disorder Not Otherwise Specified (or atypical autism)

In some cases, health care providers use a broader term—*pervasive developmental disorders (PDD)*—to describe autism. The PDD category includes the ASDs mentioned above and: Childhood disintegrative disorder, and **Rett syndrome**.

Depending on specific symptoms, a person with autism may fall into the ASD or the PDD category. Sometimes, the terms “*ASD*” and “*PDD*” are used to mean the same thing because autism is in both categories.

What causes autism?

Scientists don’t know exactly what causes autism at this time.

Much evidence supports the idea that genetic factors—that is, **genes**, their function, and their interactions—are one of the main underlying causes of ASDs. But, researchers aren’t looking for just one gene. Current evidence suggests that as many as 12 or more genes on different **chromosomes** may be involved in autism, to different degrees.

Some genes may place a person at greater risk for autism, called **susceptibility**. Other genes may cause specific symptoms or determine how severe those symptoms are. Or, genes with changes or **mutations** might add to the symptoms of autism because the genes or gene products aren’t working properly.

Research has also shown that environmental factors, such as viruses, may also play a role in causing autism.

While some researchers are examining genes and environmental factors, other researchers are looking at possible neurological, infectious, metabolic, and immunologic factors that may be involved in autism.

Because the disorder is so complex, and because no two people with autism are exactly alike, autism is probably the result of many causes.

Is there a link between autism and vaccines?

To date, there is no conclusive scientific evidence that any part of a vaccine or any combination of vaccines causes autism, even though researchers have carried out many studies to answer this important question. There is also no proof that any material used to make or preserve vaccines plays a role in causing autism.

Although there have been reports of studies that relate vaccines to autism, the findings have not held up under further investigation. Researchers have been unable to **replicate** the studies that reportedly found a link between autism and vaccines.

There is a great deal of research and discussion on the topic of vaccines and autism—too much to cover here. The *U.S. Centers for Disease Control and Prevention (CDC)* conducts and supports most of the federal **epidemiological studies** that seek to answer questions about vaccines and autism.

Currently, the CDC provides the most accurate and up-to-date information about research on autism and vaccine research, both supported by the federal government and funded independently. For more information, visit <http://www.cdc.gov/nip/vacsafe/concerns/autism/default.htm>.

How many people have autism?

Currently, researchers don't know the exact number of people with an ASD in the United States.

Researchers use different ways to determine **prevalence** that often give different results.

Some estimates of prevalence rely on previously published studies. Researchers review all the published data on a topic and take the averages of these calculations to determine prevalence. Independent researchers³ recently conducted two such reviews. Based on these studies, the best conservative estimate⁴ of the prevalence of ASDs in the United States is that one child in 1,000 children has an ASD.

Is autism more common now than it was in the past?

Researchers are not certain whether autism is more prevalent now than in the past for a number of reasons. Although more cases of autism are being identified, it is not clear why. Some of the increase may result from better education about the symptoms of autism or from more accurate diagnoses of autism.

The new definition of autism as a spectrum disorder means that even people with mild symptoms can be classified as having an ASD, which could also account for the increase in identified cases. As research moves forward using the current definition of ASDs, more definite numbers may be available to answer this question.

Is autism more common in certain groups of people?

Current figures show that autism occurs in all racial, ethnic, and social groups equally, with individuals in one group no more or less likely to have ASDs than those in other groups. Three groups are at higher-than-normal risk for ASDs, including:

- *Boys.* Statistics show that boys are three to four times more likely⁵ to be affected by autism than are girls.
- *Siblings of those with ASDs.* Among families that have one child with an ASD, recurrence of ASD in another sibling is between⁶ 2 percent and 8 percent, a figure much higher than in the general population.
- *People with certain other developmental disorders.* For certain disorders, including **Fragile X syndrome, mental retardation,** and **tuberous sclerosis,** autism is common in addition to the primary symptoms of the disorder.

When do people usually show signs of autism?

A number of the behavioral symptoms⁷ of autism are observable by 18 months of age, including: problems with eye contact, not responding to one's name, joint attention problems, underdeveloped skills in pretend play and imitation, and problems with non-verbal communication and language.

Some studies also note that, although more subtle, some signs of autism are detectable at eight months⁸ of age.

In general, the average age of autism diagnosis is currently three years old. In many cases, a delay in the child's starting to speak around age two brings problems to parents' attention, even though other, less noticeable signs may be present at an earlier age.⁹

Studies¹⁰ also show that a subgroup of children with ASDs experiences a "*regression*," meaning they stop using the language, play, or social skills they had already learned. This regression usually happens between the first and second birthdays.

Researchers are still learning about the features of regression in ASDs, and whether the features differ from those shown by individuals who show signs of autism in early life.

What are some of the possible signs of autism?

Parents, caregivers, family members, teachers, and others who spend a lot of time with children can look for "*red flags*." Some may mean a delay in one or more areas of development, while others are more typical of ASDs. A list of red flags appears to the right.

Possible Red Flags for Autism¹¹

- The child does not respond to his/her name.
- The child cannot explain what he/she wants.
- The child's language skills are slow to develop or speech is delayed.
- The child doesn't follow directions.
- At times, the child seems to be deaf.
- The child seems to hear sometimes, but not other times.
- The child doesn't point or wave "bye-bye."
- The child used to say a few words or babble, but now he/she doesn't.
- The child throws intense or violent tantrums.
- The child has odd movement patterns.
- The child is overly active, uncooperative, or resistant.
- The child doesn't know how to play with toys.
- The child doesn't smile when smiled at.
- The child has poor eye contact.
- The child gets "stuck" doing the same things over and over and can't move on to other things.
- The child seems to prefer to play alone.
- The child gets things for him/herself only.
- The child is very independent for his/her age.
- The child does things "early" compared to other children.
- The child seems to be in his/her "own world."
- The child seems to tune people out.
- The child is not interested in other children.
- The child walks on his/her toes.
- The child shows unusual attachments to toys, objects, or schedules (i.e., always holding a string or having to put socks on before pants).
- Child spends a lot of time lining things up or putting things in a certain order.

In addition, your child’s health care provider will send your child for an evaluation if you report any of the behaviors listed below; such an evaluation would consider ASDs, among other possible causes.¹²

If the child...

- Does not babble or coo by 12 months of age
- Does not gesture (point, wave, grasp, etc.) by 12 months of age
- Does not say single words by 16 months of age
- Does not say two-word phrases on his or her own (rather than just repeating what someone says to him or her) by 24 months of age
- Has *ANY* loss of *ANY* language or social skill at *ANY* age

What should I do if I think my child has a developmental problem or autism?

Tell your child’s health care provider *immediately* if you think something is wrong.

According to the *American Academy of Pediatrics (AAP)*¹³, “Pediatricians should listen carefully to parents discussing their child’s development. [Parents] are reliable sources of information and their concerns should be valued and addresses immediately.”

Your child’s health care provider will note your comments and concerns, will ask some other questions, and will determine the best plan of action. In some cases, the health care provider will ask you to complete a questionnaire about your child to get more specific information about symptoms. To rule out certain conditions, the health care provider will also test your child’s hearing and check your child’s lead level before deciding on a course of action.

If *red flags* are present, and if the lead and hearing tests show no problems, your child’s health care provider may refer you to a specialist in child development or another specialized health care provider. The specialist will conduct a number of tests to determine whether or not your child has autism or an ASD.

What if I don’t notice any symptoms?

If you don’t report any of these signs, your child’s health care provider will continue to check for problems at every well-baby and well-child visit.¹⁴ If your child’s health care provider does not routinely check your child with such tests, you should ask that he or she do so.

In this **developmental screening**, the provider asks questions related to normal development that can help measure your child’s specific progress. Typically, these questions are similar to the red flags listed earlier. Based on your answers, the health care provider may send your child for further evaluation.

The AAP recommends¹⁵ that health care providers ask questions about different aspects of development. These questions include (but are not limited to) those listed here.

Does your child...¹⁵

- Not speak as well as other children his/her age?
- Have poor eye contact?
- Act as if he/she is in his/her own world?
- Seem to “tune out” others?
- Not smile when smiled at?
- Seem unable to tell you what he/she wants, and so takes your hand and leads you to what he/she wants, or gets it him/herself?
- Have trouble following simple directions?
- Not play with toys in a usual way?
- Not bring things to you to “show” you something?
- Not point to interesting things or direct your attention to items of interest?
- Have unusually long or severe temper tantrums?
- Show an unusual attachment to objects, especially “hard” ones, such as a flashlight or key chain, instead of “soft” ones, such as a blanket or stuffed animal?
- Prefer to play alone?
- Not pretend or play “make believe” (if the child is older than age two)?

Is there a cure for autism?

To date, there is no cure for autism, but sometimes, children with ASDs make so much progress that they no longer show the full syndrome of autism when they are older.

Research¹⁶ shows that early diagnosis and interventions delivered early in life, such as in the preschool period, are more likely to result in major positive effects on later skills and symptoms. The sooner a child begins to get help, the more opportunity for learning. Because a young child’s brain is still forming, early intervention gives children the best start possible and the best chance of developing their full potential. Even so, no matter when a person is diagnosed with autism, it’s never too late to benefit from treatment. People of all ages with ASDs at all levels of ability generally respond positively to well designed interventions.

*Public Law 108-77: Individuals with Disabilities Education Improvement Act*¹⁷(2004) and *Public Law 105-17: Individuals with Disabilities Act, or IDEA*¹⁸ (1997) require your child’s primary care provider to refer you and your family to an early intervention service. Every state operates an early intervention program for children from birth to age three; children with autism should qualify for these services. Early intervention programs typically include behavioral methods, early developmental education, communication skills, occupational and physical therapy, and structured social play.

What are the treatments for autism?

Currently there is no definitive, single treatment for ASDs. However, there are a variety of ways to help minimize the symptoms and maximize learning. Persons with an ASD have the best chance of using all of their individual capabilities and skills if they receive appropriate behavioral and other therapies, education, and medication. In some cases, these treatments can help people with autism function at near-normal levels.

Some possible treatments for autism are explained below. If you have a question about treatment, you should talk to a health care provider who specializes in caring for people with autism.

Behavioral therapy and other therapeutic options

In general, **behavior management therapy** works to reinforce wanted behaviors and reduce unwanted behaviors. At the same time, these methods also suggest what caregivers should do before or between episodes of problem behaviors, and what to do during or after these episodes. Behavioral therapy is often based on **Applied Behavior Analysis (ABA)**. Different applications of ABA commonly used for people with autism include: Positive Behavioral Interventions and Support (PBS), Pivotal Response Training (PRT), Incidental Teaching, Milieu Therapy, Verbal Behavior, and Discrete Trial Teaching (DTT), among others.

Keep in mind that other therapies, beyond ABA, may also be effective for persons with autism. Talk to your health care provider about the best options for your child.

A variety of health care providers can also help individuals with ASDs and their families to work through different situations.

- *Speech-language therapists* can help people with autism improve their general ability to communicate and interact with others effectively, as well as develop their speech and language skills. These therapists may teach non-verbal ways of communicating and may improve social skills that involve communicating with others. They may also help people to better use words and sentences, and to improve rate and rhythm of speech and conversation.
- *Occupational therapists* can help people with autism find ways to adjust tasks and conditions that match their needs and abilities. Such help may include finding a specially designed computer mouse and keyboard to ease communication, or identifying skills that build on a person's interests and individual capabilities. Occupational therapists may also do many of the same types of activities as physical therapists do (see below).
- *Physical therapists* design activities and exercises to build motor control and to improve posture and balance. For example, they can help a child who avoids body contact to participate in activities and games with other children.

Special services are often available to preschool and school-aged children, as well as to teens, through the local public school system. In many cases, services provided by specialists in the school setting are free. More intense and individualized help is available through private clinics, but the family usually has to pay for private services, although some health insurance plans may help cover the cost.

Educational and/or school-based options

Children with ASDs are guaranteed free, appropriate public education under federal laws. *Public Law 108-77: Individuals with Disabilities Education Improvement Act*¹⁷ (2004) and *Public Law 105-17: The Individuals with Disabilities Education Act—IDEA*¹⁸ (1997) make it possible for children with disabilities to get free educational services and educational devices to help them learn as much as they can. Each child is entitled to these services from age three through high school, or until age 21, whichever comes first.

The laws state that children must be taught in the least restrictive environment, appropriate for that individual child. This statement does not mean that each child must be placed in a regular classroom. Instead, the laws mean that the teaching environment should be designed to meet a child's learning needs, while minimizing restrictions on the child's access to typical learning experiences and interactions. Educating persons with ASDs often includes a combination of one-to-one, small group, and regular classroom instruction.

To qualify for special education services, the child must meet specific criteria as outlined by federal and state guidelines. You can contact a local school principal or special education coordinator to learn how to have your child assessed to see if he or she qualifies for services under these laws.

If your child qualifies for special services, a team of people, including you and your family, caregivers, teachers, school psychologists, and other child development specialists, will work together to design an **Individualized Educational Plan (IEP)**¹⁹ for your child. An IEP includes specific academic, communication, motor, learning, functional, and socialization goals for a child based on his or her educational needs. The team also decides how best to carry out the IEP, such as determining any devices or special assistance the child needs, and identifying the developmental specialists who will work with the child.

The special services team should evaluate and re-evaluate your child on a regular basis to see how your child is doing and whether any changes are needed in his or her plan.

A number of parents' organizations, both national and local, provide information on therapeutic and educational services and how to get these services for a child. Visit <http://www.nlm.nih.gov/medlineplus/autism.html> for a listing of these organizations, or check the local phone book.

Medication options

Currently, there is no medication that can cure ASDs or all of the associated symptoms. Further, the *Food and Drug Administration (FDA)* has not approved any drugs specifically for the treatment of autism or its causes. But, in many cases, medication can treat some of the symptoms associated with ASDs.

Please note that the NICHD does not endorse or support the use of any of these medications for treating symptoms of ASDs, or for other conditions for which the medications are not FDA approved.

Medication can improve the behavior of a person with autism. Health care providers often use medications to deal with a specific behavior, such as reducing self-injurious behavior. With the symptom minimized, the person with autism can focus on other things, including learning and communication. Some of these medications have serious risks involved with their use; others may make symptoms worse at first or may take several weeks to become effective.

Not every medication helps every person with symptoms of autism. Health care providers usually prescribe medications on a trial basis, to see if it helps. Your child's health care provider may have to try different dosages or different combinations of medications to find the most effective plan. Families, caregivers, and health care providers need to work together to make sure that medications are working and that the overall medication plan is safe.

Medications used to treat the symptoms of autism²⁰ may include (but are not limited to):

- *Selective serotonin re-uptake inhibitors (SSRIs)* are a group of antidepressants that treat problems, such as obsessive-compulsive behaviors and anxiety, resulting from an imbalance in one of the body's chemical systems that are sometimes present in autism. These medications may: reduce the frequency and intensity of repetitive behaviors; decrease irritability, tantrums, and aggressive behavior; and improve eye contact.
- *Tricyclics* are another type of antidepressant used to treat depression and obsessive-compulsive behaviors. Although these drugs tend to cause more side effects than the SSRIs, sometimes they are more effective for certain people.
- *Psychoactive or anti-psychotic medications* affect the brain of the person taking them. Use of this group of drugs is the most widely studied treatment for autism. In some people with ASDs, these drugs may decrease hyperactivity, reduce stereotyped behaviors, and minimize withdrawal and aggression.
- *Stimulants* may be useful in increasing focus and decreasing hyperactivity in people with autism, particularly in higher-functioning individuals. Because of the risk of side effects, health care providers should monitor those using these drugs carefully and often.
- *Anti-anxiety drugs* can help relieve anxiousness and panic disorders associated with autism.

What is secretin and is it an effective treatment for autism?

Secretin is a hormone produced by the small intestine that helps in digestion. Currently, the FDA approves a single dose of secretin only for use in diagnosing digestive problems.

In the 1990s, news reports described a few persons with autism whose behavior improved after getting secretin during a diagnostic test.

However, a series²¹ of clinical trials funded by the NICHD and conducted through the *Network on the Neurobiology and Genetics of Autism: Collaborative Programs of Excellence in Autism (CPEAs)* found no difference in improvement between those taking secretin and those taking placebo. In fact, of the five case-controlled clinical trials published on secretin, not one showed secretin as any better than placebo, no matter what the dosage or frequency. For this reason, secretin is not recommended as a treatment for ASDs.

Are there other disorders associated with ASDs?

In about 5 percent²² of autism cases, another disorder is also present. Studying this kind of co-occurrence helps researchers who are trying to pinpoint the genes involved in autism. Similar disorders or disorders with similar symptoms may have similar genetic origins. In cases of one disorder commonly occurring with another, it could be that one is actually a risk factor for the other. This kind of information can provide clues to what actually happens in autism.

Some of these co-occurring disorders include:

- **Epilepsy** or **seizure** disorder—Nearly one-third²³ of those with autism also show signs of epilepsy by adulthood. In most cases, medication can control and treat epilepsy effectively.
- **Tuberous sclerosis**—About 6 percent²⁴ of those with autism also have tuberous sclerosis, a disorder that shares many symptoms with autism, including seizures that result from lesions (cuts) on the brain.
- **Fragile X syndrome**—Nearly 2.1 percent²⁵ of those with autism also have Fragile X, the most common inherited form of mental retardation.
- **Mental retardation**—About 25 percent²⁶ of persons with autism also have some degree of mental retardation.

Many people have treatable conditions in addition to their autism. Sleep disorders, allergies, and digestive problems are commonly seen in those with ASDs, and many of these can be treated with environmental interventions and/or medication. Treatment for these conditions may not cure autism, but it can improve the quality-of-life for people who have autism and their families.

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Glossary

The word...	Is pronounced...	And means...
Applied Behavior Analysis	ah-PLYED bee-HAY-vyur ah-NALL-uh-siss	An intervention that relies on the theory that rewarded behavior is more likely to be repeated than ignored behavior. This theory provides the foundation of several different methods of behavioral management often used with persons who have autism and other developmental disorders.
Behavior Management Therapy	bee-HAY-vyur MANN-ej-ment thee-ree	A method of therapy that focuses on managing behavior—that is, changing unwanted behaviors through rewards, reinforcements, and by confronting something that arouses anxiety, discomfort, or fear and overcoming the unwanted responses.
Chromosomes	kro-mu-SOM	One of the "packages" of genes and other DNA in the nucleus of a cell. Humans have 23 pairs of chromosomes, 46 in all. Each parent contributes one chromosome to each pair, so children get half of their chromosomes from their mothers and half from their fathers.
Developmental screening	dee-vel-up-menn-tul skree-ning	A check-up similar to the physical check-up a child gets from a health care provider, but that focuses on a child's social, emotional, and intellectual development. This screening monitors and charts development to make sure that the child is developing as expected for his or her age.
Epidemiological studies	epp-ih-DEEM-me-oh- loj-i-kul STUH-dees	Studies of the number of people with a disease(s), the locations of these people, the patterns of the disease(s), and what contributes to or causes the disease(s) or related events in certain groups.
Epilepsy	epp-ih-LEPP-see	A brain disorder in which clusters of nerve cells, or neurons, in the brain sometimes signal abnormally. In epilepsy, the normal pattern of neuronal activity becomes disturbed, causing strange sensations, emotions, and behavior or sometimes convulsions, muscle spasms, and loss of consciousness.
Fragile x syndrome	FRA-jell EKS sinn-DROM	Is the most common form of inherited mental retardation. A mutation in a single gene, the <i>FMR1</i> gene located on the X chromosome, causes Fragile X syndrome and can be passed from one generation to the next. Symptoms of Fragile X syndrome occur because the mutated gene cannot produce enough of a protein that is needed by the body's cells, especially cells in the brain, to develop and function normally.
Gene	jeen	Pieces of DNA. They contain the information for making a specific protein.

Courtesy of NICHD

Glossary (Continued)

The word...	Is pronounced...	And means...
Individual Education Plan (IEP)	INN-div-ih-djewel ED-djew-kay-shun plan	A written set of instruction goals, or specific skills, for every child in a special education program that is required by law. The document is an agreement between the school and the family about a child's educational goals. The IEP is reviewed every year and, if needed, changed to meet a child's new or changing needs.
Mental retardation	MENN-tul ree-tarr-DAY-shen	A term used when a person has certain limitations in mental functioning and in skills such as communicating, taking care of him or herself, and social skills.
Prevalence	prev-uh-lens	The number of people in a given population who have a certain condition or disease.
Replicate	repp-li-KATE	Describes a situation in which many studies that use the same methods and steps have gotten the same outcome, suggesting that a finding is likely to be true.
Rett syndrome	RETT sinn-DROM	Mostly caused by mutations in the <i>MECP2</i> gene on the X chromosome. Rett syndrome is a disorder of brain development that occurs almost exclusively in girls. After a few months of apparently normal development, affected girls develop problems with language, learning, coordination, and other brain functions.
Seizures	SEE-jurs	A sudden attack, often one of convulsions, as in epilepsy. Seizures don't necessarily involve movement or thrashing; they can also make someone seem as though they are frozen, unmoving.
Stereotyped Behaviors	STARE-ee-oh-tipd bee-HAY-vyurs	Actions that are repeated without change.
Susceptibility	suss-ept-ih-BULL	The state of being predisposed to, sensitive to, or of lacking the ability to resist manifestations of something (such as a pathogen, familial disease, or a drug); a person who is susceptible is more likely to show symptoms of a disorder.
Tuberous sclerosis	TOOB-er-us sklar-OH-siss	A rare, multi-system genetic disease that causes non-cancerous tumors to grow in the brain and on other vital organs such as the kidneys, heart, eyes, lungs, and skin. It commonly affects the central nervous system and results in symptoms including seizures, developmental delay, behavioral problems, skin abnormalities, and kidney disease.

How can I get involved with studies of autism?

If you are interested in taking part in one of the CPEA studies, or if you want more information about one of the CPEA sites, visit <http://www.nichd.nih.gov/autism/cpea.cfm>. You and your family are welcome to take part in many different studies, but you can only take part in one genetics study at a time.

To find out what studies related to autism are currently looking for participants, go to <http://www.nichd.nih.gov/autism/research.cfm> and choose the “Autism clinical trials currently recruiting patients” link.

You can also visit <http://www.clinicaltrials.gov> or call 1-800-411-1222 for more information on federally funded studies that are seeking participants.

Where can I go for more information about autism?

For more information about the CPEA Network, genetic studies, or autism research, contact the NICHD. The NICHD supports and conducts research on topics related to the health of children, adults, families, and populations, including autism and developmental disabilities. The mission of the NICHD is to ensure that every person is born healthy and wanted, that women suffer no harmful effects from the reproductive process, and that all children have the chance to fulfill their potential for a healthy and productive life, free of disease or disability, and to ensure the health, productivity, independence, and well-being of all people through optimal rehabilitation. You can contact the NICHD through the **NICHD Information Resource Center** at:

Mail: P.O. Box 3006, Rockville, MD 20847

Phone: 1-800-370-2943 (TTY: 1-888-320-6942)

Fax: 1-866-760-5947

E-mail: NICHDInformationResourceCenter@mail.nih.gov (Please use AUTISM in the subject line)

Internet: <http://www.nichd.nih.gov/autism>

The National Library of Medicine also provides information on ASDs at <http://www.nlm.nih.gov/medlineplus/autism.html>. The NIH Web site also has information about ASDs at <http://health.nih.gov/result.asp/62>.

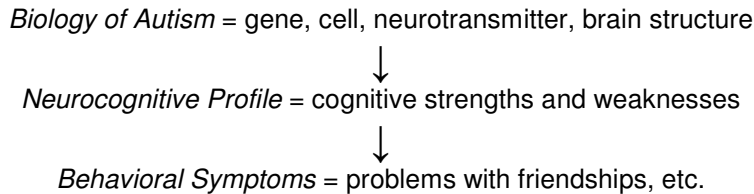


NEUROPSYCHOLOGICAL PROFILES: SOCIAL COGNITION, AND EXECUTIVE FUNCTIONS

CENTER FOR AUTISM SPECTRUM DISORDERS, CHILDREN'S NATIONAL MEDICAL CENTER

NEUROPSYCHOLOGICAL PROFILES

Autism is defined by the behavioral symptoms it produces, such as poor social reciprocity, trouble communicating effectively, or repetitive behaviors. But autism is largely caused by genetic factors that alter brain functioning and create an unusual pattern of cognitive strengths and weaknesses. Those cognitive strengths and weaknesses are what drive the problem behaviors, or symptoms of autism.



Although we don't yet fully understand the biology of autism, it is helpful to define the cognitive profile or brain-based problem solving strengths and weaknesses that underlie its behavioral symptoms. This allows us to:

1. **Better understand the logic of problem behaviors** (e.g. child has a temper tantrum every day in lunch room at school because he is cognitively overloaded by all the people, noise, etc.)
2. **Anticipate and prevent problem behaviors instead of reacting to them after the fact** (e.g. have child eat lunch in a smaller group vs. trying to treat meltdowns after they happen)
3. **Celebrate the child's cognitive strengths and use them to compensate for weaknesses** (e.g. child who is easily disorganized in new situations, but has good verbal skills is often helped by a written recipe or checklist outlining what to do next).

Every child with an autism spectrum disorder has a unique neuropsychological profile. It can be useful to get a neuropsychological evaluation of your child so that her individual strengths and weaknesses can be fully understood. Then we can predict the specific situations and tasks that are likely to produce success or risk for your child, and plan accordingly. It is also true that there are common patterns of strengths and weaknesses in autism spectrum disorders:

COMMON STRENGTHS

- Rote memory.
- Capacity to notice and remember unusual details, without being distracted by context. Sherlock Holmes is an excellent example of this.
- Ability to focus intensively in a certain area and amass impressive databases of facts and knowledge.
- May have a strong vocabulary.
- Excellent capacities to replicate and understand abstract visual information.
- Systematic, logical thinking.
- Once a routine or a procedure is learned it is followed faithfully.
- Good computer skills and mechanical abilities.
- May be good at physics and engineering.

COMMON WEAKNESSES

- Social Cognition
- Executive Function
- Language Pragmatics
- Fine Motor
- Intuitive, Inferential Learning

SOCIAL COGNITION

Social Cognition refers to the many things that our brains do that help us understand social and emotional information about others and ourselves. It includes components such as being able to:

- Recognize faces
- Understand and express emotion with: voice intonation, facial expression, body language, gesture, verbal nuance (e.g. a young woman with high functioning autism said, “People talk to each other with their eyes, but I don’t know what they are saying”)
- Recognize one’s own emotional state (e.g. know when you are feeling anxious)
- Label emotions in self and others
- Describe other people meaningfully (e.g. she is a shy person, he is funny)
- Discern social rules (e.g. know that you shouldn’t pick your nose in public)
- Understand human relationships (e.g. what is a friend)
- Understand the meaning of different human roles (e.g. speak respectfully to teachers)
- Understand the meaning of different social contexts (e.g. acceptable behavior in a party is different from acceptable behavior in church)
- Reason and problem solve with social information
- Engage in imaginative play (e.g. act out unique stories with characters and spontaneously respond to the play of others)
- Have a *theory of mind*. Theory of mind emphasizes the importance of being able to ascribe beliefs and desires to other people in order to infer their mental states and predict behavior. It requires the ability to realize that inner emotional states need not correspond to outer expression. Theory of Mind is involved in an awareness of pretense, irony, deception, cause and effect, and motivation.

Social Cognition drives many language pragmatic or conversational skills, such as being able to:

- Initiate, maintain, and end topics (e.g. sticking with a topic in conversation)
- Know when and how to shift topics (e.g. recognizing when someone is bored with a topic)
- Recognize misunderstandings and know how to correct them (e.g. recognizing that you have hurt someone’s feelings)
- Take the perspective of others in conversation (e.g. partner doesn’t know as much about a topic as you do and needs some background)
- Sensitivity to conversational partner (e.g. recognizing that your conversational partner is bored)
- Turn-taking in conversation

EXECUTIVE FUNCTIONS

Executive Functions are a group of abilities, including impulse control, organization, flexibility, planning, and working memory (or on-line processing), which play a major role in autism spectrum disorders. Because of their executive dysfunction, children with autism spectrum disorders have difficulty:

- Organizing, or integrating their world into a meaningful whole (think of a person who stands too close to a mosaic and sees only individual pieces of the design, not the big picture). They have good attention to detail, but miss the forest for the trees, unless people work with their detail analysis strengths to help them build a big picture, piece by piece.
- Flexibly shifting gears from one thing to another. This means that they can get stuck on irrelevant details and have problems generating new ideas. Often inflexible thinking patterns drive “stubborn” behaviors. Repetitive behaviors and over focused interests are also related to inflexibility.
- Keeping track of multiple step tasks.
- Keeping track of, and using directions and information spoken to them by others.

These executive problems interfere with social interaction skills, daily living skills, and academic skills (especially written expression, reading for meaning, making inferences, long-term projects, note-taking, and studying for tests). These executive problems pose greatest risk in situations that are

- New or unfamiliar (e.g. the first day of school)
- Unexpected or unpredictable (substitute teacher)
- Unstructured or chaotic (lunch room, bus, field trip)
- Group activities that involve more than a few people
- Demanding of listening skills (new procedure is explained orally)
- Social.



AUTISM SPECTRUM DISORDERS: AN OVERVIEW FOR FRIENDS AND FAMILY

CENTER FOR AUTISM SPECTRUM DISORDERS, CHILDREN'S NATIONAL MEDICAL CENTER

Autism spectrum disorders are a specific group of social, communication, and restricted or repetitive behaviors that negatively affect an individual's development. Possible causes of autism spectrum disorders include genetics, prenatal infection, and developmental differences in the brain. Extensive research has shown that autism spectrum disorders are brain-based disorders that are NOT caused by bad parenting.

Children with autism spectrum disorders may act unusually not because they are being difficult, but rather because they are just being themselves. The following are common challenges and strengths of children with autism spectrum disorders, though no child will have all of these characteristics:

COMMON CHALLENGES

Social Interactions

- Wants to make friends but doesn't know how
- Often doesn't "get" social cues or understand unwritten social rules
- Doesn't usually make eye contact
- Doesn't always understand facial expressions and body language
- Makes inappropriate facial expressions

Communication

- May or may not have difficulty with spoken language, especially pronouns ("I," "you"), figures of speech, and sarcasm
- Uses memorized phrases and quotes
- May not respond when spoken to
- Speaks in an unusual tone of voice, for example sounding bored

Behavior

- Has over- or under-sensitive senses of smell, taste, sight, sound, pain, or touch
- Shows repetitive body movements
- Shows limited imaginative play
- Strongly opposes change; likes routines
- Has intense tantrums
- Has narrow, intense interests
- Can't move off of a single topic of interest
- Is easily overwhelmed, even in small groups
- Notices details but can miss the "big picture"

COMMON STRENGTHS

Social Interactions

- Has the same emotions as everyone else, but expresses them differently
- Wants to be included and have friends, but doesn't know how
- Behaves with honesty and integrity
- Is genuine and open
- Is very willing to follow clear rules and schedules
- Has a charming innocence
- Often has a great sense of humor

Thinking

- Memorizes information, especially visual information, easily
- Has an unusually strong long-term memory
- Pays strong attention to details, especially visual details
- Has an excellent sense of direction
- Works precisely, and is a perfectionist
- Thinks and solves problems logically
- Able to maintain focus on interesting activities well
- May have passionate interests
- May have special talents

WAYS TO HELP

- Be sensitive to the fact that children with autism spectrum disorders have the same feelings as everyone else. **They are hurt just as much as "typical" children by being excluded.** Ask how you can include him/her in activities you are planning.
- Don't be offended if the child doesn't make eye contact, sounds annoyed or bored, or ignores you. These behaviors are caused by physical differences in his/her brain, not by a bad attitude.
- Understand that bright lights, loud sounds, and strong smells can be so overwhelming they are painful to the child. Many tantrums are caused by these sensory difficulties.
- Use clear, literal language and stick to predictable schedules around the child.
- If you don't know what to do or how to help, just ask. Families are generally happy to answer well-meaning questions about their children's disabilities.
- Recognize that although people with autism spectrum disorders have a different way of being in the world, they still have tremendous potential.

Your support of children with autism spectrum disorders and their families is crucial to helping them fulfill their potential and become integrated into our community. Thank you!

GROWING UP

Together



4340 East-West Highway, Suite 350, Bethesda, Maryland 20814

Phone: 301.657.0881 or 1.800.3AUTISM | Fax: 301.657.0869

Web: www.autism-society.org

The *Growing Up Together* information was developed by the Autism Society and revised by Brian Ketzner (Indiana Resource Center for Autism) and Kristie Lofland (Hamilton-Boone-Madison Special Services Cooperative).

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**Easter Seals
Crossroads**



**Our world is
made up of
many different
kinds of people.**

Each one of us is
special in our own way, but
we are all very much alike.

We all have friends and
families, go to school, and
have hobbies such as
soccer, art, or music.

Children with autism may look like other kids, but if you met them you would find they are different in some ways. It may be hard for them to play, to make friends or to learn new things. Some may have trouble talking or understanding what people say. Some may talk too much about a favorite topic. But, just like you, children with autism are very special in many ways. They have families who love them very much, they go to school, and they have special interests.

**This booklet is about people
you may meet who have autism
and how you can be their friend.**

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What Is Autism?

Autism affects the way a person's brain and body works. It is not a disease and is not contagious. You cannot catch autism from a classmate or friend. A person with autism may have a hard time communicating with other people, making friends, or following directions. However, with the help of teachers, classmates, families, and friends, children with autism often can find it easier to learn in spite of these challenges.

How Do Kids with Autism Act?

Children with autism may act in some unusual ways. Some may have difficulties with certain activities, but they may have strengths in other areas. For instance, a child with autism may be a math whiz, a great artist or unbeatable at computer games. Still, they may have trouble putting their thoughts into words or understanding what you say.

Some children with autism prefer that schedules stay the same or that people always sit in the same seats. They may have a difficult time when things change. Changes may be scary for them, so they may try telling others what to do or where to sit. You may think they are being "bossy" but it is really them trying to adjust to the changes. When schedules change and they do not know what is coming next, they can be very upset, sad or angry.



Some kids with autism may:

- Have trouble talking, make strange sounds, or not talk at all;
- Flap their hands, spin, or laugh a lot;
- Sit quietly and not look at others;
- Play or behave differently than other friends;
- Be very active or be very quiet and like to spend time alone;
- Have trouble looking directly at you; or
- Do or say the same things over and over again (like lining up toys or repeating a line from a movie).

Just because someone with autism may not be able to use words, it does not mean he can't understand your words.

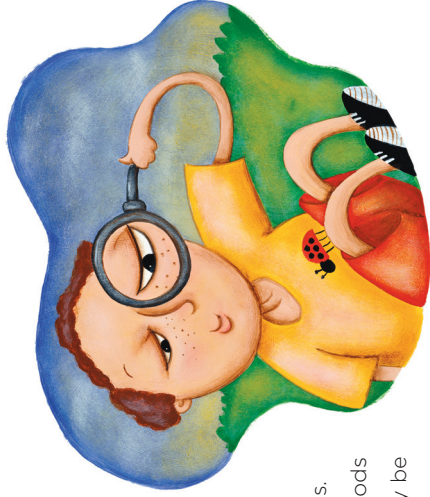
Why Do Children with Autism Act This Way?

Some children with autism do not see, hear, or feel things the same way we do. For instance, the sound of the school bell or the noise of a parade may hurt their ears. Some may have trouble eating certain foods because of the way they taste. Others may be very sensitive to certain smells. Smells you like, such as cookies baking, may make them feel sick. On the other hand, things that bother most of us, like a bee sting, may not appear to be as painful to them.

It is hard for some children with autism to understand what we say or what our facial and body expressions mean. For example, if you are frowning or showing an angry expression on your face, your classmate with autism may not be able to understand that you are angry. However, this does not mean you should stop trying to talk to them.

Sometimes showing them a picture or an object helps them understand things better. For example, if you are talking about baseball, pointing to a baseball card or a bat may help your friend know what you mean. Just because someone with autism may not be able to use words, it does not mean he can't understand your words. Please talk to him as you do with your other friends.

Like all people, sometimes kids with autism can get frustrated and angry but they often cannot tell us why. Instead of words, they may use actions to express their feelings. When they are upset, confused, or bored, they may make noises or spin around. When they are excited or happy, they may flap their hands, jump up



and down, or run in circles. Or they may do all these things at once to help them calm down.

Many children with autism get upset when their surroundings or schedules change because new or different things can be very difficult or scary for them. They may cry, hold their hands over their ears, or run away. They are not choosing to misbehave. Children with autism may have a hard time controlling their behavior because they have difficulty understanding or dealing with the world around them.

Approximately 1,500,000 people in the United States have autism, and it is more common in boys than girls.

What Causes Autism?

No one knows why some people have autism, and there may be many different causes. Scientists are still trying to find out just what those causes are and how to best help people with autism. Approximately 1,500,000 people in the United States have autism, and it is more common in boys than girls.

Where Do Kids with Autism Go To School?

Kids with autism can be in many different types of classrooms and schools. They may be a member of your class or may be in a classroom that was set up especially for them. Many children with autism also participate in after-school activities with classmates, friends, and neighbors.

You may see some special arrangements used to help a child with autism participate in your class. He or she may have a special "coach," sit at a special desk or table, or use pictures or symbols to communicate with you and the teacher. Some kids may even have special computers that "talk" for them. Friendly classmates can be the best help of all to a child with autism.

How Can I Be a Friend To Someone with Autism?

When you become a friend to a person with autism, you both learn a lot from each other. Here are some ideas that can help you be a better friend to a kid with autism:

- Accept your friend's differences.
- Know that some kids with autism are really smart, just in a different way.
- Protect your friend from things that bother him or her.
- Talk in small sentences with simple words and use simple gestures like pointing.
- Use pictures or write down what you want to say to help your friend understand.
- Join your friend in activities that interest him or her.
- Be patient - understand that your friend doesn't mean to bother you or others.
- Wait - give him or her extra time to answer your question or complete an activity.
- Invite your friend to play with you and to join you in group activities. Teach your friend how to play by showing them what they can do in an activity or game.
- Sit near your friend whenever you can, and help him or her do things if they want you to.
- Never be afraid to ask your teacher questions about your classmates with autism.
- Help other kids learn about autism.



For more information about autism, written by or for kids, look for these and other books in your local library:

- Amenta, C. (1992). *Russell is extra special: A book about autism for children*. New York: Magination Press.
- Bishop, B.(2002). *My friend with autism*. Arlington, TX: Future Horizons, Inc.
- Bleach, F. (2001). *Everybody is different: A book for young people who have brothers or sisters with autism*. Shawnee Mission, KS: Autism Asperger Publishing Company.
- Edwards, A.(2001). *Taking autism to school*. Plainview, NY: JayJo Books, LLC.
- Ely, L., & Dunbar, P. (2004). *Looking after Louis*. Morton Grove, IL: Albert Whitman & Company.
- Keating-Velasco, J. (2007). *A is for autism, F is for friend*. Shawnee Mission, KS: Autism Asperger Publishing Company.
- Lowell, J., & Tuchel, T. (2005). *My best friend Will*. Shawnee Mission, KS: Autism Asperger Publishing Company.
- Messner, A. W. (1995). *Captain Tommy*. Stratham, NH: Potential Unlimited Publishing.
- Murrell, D. (2001). *Tobin learns to make friends*. Arlington, TX: Future Horizons, Inc.
- Simmons, K. (1997). *Little rainman: Autism through the eyes of a child*. Arlington, TX: Future Horizons, Inc.

Thompson, M. (1996). *Andy and his yellow frisbee*. Bethesda, MD: Woodbine House.



ADVICE FROM EXPERIENCED PARENTS
*PARENT ADVISORY COMMITTEE, CENTER FOR AUTISM SPECTRUM DISORDERS,
CHILDREN'S NATIONAL MEDICAL CENTER*

We are a volunteer group of parents of children and adolescents with ASDs who act as community liaisons for CASD. We have all been through the experience of having a professional diagnose one or more of our children with an ASD.

On first hearing the ASD diagnosis, many of us felt sad, angry, lonely, or even utterly devastated. Some of us were also relieved that we had finally found a professional who understood our child, and who might hold a key to interventions that would help. We all reacted differently, and sometimes our reactions were very different than those of our partner.

For some of us, the fact that our child suddenly had a diagnostic "label" was highly significant: It validated our sense that our children are extraordinary in complicated ways, and that our parenting struggles were not due to inadequacies on our part. On the other hand, some of us were not terribly interested in whether or not our child had a label, as long as s/he could get necessary services: After all, we adore our endlessly fascinating, wonderful children just as much with or without their labels.

Following is some advice we compiled based on our experiences parenting children and adolescents who have ASDs:

- **You and your other children need as much love, support, and professional help as your child with an ASD needs – maybe more.** If you don't take good care of yourself, you won't be able to take the best care of your children.
 - **Ask for help often, from many people.**
 - **Find someone (partner, friend, family, spiritual leader, doctor) to talk to about your feelings.** Surround yourself with people who reflect the positive aspects of a situation back to you.
 - **Don't neglect your close relationships.** Often partners have different emotional reactions to their child's diagnosis, have difficulty sharing their feelings, disagree on how to proceed with evaluations and interventions, and experience stressful financial and time constraints. Communicate, protect your time together, and try not to judge each other.
- **Connect with other parents of children with ASDs, for example by joining a support group.** Parenting a child with an ASD can be extremely isolating. Our children look beautiful; people can think they act out because they're just "brats" or we're bad parents. Other parents of kids with ASDs will "speak the same language" as you. They'll understand why your child had a meltdown in the grocery store, or why you're so frustrated with your child's school. When you're going through tough times with your child and you're looking at everything up close, you'll need another parent who has been through the same thing to help you gain perspective.
- **Focus on the positive, be very selective in what you choose to be upset about, and keep your sense of humor.** Sometimes things get too intense, and we just need to doggie paddle to the side of the pool and regroup. If we worried about every little thing, we'd be overwhelmed – in fact, we'd be gelatinous blobs on the floor. It can be very freeing to focus only on things that are really important.

"Parents need as much love and professional help as their ASD child needs, maybe more. Most people get through parenting by the seat of their pants; parents of ASD children aren't even provided pants. If the ASD child has siblings, provide proactive professional help to them as early as possible. Living with an ASD child is far from all bad, but it is all different."

- Parent of a child with ASD

* On websites and in the popular press, parents' reactions to an ASD diagnosis are often compared to the so-called stages of grief theory (denial, anger, sadness, bargaining, acceptance). In fact, very few parents experience all of these emotions in this sequence. The stages of grief theory is not based on strong evidence, and does not define or predict a "normal" reaction to difficult experiences.

- **Helping your child will probably involve addressing your own or your loved ones' difficulties.** Autistic-like traits, including social awkwardness, language difficulties, and rigidity, tend to cluster in families. For many of us, our child's diagnosis led us to understand ourselves and our families in new and empowering ways. This increased our tolerance and strengthened some of our relationships, but it also sometimes led us to be more frustrated and irritated with our own and our partners' autistic-like traits. Don't feel guilty if you feel your child has inherited your or your partner's weaknesses. S/he has also inherited many of your strengths, which you are building on by seeking out evaluations and interventions.
- **The professionals may be experts on autism, but you're the expert on your child.** You can understand and communicate with your child in a way that professionals simply can't. Professionals can be wrong; evaluate their recommendations with a critical eye. Sometimes relying on professionals won't work, so you'll need to use your own instincts to get things moving the right direction again. Parenting a child with an ASD is like golf: you focus on trying to hit the ball straight, and if you end up in the rough (which you will sometimes), you focus on trying to get back on the green.
- **Read and ask questions until you fully understand your child's evaluations, IEPs, and other documents.** Professionals have a responsibility to explain jargon to you, and to include you in your child's interventions and education. If you understand what is going on at school or in therapy, you will be more able to reinforce those interventions at home. For example, if a report recommends your child has a visual schedule at school, ask the professional how you can make a visual schedule to use at home also.
- **Get organized early – make a three-ring binder or file folders.** Keep every report, evaluation, and IEP-related document in one place. Save examples of your child's schoolwork so you have hard evidence of positive or negative trends in their work.
- **You are your child's best advocate – no one else is going to fight as hard for your child as you will.** Emotions will make you forget what you wanted to ask in a meeting or appointment, so be sure to go into a meeting prepared. Write down your questions in advance, and don't be afraid to ask them. It can help to give a list of your questions or a copy of your agenda to professionals in advance, or at the beginning of the meeting/appointment. (See the Schools section of this book for more suggestions on advocating for your child during IEP meetings.)
- **Don't ever let a professional tell you what your child can't do.** There are many examples of kids whose abilities were underestimated because of their disabilities. Your job is to get professionals to focus and build on what your child *can* do.

"A professional told me my son is transition age, and asked about my expectations for him. I said he loves the computer. The professional looked at his record, and I know saw my son's IQ score. He told me and my husband that my son needed to do things like stuff envelopes. Well guess what...I asked at my son's last IEP meeting that he begin to do some typing. We had a parent conference recently and the teacher told me my son typed sentences that he thought up himself, and that he typed really fast. When I see the professional for a follow-up appointment, I will tell him the 'paper tasks' my son should do ARE on the computer!! Yes!!"

- Parent of a child with ASD

WHEN TO SEEK HELP

Parents often find that seeking out mental health support for themselves helps them to care more effectively for their children. You should talk to your doctor or a licensed mental health provider if:

- You find yourself taking out your feelings on your child or loved ones
- You feel trapped, like there's nowhere to turn
- You worry excessively and can't concentrate
- The way you feel affects your sleep, your eating habits, your job, your relationships, your everyday life.

ADDITIONAL INFORMATION

- Autism Speaks. *First 100 Days Kit*, pgs. 11-18. www.autismspeaks.org/community/family_services/100_day_kit.php.
- Autism Society of America. "Stress on Families." www.autism-society.org/site/PageServer?pagename=life_fam_stress.
- Boyd, Brenda. *Parenting a Child with Asperger Syndrome*. Philadelphia: Jessica Kingsley, 2003.

“FORWARD” TO *GRAVITY PULLS YOU IN: PERSPECTIVES ON PARENTING CHILDREN ON THE AUTISM SPECTRUM*
BY JOHN ELDER ROBISON

Have you ever wondered what it would be like to raise a kid with special needs? I have. You'd think I'd know, since I was a kid with special needs myself. I have Asperger's syndrome, a form of autism. The autism spectrum encompasses a wide range of conditions from total disability to mild eccentricity. I'm fortunate to be at the less-impaired end of the spectrum.

The one thing all of us have in common is some degree of social impairment. We may also have speech, coordination, learning, and health issues. Most of the kids who populate *Gravity Pulls You In* have some kind of autism.

I recognize myself in many of their stories. They bumble and struggle and fail, and I remember experiencing those very same things long ago. Then I read of their triumphs, and I remember my own small victories. Exceptional clarity of memory is fairly common among people on the spectrum.

With all the names I was called growing up, it's no surprise I saw myself as a misfit child. With that self image, I naturally thought anyone like me must be a misfit, too. However, I know different now. Today I realize that the autistic condition is really the human condition. Our hopes, dreams, and feelings are exactly the same as anyone else's. We just don't show our feelings in the conventional way, and we don't respond to other people's signals as expected.

Yet inside, we are all the same.

It's very frustrating how much of the world is oblivious to that simple truth. In fact, my own distress over that bit of ignorance is one of the things that drives me to be a writer, speaker, and advocate today.

I thought I could contribute a story from the special needs child's perspective, but as I read what others had written I saw my own experience was fundamentally different. I am indeed a person with Asperger's, and I have been this way all my life, but there is a very important distinction. When I was a child, I didn't know I was autistic, and neither did anyone else. I was just a regular kid with a lot of problems and very few friends. I was also a kid who did strange things. And I was a kid who got into a lot of trouble.

You might also think I'd understand the special needs perspective because I raised a kid with special needs thirty-some years later. My son, who is now 19, also has Asperger's. However, I didn't know he was Aspergian until he was seventeen, and by then, the kid-raising was mostly done.

My special needs parent experience was limited to watching Cubby get tested, listening to inconclusive results, and arguing with an uncooperative school system. Eventually, I gave up. "He's just not applying himself," they said. That was the same line they fed me, thirty-some years earlier, and I gave up then too. At one level I knew they were wrong, but I did not know exactly how to counter them. Naively, I believed they had my son's best interests at heart. I don't know why I would have thought that, because I knew they were not on my side as a kid, but there you have it. Maybe it's the eternal optimist in me. Anyway, I now know better. If I get a third chance, with an Aspergian grandson, I will not send him to that school system. I will make better choices.

Faced with failure and an endless hassle, I dropped out of high school, and so did Cubby. He's in college now, but he's had a harder time than he might have, had the school been a little smarter or a little more cooperative, or if I'd pushed them a lot harder. But it's not my nature to whine about such things. Cubby is in school and working two jobs, and he's making his way. That's all any of us can hope for, short of rigging a lottery machine and getting away with it.

I guess my experiences show that it was possible to raise a special needs kid in ignorance in the sixties, and it's still possible to do it today. But can parents do a better job with the benefit of additional knowledge? My sense is, they can. That's why books like this exist. I wish I'd read some myself, long ago.

I also wish someone had told me about Asperger's when I was a teenager. I knew I had problems, and in the

absence of an explanation like autism, I assumed I was just defective. The corrosive aftereffects of that childhood assumption followed me right into middle age, when I finally received a proper diagnosis. Much suffering could have been avoided if I'd known at fifteen.

That's one good side to early diagnosis. Another is the benefit of early intervention. Countless medical studies have shown that kids who receive early diagnosis followed by aggressive therapy do better than kids like me, who grew up in a free-range state.

So those are two great reasons to raise kids in a state of awareness and focus. Every parent in this book does that. If I could go back in time and raise myself again, or start over with my son, I'd do the same. What parent wouldn't?

So what's the downside? I can sum it up in two words: Reduced expectations. There is a real risk that a diagnosis will place limits on a kid's development because people will forevermore say or think, He has autism, so he can't do that . . . When I grew up, no one had any knowledge of Asperger's syndrome. That meant I was held to the same standards as every other child on the street. I had to learn to get along, attend classes, and get passing grades just like everyone else. At least, that was the idea. I followed that path till tenth grade, and then I dropped out and went my own way.

There was absolutely nothing to hold me back except myself. In fact, I often had more incentive to make my own way because I was always on the edge of starvation and ruin. In my early adult years I lived as an outlaw, working with traveling music groups, riding with bikers, and even living in the woods. I did those things because I failed in my efforts to follow the conventional path. I dropped out of school because I could not learn in the manner the teachers taught. I could not attend college because I lacked a high school diploma. And I couldn't get a good job because I wasn't a college graduate.

But I didn't let that stop me. I made my own path and found some measure of success. However, the fact that I was an outlaw and an outsider always weighed heavily on me. I was always gazing in the windows of legitimate life, wondering what it might be like inside. As successful as I became, that remained the hard truth.

That's where things stood when I finally got The Diagnosis.

By the time Asperger's officially entered my life, I was forty years old. I had married and fathered a child. I had designed video games at Milton Bradley, directed research at Simplex, and then left the corporate life to found J E Robison Service Co, a specialty automobile business. Chicopee Savings Bank had named me to their board, and I was involved in my community. By most standards, I had a full life. If you asked me who I was, I'd have defined myself by those achievements.

If you asked for more, I might have fallen back on the basics. I was a white male, six foot three, two hundred twenty five pounds. Born in Athens, Georgia. If you pressed me some more, I'd volunteer that I was middle class, and generally conservative. That was how I'd describe myself.

Suddenly, with the receipt of The Diagnosis, none of that mattered. The whole concept of "people like me," took on a whole new meaning. All those former adjectives were out the window; rendered meaningless. From D-Day forward, I was a guy with Asperger's. Everything else was rendered secondary to that new facet of me.

The doctors are quick to tell you autism isn't lethal. Yet it's still one of the big scary words in medicine, like AIDS or cancer or Alzheimer's. As such, it's no surprise it came to dominate my thinking. I thought of what I'd previously known – or thought I'd known about autism. I thought of Tommy, the kid on the St. Elsewhere television show. I thought of Rain Man. I thought of all the silent lost people on the grounds of the Belchertown State School. Were they autistic, too?

Alzheimer's doesn't kill you, but it gradually takes away your mind. Would autism do that to me? Luckily, my reading abilities were still good. Nothing had started failing. Yet. I set out to learn as much as I could, while I could still read and speak.

I was in a state of extreme anxiety at first. My new diagnosis left me feeling as if I had just caught a new and deadly disease. I soon learned that wasn't the case. My midlife diagnosis was attributable to new medical knowledge, not my own deterioration. I was relieved to learn that I am actually getting slowly and steadily "better"

through a lifelong process of learned adaptation and acquired wisdom.

So many things suddenly made sense. For the first time, I understood how I could be smart and yet get straight Fs in school. I saw how Asperger's had made school hard for me, and I'd done some pretty unusual stuff after dropping out. New insight brought those memories into focus, and I saw how the differences in my brain had shaped the course of my life in countless subtle ways. Yet I also realized the success I enjoyed as an adult was real, and it wasn't going away. In fact, as I moved forward with new knowledge and confidence, I saw my life was getting better every day.

Asperger's is not a disease. It's a way of being that comes from non-standard wiring in the brain. The latest science suggests we're born different, or else we become Aspergian early in infancy. That means Aspergian life is the only life we've ever known; we don't get sick and get Asperger's as teenagers. We will always be aliens when we gaze at people who don't have Asperger's, and they will always struggle to understand our thinking.

How does that affect the parents? I never really considered that question until quite recently. This book contains many stories that describe the joy, pain, confusion, frustration, and triumph of raising a kid like me. I had no idea. It also contains stories of resolve and determination that surprise even me. Some of these people are what you might call High Performance Parents.

One thing strikes me in almost every story. Autism has taken over the lives of these people, perhaps to a greater degree than it took over my own life. I talk about life as an autistic outsider, gazing in at the world of normal people. Autism has made these parents outsiders, gazing into the unreadable minds of their own children. What a strange reversal.

When you're a kid on the spectrum, autism is all you know; all you ever knew. There's frustration at things we can't do, and even rage. But there's no sense of loss, because we never possessed what autism is said to have "taken away" from us. We start with a certain set of abilities, and we build on them. Sure, we may have less ability in some areas than other kids, and it can hurt to realize that, but we make the most of what we have. What else can we do?

The situation for aware parents is very different. They see and imagine all manner of things their disabled kids (us) are lacking, and they suffer terribly for us. At least, that's the impression I get from talking to parents today. Was my own mother that way? I really don't know. Oblivion to others is, after all, an Asperger trait. I know I wasn't that way raising Cubby. In that sense, ignorance is indeed bliss.

But does this awareness, focus, and worry produce a better kid? Or does it just produce a more stressed parent? I really don't know. That is one of the great mysteries of kid-raising. Any of us – if aware – would do all the things parents in this book do. And the evidence in favor of early and aggressive intervention is strong. But it's a hard road, not matter how you do it.

John Robison's introduction first appeared in the anthology, *Gravity Pulls You In*, edited by Kyra Anderson and Vicki Forman and published by Woodbine House. Permission to reprint granted by the publisher, author and editors. For more information, visit www.woodbinehouse.com.

Be Your Own Best Advocate

What does it mean to advocate for yourself? Being your own advocate means that you ask for what you need while respecting the needs of others. For example, if you are at a store and a clerk ignores you, you are able to ask in a polite way to be served. Self-advocacy is asking for what you need in a direct, respectful manner.

Why is this skill important? Self-advocacy helps you:

- Obtain what you need
- Make your own choices
- Learn to say no without feeling guilty
- Express disagreement respectfully

How to Advocate for Yourself

You become a self-advocate by taking the initiative to ask directly and specifically for what you need. When you ask, you are polite. You listen to the other person's response without interrupting. You are patient, knowing that change might take some time.

“Asking for help is one way of advocating for yourself.”

If you feel nothing is changing despite your best attempts, you ask for help from a parent, teacher, or other adult.

Here are a few ideas to help you advocate for yourself. You may want to practice them with a friend or family member.

- 1. Take a deep breath.** Deep breathing gives your body lots of oxygen, and oxygen helps you feel calmer and think more clearly.
- 2. Think about what just happened.** Before you react to something someone said or did, think about it a bit. Ask yourself questions such as: “Did that person really mean to bump into me, or was it just an accident?” or “Is the clerk really ignoring me or is she just very busy? Maybe I need to be more patient.”

3. Think about what you want to be different. Before you talk to the other person, make sure you know what you want to happen. Do you want to be treated differently? Do you want that person to stop doing something?

4. Speak clearly and slowly. Start by saying something like, “I would like to talk with you about...” and then calmly describe how you see the situation.

5. Let the other person speak. Being a self-advocate doesn't mean that only you talk. The other person needs a chance to respond to what you are saying. If that person becomes impatient, try to stay calm and take a deep breath.

6. Don't expect immediate results. Change is not always instant or lasting. Sometimes it takes many conversations with the other person before anything changes. You may even have to remind the person more than once.

7. Ask someone to help. There may be times when you and the other person cannot agree or the other person becomes unreasonable. One of the best parts of being your own advocate is that you don't have to solve all the problems on your own. You can and should ask for help. Asking for help is also advocating for yourself.

When to Advocate for Yourself

You may need to advocate for yourself in many situations. Here are some times when you might need to stand up for your rights or make sure your voice is heard. You may want to role-play these and other scenarios with a family member or friend:

- A substitute teacher hands out a test. You have an accommodation to take your tests in a quiet room, but the substitute does not know this. How do you respond?
- Your bus arrives and someone you don't know offers to help you go up the steps.

You don't want to be rude, but you would rather not have help, even if it takes you a few minutes longer to board and take your seat. How do you respond?

- You have a reading tutor who works with you in the library's learning center. The tutor has been late three times and is late again. How do you respond?

How to Learn More about Self-advocacy

No one is born knowing how to be their own self-advocate. It is a learned skill. You can find out more about it by watching someone who is a good advocate (a parent, aunt, uncle, or neighbor, for example). What is the tone of their voice? How do they stand? Do they make eye contact? What else do you notice?

You also can check out these helpful resources for teens and families.

For Teens:

www.fvkasa.org

This site is from Kids as Self Advocates (KASA), a national, grassroots network of youth with disabilities and needs speaking out about living with disabilities, health care, transition issues, school, work, and more.

www.mcil-mn.org

This site is from the Metropolitan Center for Independent Living in Minnesota, which helps people with disabilities live independently, pursue meaningful goals, and enjoy the same opportunities and choices as all persons. Programs are often available for transition age self-advocacy training

www.cmhn.org/aboutus.htm#advocacy

Check out these online favorites of the Minnesota Statewide Family Network Youth Advisory Board.

www.nichcy.org/kids/index.htm

Zigawhat! offers lots of links to sites for teens with disabilities. It's maintained by the National Dissemination Center for Youth with Disabilities.

For Families:

Developing Positive Assertiveness: Practical Techniques for Personal Success by Sam R. Lloyd, (2001). Crisp Publications, Los Altos, CA

This book is for anyone who wants to take charge of their life. It includes a helpful collection of practice situations. Available at www.amazon.com.

Self-Determination for Youth with Disabilities: A Family Education Curriculum by B. Abery, et. al.

This curriculum is designed for use with families, with the guidance of facilitators.

Institute on Community Integration, University of Minnesota Phone: 612-624-4512

<http://ici.umn.edu/products/curricula.html#self>

Self-Determination Synthesis Project | www.uncc.edu/sdsp

This project includes information about self-determination resources, such as research references, curricula, Web links, and other materials. From the University of North Carolina, Charlotte, it includes links to many lesson plans.

Self-determination Across the Life Span: Independence and Choice for People with Disabilities by D. J. Sands & M.L. Wehmeyer, (Eds.). (1996). Baltimore: Paul H. Brookes.

This forward-thinking book offers practical strategies for parents of children with disabilities as it examines transitions from youth to old age. Available at www.amazon.com.

Self-Determination for Middle and High School Students
National Center on Secondary Education and Transition (NCSET)

This NCSET handout is a helpful resource for those addressing self-advocacy and self-determination issues. NCSET coordinates national resources, offers technical assistance, and disseminates information related to secondary education and transition for youth with disabilities. Available at <http://ncset.org/topics/sdmhs/default.asp?topic=30>.



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PRINCIPLES OF INTERVENTION IN AUTISM SPECTRUM DISORDERS

CENTER FOR AUTISM SPECTRUM DISORDERS, CHILDREN'S NATIONAL MEDICAL CENTER

Children with autism spectrum disorders typically require **two types of intervention: modification of their environment and training in new skills**. The first type of intervention emphasizes the importance of changing the demands on your child to avoid situations and tasks that put him at risk of overload. The second type of intervention emphasizes teaching your child new skills so that he will be better able to cope with difficult demands, or to adapt difficult tasks to better suit his thinking style. As is developmentally appropriate, the balance between these two interventions shifts in favor of the latter as a child gets older, but both types of intervention are required throughout childhood.

As is true for all of us, **“an ounce of prevention is worth a pound of cure.”** By changing the demands on your child or giving her the tools to meet demands more effectively, we can prevent problems before they occur instead of reacting to them after the fact. The biggest risk that children with autism experience is that of being overloaded. Because their brains are typically suited for dealing with information one unit at a time, they can get easily overloaded when they have to incorporate multiple inputs at once. Once they are overloaded, they often fail to process information that they could otherwise understand and also can lose behavioral control, becoming more repetitive, impulsive or inattentive. By teaching your child to manage multiple inputs more effectively and by changing her environment to directly limit overload, you can avoid overwhelming her with anxiety provoking experiences and thus avoid the negative cycle of poor self esteem that both drives and is driven by ineffective performance and inappropriate behavior.

Interventions are most effective when they **build on cognitive strengths**:

- **Modify your child's environment** to prevent her experience of overload by reducing: the number of people, visual distractions, unexpected events, oral directions, and unstructured peer interactions she encounters. Children with autism spectrum disorders do best in small, structured, calm, orderly, and predictable settings.
- **Teach your child new skills** by methods that emphasize explicitly taught information in step-by-step formats. When learning difficult tasks, whether in the daily living, social skills or academic domains, your child will benefit from recipes, routines, and checklists that take him through materials one step at a time. It will help him to explicitly learn and memorize procedures and skills and to perform them in the same manner in all settings. Complex situations should be broken down and explained in logical steps. This is one reason Social Stories work well.

Successful intervention depends on a collaborative relationship with your child. Seek her input about how to solve problems, what gets in her way and what would help her. Share information, don't demand it. Assist her to elaborate her thoughts: introduce topics of interest in a structured format, help her to stick to the topic at hand, organize information by structuring it sequentially in steps, or by elaborating on causality (e.g. "he cried, because they teased him"), etc. When teaching new skills it is essential to target everyday problems that the child encounters, and provide techniques which increase her efficiency at reaching goals she cares about.

Because children with ASD typically learn on a case by case basis, it is essential to specifically target generalization of new skills:

- Intervene in everyday activities with everyday people: teachers/parents act as models and "coaches."
- Teach routines in the context of a problem, not as a separate skill.
- Start at your child's level of concreteness and systematically progress upward in complexity.
- Teach skills in a supportive 1:1 setting with an adult, then slowly shift to practicing skills in real world settings. Only consider the skill learned if it can be independently demonstrated in a group setting.
- Begin by actively modeling, coaching, and guiding the child through the new skills and then slowly fade adult support to cueing and monitoring over time.
- Practice, practice, practice. Use a coaching model and do not expect that social and executive skills will be learned and generalized after being taught once. Expect to return to the same skills over and over.
- Provide rewards for learning new skills and for demonstrating them in the real world. (This is hard work!)

Examples of modifications of the environment/task that target problems with organization, flexibility and keeping track of directions (i.e. executive functioning):

- Make a task shorter or break it into pieces.
- Replace oral directions or information with written materials.
- Accompany a task with a written checklist, recipe or routine, describing how to do the task.
- Give child control or a choice whenever possible.
- Give lots of concrete examples of a task before asking the child to complete it.
- Make a task more structured (e.g. instead of asking “How was your day?” ask “What did you have for lunch?” use multiple choice, fill in the blank or other structured formats, and scaffold conversations).
- Explicitly put a new task or concept into the context of old information or skills.
- Provide scoring rubrics and explicit expectations for performance.
- Limit the time spent on each task (use timer),
- Provide many external cues for on task behavior: (e.g. verbal reminders, visual cues, posted schedules, taped messages, watch alarms, and pager cues).
- Give the child supportive technology (e.g. graphic organizers; computer software that helps with spelling, grammar, outline organization; palm pilots that have recipes and routines for doing daily living and academic activities).
- Reduce the size of the groups your child is in.
- Make the environment (physical setting, schedule, people present) as predictable as possible and explicitly warn of changes.
- Allow the child to screen out stimulation through use of a cap with visor, earphones, etc.
- Use consistent routines, expectations, and language across different settings (home school and therapy).
- Avoid using metaphorical language and requiring independent inference generation.

Examples of training in new skills that target common problems with organization, flexibility and keeping track of directions:

- Explicitly teach a flexibility script and flexibility skills (“This is not part of the plan, is there a new plan?”).
- Build self-knowledge and self advocacy skills. A great project for an older child is to make an autobiographical video with an adult. This video provides the opportunity for the child to increase her awareness of her cognitive strengths, weaknesses and needs. It also creates a product that she can show to teachers and others to advocate for herself and her special learning style.
- Teach strategies for specific academic weaknesses such as expository writing, making inferences, or taking tests.
- Carefully monitor daily living skills and create checklists and routines at home.



INTERVENTIONS FOR CHILDREN AND ADOLESCENTS WITH AUTISM SPECTRUM DISORDERS

CENTER FOR AUTISM SPECTRUM DISORDERS, CHILDREN'S NATIONAL MEDICAL CENTER

BEHAVIORAL THERAPIES

Behavioral therapies all rely on the core principle that rewarding a behavior tends to increase the frequency of that behavior, while ignoring a behavior tends to decrease that behavior. During a behavioral therapy, children are rewarded, for example with verbal praise or play with a favorite toy, when they demonstrate a desired target behavior. Modern behavioral therapy does not involve punishment or potentially unpleasant or harmful consequences for the child.

There is strong scientific evidence that behavioral therapies are beneficial for children with autism spectrum disorders (ASDs) when the children receive at least 30 to 40 hours a week of instruction, and when parents are taught how to incorporate the therapy into their everyday life.

Types of behavioral therapy include:

- **Applied Behavioral Analysis (ABA)** – ABA is the most widely used and widely studied form of behavioral therapy. Skills are taught according to a set curriculum, in which complex tasks are broken down into simpler components and practiced repeatedly in a variety of settings. A child's progress is measured quantitatively through direct observation so the curriculum can be adjusted as necessary.
- **Verbal Behavioral Therapy (VB)** – VB is a variant of ABA that focuses on teaching children verbal communication using an established theoretical framework. VB is often used as an adjunct to ABA.
- **Pivotal Response Treatment (PRT)** – PRT is a behavioral therapy that targets a few "pivotal" behaviors, such as motivation, self-management, and social initiation. The therapy's overall goal is for improvement in these pivotal behaviors to have widespread positive effects on other areas of a child's functioning, like communication and social skills, which are not directly targeted by the therapy. While ABA is often taught according to a set curriculum, PRT is generally child-driven, meaning the child's interests and the situation determine what activities and rewards are used.

OTHER INTERVENTIONS ADDRESSING THE CORE SYMPTOMS OF AUTISM SPECTRUM DISORDERS

Developmental, Individual Difference, Relationship-based (DIR)/Floortime – This method aims to improve a child's social interactions through developmentally appropriate, child-centered play. Therapy can occur in a variety of settings (home, school, community), and often takes place on the floor (hence the name Floortime). There is some limited scientific evidence for the benefits of DIR/Floortime.

Relationship Development Intervention (RDI) – RDI attempts to improve functioning in six core social, communication, and cognitive areas by teaching parents to help their children respond flexibly to new problems and situations. There is currently limited scientific evidence for the benefits of RDI.

Training and Education of Autistic and Related Communication Handicapped Children (TEACCH) – TEACCH is a structured, classroom-based intervention used primarily in North Carolina. The TEACCH program aims to capitalize on the relative strengths of children with ASDs by modifying and individualizing the physical environment, classroom routine, and instruction material. There is currently limited scientific evidence for the benefits of TEACCH.

OTHER INTERVENTIONS WELL-SUPPORTED BY SCIENTIFIC EVIDENCE

Medication – While there is no medication to treat autism itself, a wide range of medications can be helpful to treat particular symptoms in children with ASDs. Medications should only be used in combination with an intensive, individualized program of behavioral and educational interventions for children with ASDs. Risperdal (risperidone) and Abilify (aripiprazole) are the only medications FDA-approved for the treatment of irritability

(aggression, self-injury, tantrums, and quickly changing moods) in autism. Other medications commonly used for children and adolescents with ASDs are described in the document “Psychiatric Medications” in this booklet.

Speech and Language Therapy – After performing a comprehensive assessment, a speech and language pathologist can offer a wide range of individualized interventions to help improve the child’s ability to communicate. Strategies commonly used with children with ASD include speech and language therapy designed to improve children’s articulation and increase their understanding and expression of language concepts and structures; pragmatic therapy designed to facilitate social and conversational use of language; and augmentative communication (signs, picture books, electronic devices, and Picture Exchange Communication System) for those children who do not use words. Some speech/language pathologists can address feeding issues.

Naturalistic Teaching Strategies – Through their everyday interactions with children, parents and teachers can act as “coaches” to children, teaching new skills in the “natural environment,” that is, in the setting in which the child will need to use those skills in real life. Adults can provide a stimulating environment with choices, model how to play, encourage conversation, and reward a child’s attempts to learn (even if the child was unsuccessful).

Modeling – An adult or peer, in person or on a video, “models,” or demonstrates, a desired behavior for a child with an ASD. Through repetition, the child learns to imitate the skill and use it in a natural setting. Modeling can be used to teach simple tasks (brushing your teeth) or complex social interactions (how to behave on a playdate).

Peer Training – Children without disabilities can be taught to play and socialize more effectively with children who have ASDs. For example, a teacher can assign a peer to be a “buddy” for the child. The buddy agrees to act as a long-term social tutor and trusted friend for the child during both class and unstructured times like recess.

Schedules – These are a series of pictures or words that break down a task into a series of simple steps. For further information, see the article, “Visual Supports for Children and Adolescents with Autism Spectrum Disorders” in this booklet.

Story-Based Interventions – These short stories clearly describe what a child should expect and how a child should behave in a particular situation, for example at the dinner table or in the barber shop. Parents and teachers can create customized stories for a child, or use stories, like Carol Gray’s Social Stories, published in books and online. For further information, see the “Additional Resources” section of this booklet.

Social Skills Training – Through small group instruction, children with ASDs are taught social skills ranging from simple behaviors (e.g. eye contact, greetings) to complex interactions (e.g. how to maintain a conversation). Groups are generally comprised of similarly aged children who all have social deficits.

POTENTIALLY HARMFUL INTERVENTIONS THAT ARE UNSUPPORTED BY HIGH-QUALITY SCIENTIFIC EVIDENCE

Gluten-Free, Casein-Free Diet – A gluten-free diet eliminates grains including wheat, rye, and barley. A casein-free diet eliminates dairy products. Although early, poorly designed studies suggested some behavioral improvement after the elimination of gluten and casein from the diets of children with ASDs, higher quality research performed since 2006 does not show clear benefits. Furthermore, children following this restrictive diet are at high risk of nutritional deficiencies and bone density loss. Parents considering this diet should speak with their child’s doctor and/or a registered dietician before eliminating foods from their child’s diet.

Chelation Therapy – Chelating agents are drugs that are only FDA-approved for use in children and adults with severe heavy metal poisoning. In such cases, the drugs are administered intravenously or as an intramuscular injection in the hospital, under close monitoring. Chelating agents have a range of severe and potentially fatal side effects, including irregular heart rhythm leading to death, kidney failure, liver damage, bone marrow suppression, anemia, fever, chills, nausea and vomiting, and muscle and joint aches. A 2006 study by Cornell University researchers found that rats who had not been exposed to lead had cognitive deficits after receiving a chelating agent; the researchers suggested that children who do not have high lead levels might also be harmed by chelating agents.¹ In 2008, the National Institute of Mental Health called off a planned study of chelation

¹ DE Stangle et al. “Succimer Chelation Improves Learning, Attention, and Arousal Regulation in Lead-Exposed Rats but Produces Lasting Cognitive Impairment in the Absence of Lead Exposure.” *Environ Health Perspect.* 2007 February; 115(2): 201–209.

therapy for autism because of concerns that the risks to children in the study outweighed any likely benefits. There is no credible evidence that an excess of mercury or other heavy metals cause autism, nor is there any evidence that chelation therapy is a potentially beneficial treatment for ASDs.

Defeat Autism Now! (DAN!) Protocol – The DAN! Protocol combines a variety of discredited and potentially dangerous therapies, including restrictive diets, chelation, avoidance of immunizations, and dietary supplements, in an effort to address various hypothesized biological causes of ASDs. DAN! proponents claim to have research evidence supporting their assertions; nevertheless, these therapies, alone or in combination, are not supported by high-quality research, and carry the risk of serious physical harm to children.

Intravenous immunoglobulin G (IVIG) – IVIG, the intravenous administration of antibodies from the blood of human donors, is FDA-approved for use in a variety of conditions including some autoimmune diseases, immune suppression, and infections. Rare but serious side effects of IVIG include anaphylactic shock, kidney failure, aseptic meningitis, and the accumulation of fluid in the lungs. There is no scientific evidence that IVIG is an appropriate or potentially useful treatment for autism.

Hyperbaric Oxygen Therapy – This therapy, FDA approved for the treatment of decompression sickness, involves placing a patient in a pressurized chamber that typically contains a high level of oxygen. The increased pressure in the chamber can lead to ear pain and injury, lung injury, and sinus pain. The increased oxygen concentration can lead to seizures, visual changes, and lung injury.

Secretin – This hormone is FDA-approved for intravenous administration during diagnostic studies of the gastrointestinal system. Secretin became a popular treatment for autism in the late 1990s; by 2005, there was clear scientific evidence that secretin did not lead to symptomatic improvements in children with ASDs. Risks of secretin include anaphylactic shock, abdominal pain, and nausea and vomiting.

Facilitated Communication – In this method, a facilitator supports the hand or arm of a person with an ASD who is unable to speak. The facilitator “helps” the person with an ASD communicate via a keyboard, picture system, or other device. Professional organizations including the American Psychological Association, the American Academy of Pediatrics, the American Association of Child and Adolescent Psychiatrists, and the American Speech-Language-Hearing Association have stated that facilitated communication is a discredited and ineffective method that can present serious harm to people with disabilities including ASDs.

OTHER INTERVENTIONS THAT ARE NOT CURRENTLY SUPPORTED BY HIGH-QUALITY SCIENTIFIC EVIDENCE

Sensory Integration Therapy – This therapy, generally provided by occupational and physical therapists, seeks to identify and correct over- or under-sensitivity to physical sensations including touch, hearing, balance, and vision. Depending on the child’s symptoms, therapy can include activities like swinging, bouncing, and the application of deep pressure. Sensory disturbances are common and frequently disabling problems for many people with ASDs. The evidence in support of sensory integration therapy as a means of improving sensory problems is currently limited; however there are some research studies underway that are evaluating these interventions.

A NOTE ON IMMUNIZATIONS:

Various groups, including DAN!, claim that childhood vaccines somehow cause ASDs, either through the mercury preservative thimerosal, now eliminated from most childhood vaccines, or through vaguely hypothesized immune mechanisms. Overwhelming, high quality, international medical evidence now clearly shows that there is no association between vaccines and ASDs.

Childhood immunizations do not increase the risk of autism, but they do prevent potentially devastating and/or fatal contagious diseases. For example, complications of the measles can include pneumonia (risk: 1 per 20 infected children) that can be fatal, ear infections (1 per 10 infected children) potentially leading to hearing loss, encephalitis (brain inflammation) during the initial infection or years later (1 per 1000 infected children) that can lead to deafness and mental retardation, miscarriage or preterm labor in pregnant women, and death (1-2 per 1000 infected children).² For more information, see www.cdc.gov/vaccinesafety/Concerns/Autism/Index.html.

² “Complications of Measles.” Centers for Disease Control and Prevention. www.cdc.gov/measles/about/complications.html

Auditory Integration Training – In auditory integration training, children with ASDs wear headphones playing modified sounds, in an attempt to improve the child’s supposedly distorted hearing and sensitivities to particular sounds. This technique has not been shown to be helpful for people with ASDs.

ADDITIONAL RESOURCES:

National Autism Center. *National Standards Report*. 2009. Available free online at <http://www.nationalautismcenter.org/affiliates/reports.php>.

Association for Science in Autism Treatment. “Summaries of Scientific Research on Interventions for Autism.” Available online at www.asaonline.org/intervention/treatments_desc.htm.

Autism Speaks. *First 100 Days Kit*. 2008. Available free online at http://www.autismspeaks.org/community/family_services/100_day_kit.php.



EVALUATING INTERVENTIONS: A GUIDE FOR PARENTS

CENTER FOR AUTISM SPECTRUM DISORDERS, CHILDREN'S NATIONAL MEDICAL CENTER

When considering the strength of evidence supporting the safety and effectiveness of an intervention, scientists and clinicians weigh three main questions:

- 1) What types of studies examining the intervention have been published? (Large double blind, randomized control trials are considered the strongest type of evidence; anecdotal evidence is unreliable.)
- 2) How many studies have examined the intervention?
- 3) How consistent are the results of these published studies?

Several interventions for autism spectrum disorders (ASDs), including early intensive behavioral interventions and certain uses of medications, have very strong scientific evidence supporting their use: Multiple large, well-designed studies have consistently found that these strategies are safe and effective.

Many parents also consider pursuing therapies that have yet to be adequately studied. **Following are some questions parents should consider before committing to a new therapy:**^{1,2}

1. **Could the treatment harm your child physically?** Some interventions, like chelation therapy, are potentially fatal. Restrictive diets can lead to malnutrition if not implemented carefully, under the guidance of a clinician.
2. **Would the treatment interfere with your child's participation in proven therapies?** If so, this is a significant source of potential harm to your child's progress. Will the treatment provider collaborate with your child's other providers?
3. **Will the provider train you to provide additional therapy at home?** If so, what specific skills will you be taught, and how much time will you be expected to devote to the therapy at home?
4. **Is the treatment developmentally appropriate?** In other words, is the therapy theoretically and practically appropriate for your child's age and skills?
5. **How will your child's progress be measured?** How and when will you know if the treatment is having any positive effect?
6. **If the treatment fails, what will be the effect on your child and your family?** Parents have to calculate how best to spend their and their child's limited emotional and financial resources.
7. **What evidence is there that this treatment is better than alternatives backed by more research?** Is the promoter pursuing high-quality scientific studies in connection with a respected research center? Does s/he believe that scientific demonstration of the therapy's effectiveness is important?

RED FLAGS^{3,4}
Beware if the therapy:

- Denies potential adverse effects
- Is based on overly simplified scientific theories
- Has little objective evidence supporting its use; denies the need for controlled studies; attacks previous studies that found the therapy ineffective
- Claims to be effective for many unrelated symptoms
- Sounds "too good to be true," claiming rapid and dramatic responses and very high success rates
- Claims to be the only effective option, requiring its patients to stop using proven interventions
- Was developed by someone working outside his/her area of expertise
- Financially benefits a single individual or small group
- Requires little training to administer

Where to find out more about the evidence supporting particular therapies:

³Association for Science in Autism Treatment. "Summaries of Scientific Research on Interventions for Autism." Available online at www.asatonline.org/intervention/treatments_desc.htm.

Cochrane Collection of evidence-based medicine reviews: www.cochrane.org (in the search box, select "Cochrane reviews" and search for "autism").

National Autism Center. *National Standards Report*. 2009. Available online at: www.nationalautismcenter.org/pdf/NAC%20NSP%20Report_FIN.pdf.

⁴S. M. Myers et al. "Management of Children with Autism Spectrum Disorders." *Pediatrics*. Vol. 120, No. 5, p. 1162-1182, 2007. Available online at: pediatrics.aappublications.org/cgi/content/full/120/5/1162.

Where to find out more about how to evaluate a therapy and/or therapist:

²Autism Speaks. *100 Day Kit*, "Comparing Treatment Methods and Providers" worksheet, page 59. Available online at www.autismspeaks.org/docs/family_services_docs/100day/Useful_Forms.pdf.

¹B. J. Freeman. "Guidelines for Evaluating Intervention Programs for Children with Autism." *Journal of Autism and Developmental Disorders*, Vol. 27, No. 6, p. 641-651, 1997.

Interactive Autism Network. "Evaluating Treatments." iancommunity.org/cs/therapies_treatments/evaluating_treatments.



CARD Fact Sheet **2**

Choosing Professionals & Coordinating Services

Because autism and its related disabilities are difficult to diagnose, a child may be evaluated by a variety of professionals before a final diagnosis is determined.

Unless specifically trained in the area of developmental disabilities, physicians and psychologists may have little experience with autism spectrum disorders. Many have never seen a child with autism or a related disability such as PDD-NOS (pervasive development disorder not otherwise specified), Rett's syndrome, or Asperger's syndrome when a parent brings their child in with the first signs of the disability emerging.

The following are brief descriptions of the specialists most commonly associated with diagnosis, intervention, and treatment of autism spectrum disorder and suggestions about how to select professionals to work with you and your child.

Specialists

Developmental Pediatrician: A physician specializing in diagnosing and treating children with developmental disabilities from birth to adolescence.

Psychiatrist: A physician who focuses on diagnosing and treating mental illnesses from a biological and psychological perspective and may prescribe various medications for treatment.

Psychologist: A licensed practitioner specializing in understanding a person's behavior, emotions, and cognitive skills. They may recommend strategies to aid growth and development or help with challenging behaviors.

Neurologist/Pediatric Neurologist: A physician specializing in diagnosing and treating disorders of the nervous system.

Geneticist: A physician specializing in the study of disorders associated with heredity.

The Selection Process

Choosing a professional is not always easy. When choosing a professional to work with you and your child, it's important to look for someone who shows respect for the parents and regards parents as experts on their children.

The professional should convey a sense of hope and have a philosophy similar to your own. Look for a professional who takes an individualized approach to treatment and intervention — one who does not say that all people with autism exhibit the same characteristics.

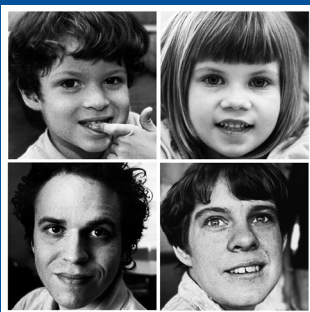
Based on your child's needs, it will take various professionals working together with you to develop a treatment and intervention plan. The most effective treatment of people with autism almost always involves a long term team approach.

Visits to the classroom, home, and community usually provide the most useful information about the child. Since frequent visits may not be possible, the professional may collect information through interviews and questionnaires.

Just as professionals ask many questions, so should you. Remember, no questions you have regarding your child are trivial or unimportant. You may want to ask some of the following questions of the physicians and therapists:

- ◆ What are my child's strengths? How can they be maximized?
- ◆ What specific activities or interventions should I do at home?
- ◆ What kind of testing and evaluations should my child have?
- ◆ Why should my child have these tests and evaluations?
- ◆ How is each test or evaluation performed?
- ◆ How will the results influence my child's intervention or treatment?
- ◆ Can you put me in touch with another family you are currently working with?
- ◆ Do you have any articles or resources on autism or autism spectrum disorders?
- ◆ Can I have a copy of your report? How soon will it be until I receive it?

RELATED DISABILITIES



Obtaining and reviewing all reports is very helpful in understanding your child's needs, progress, and how recommendations can maximize your child's potential.

Service Coordination

Sometimes evaluations and recommendations may be different or conflicting. This can be confusing and exhausting. A case manager or service coordinator can help when questions, problems, or concerns arise.

A case manager keeps current records and, when appropriate, shares information about a child with professionals involved in that child's care. It's one very effective way to make sure a child's needs are being met.

Case managers may also help by making sure all appointments are scheduled, tests are performed, evaluations conducted, and that appropriate and effective follow-up care is being provided.

If an evaluation has been performed at a Child Development and Evaluation Center or if the child is receiving services through a state funded program, chances are that one person has been designated as a service coordinator or case manager.

If this is not the case, you can ask for help from your pediatrician or family physician, local Autism Society of America chapter, your local school district special education department, or CARD.

Some parents elect to perform this role themselves.

Working Together

Parents and professionals communicating effectively and respectfully as partners is an important factor in achieving progress and success for any person with autism or a related disability.

Working as a team by sharing information and responsibility can be the most effective approach when developing a treatment plan.

Parents often have the best understanding of their children's behavior, communication, preferences, and motivations.

Professionals may suggest various ways to help a child but parents know what activities are practical for their family life. Parental perspective is integral when developing an intervention plan.

Professionals, specializing in autism and related disabilities, have specific knowledge and training with regard to evaluation and development of education and treatment plans.

By working together and respecting each other as equally important partners in a child's care, parents and professionals can optimize the potential for a child's development.

The Center for Autism and Related Disabilities

The Center for Autism and Related Disabilities (CARD) seeks to provide support and assistance with the goal of optimizing the potential of people with autism, dual sensory impairments, and related disabilities. Located at six university sites throughout Florida, CARD develops programs offering support and training for individuals, families, professionals, and peers throughout Florida. This fact sheet is made possible through the cooperative efforts of Florida's CARD Centers.

For More Information Contact:

Center for Autism and Related Disabilities Sites:

Florida State University

625-B North Adams St.
Tallahassee, FL 32301
(800) 769-7926 or (850) 644-4367
Fax: (850)644)3644
<http://autism.fsu.edu>

University of South Florida

CARD-USF MHC2113A
13301 Bruce B. Downs Blvd.
Tampa, FL 33612-3899
(800) 333-4530 or (813) 974-2532
Fax: (813) 974-6115
<http://card-usf.fmhi.usf.edu>

University of Florida at Gainesville

P. O. Box 100234
Gainesville, FL 32610-0234
(800) 754-5891 or (352) 846-2761
Fax: (352) 846-0941
<http://www.card.ufl.edu>

University of Florida at Jacksonville

6271 St. Augustine Rd, Suite 1
Jacksonville, FL 32217
Phone: (904) 633-0760
Fax: (904) 633-0751
<http://centerforautism.org>

University of Central Florida

12001 Science Drive, Suite 145
Orlando, FL 32826
(888) 558-1908 or (407) 737-2566
Fax (407) 737-2571
<http://www.ucf-card.org>

University of Miami

Dept. of Psychology
5665 Ponce de Leon Boulevard
PO Box 248768
Coral Gables, FL 33124-0725
800/9-AUTISM or 305/284-6563
Fax 305/284-6555
<http://www.umcard.org>

Florida Atlantic University

Dept. of ESE
777 Glades Road
Boca Raton, FL 33431
(888) 632-6395 or (561) 297-2023
Fax (561) 297-2063
<http://www.coe.fau.edu/card/>

EVALUATING AUTISM WEBSITES: A GUIDE FOR PARENTS

Adapted from National Center for Complementary and Alternative Medicine, National Institutes of Health, *Evaluating Web-Based Health Resources*, 2009 (available online at nccam.nih.gov/health/webresources).

The internet provides a wealth of both information and misinformation about autism spectrum disorders. The following questions, adapted from guidelines provided by the National Institutes of Health, are intended to help parents critically evaluate the quality and reliability of health information they find online.

Who runs the site? The person or organization responsible for the website should be readily apparent and reputable.¹ The website should have a clearly stated purpose.

Who pays for the site? The website's source of funding can affect what information is presented, and what the website owners hope to accomplish with the site.

What is the source of the information presented? If the website's author did not create the information himself/herself, the source of information should be given. Opinions, advice, and testimonials should be set apart from objective, research-based claims. Research-based claims should cite articles published in respected professional journals.²

How is the information selected and reviewed? Look for an editorial board of professionals with excellent credentials¹ who review content before publication.

Is the information current? Research advances rapidly. Out of date information can be misleading or even harmful. The date of the website's last review should be clearly stated.

How credible are the linked sites? Some websites link to any site that asks or pays, while others have stricter criteria.

Does the website require you to enter personal information? If so, how will this information be used, and how will your privacy be protected?

Whom can you contact with questions or concerns about the site? Are forums moderated? Are you comfortable with the discussions on the site?

A NOTE ABOUT TESTIMONIALS:

Many websites contain passionate and compelling accounts of how individuals with autism spectrum disorders improved dramatically after undergoing a particular intervention. In deciding whether the costs and risks of such an intervention are worth the likely benefits, parents should take into account the following issues:

1. **the placebo effect** - Simply participating in an intervention can have a powerful positive effect on symptoms, whether or not the intervention itself is effective. For example, patients in the placebo groups of clinical trials for new drugs consistently experience significant improvements, even though they were only given sugar pills, not actual medication. Unfortunately, when this placebo effect is taken into account in well-designed research studies, the apparent effectiveness of many interventions, for example secretin, disappears.
2. **confounding factors** – When we consider only one child at a time, it is impossible to know whether a child's improvement was coincidence, or truly due to the intervention. A child described in a testimonial may indeed have improved dramatically around the time a treatment was started, but that improvement may have occurred for a totally unrelated reason. Children with ASDs acquire new skills because they are constantly learning from and reacting to their environment, their brains are growing and developing rapidly, and they are participating in therapies. To determine whether a therapy truly helps children acquire skills more quickly, it is necessary to compare children who received the therapy to those who did not. See the "Evaluating Research Studies" handout in this booklet for more information.

¹ Search the internet for the organization's or professional's name: Look for formal associations with well-known hospitals and universities, and be wary of controversies or conflicts of interest. Providers who receive NIH research funding (indexed at projectreporter.nih.gov/reporter.cfm) are reputable. Also talk to your healthcare provider.

² Journals that are indexed in the National Library of Medicine's database Medline (www.ncbi.nlm.nih.gov/journals) are generally reputable. Not all reputable journals are listed in Medline, so also talk to your healthcare provider.



EVALUATING RESEARCH STUDIES: A GUIDE FOR PARENTS

CENTER FOR AUTISM SPECTRUM DISORDERS, CHILDREN'S NATIONAL MEDICAL CENTER

The flood of information about autism spectrum disorders (ASDs) available to parents can be both empowering and overwhelming. This page is designed to give parents an overview of how to assess peer-reviewed research articles, which professionals consider to be the most reliable source of new information about ASDs. Peer-reviewed articles have been critiqued and approved by experts in the field before their publication.

QUESTIONS TO ASK ABOUT A STUDY^{1, 4}

What is the study's design? See below for descriptions of study designs. Randomized controlled trials provide the strongest evidence, while case reports provide only weak evidence.

Are the subjects in the study like my child? The more similar a study's subjects are to your child, the more relevant its results will be.

How does the study control for the placebo effect? Simply being involved in an intervention can have a powerful positive effect on subjects, regardless of whether the intervention itself is effective. For example, in most randomized controlled trials of new drugs, patients given placebos (sugar pills) report significant improvement in symptoms, even though they were not given any biologically active medication. Randomized controlled trials control for the placebo effect by randomly assigning subjects to the treatment or control group. There should be no difference between the two groups other than the presence or absence of the intervention.

What is the study's margin of error? Small studies (for example with 15 or fewer subjects) have larger margins of error, so there is a larger chance that their results occurred only by chance.

How plausible is the result? If there is no reasonable scientific explanation for a result, there is a higher likelihood that it occurred due to chance or a flaw in the study design.

STUDY DESIGNS^{2, 3}

Randomized Controlled Trial (RCT) – This is the gold standard of medical evidence. Study subjects are randomly assigned to either a treatment group or a control group. Subjects in the treatment group receive the intervention being studied; subjects in the control group do not. In a double-blind RCT, neither researchers nor subjects know which subjects are in the treatment group.

Cohort/Longitudinal Study – Researchers follow a group of subjects (a “cohort”) over a period of time, noting which subjects develop the outcome being studied. For example, a cohort study might investigate whether children who have poor imitation skills at 6 months of age have a harder time learning language at 14 months.

Cross-Sectional/Correlational Study – Researchers look at the characteristics of a group of subjects at a single point in time. If two characteristics are correlated, they tend to occur together, but one does not necessarily cause the other. For example, the number of snowplows on the streets is correlated with the amount of snow on the ground, but snowplows do not cause snow.

Case Report/Study – This detailed description of the experience of a single subject can be an important starting point for further studies. However, case reports cannot easily be generalized to other individuals; it is impossible to know what particular characteristics of the subject led to the reported outcome.

WHERE TO FIND PEER-REVIEWED STUDIES²

- PubMed (National Institutes of Health): www.pubmed.gov
- SCIRUS (Elsevier Science): www.scirus.com
- ERIC (US Department of Education): www.eric.ed.gov

RESOURCES FOR EVALUATING RESEARCH STUDIES

²Organization for Autism Research. *Life Journey Through Autism: A Parent's Guide to Research*. 2003. Available online at <http://www.researchautism.org/uploads/parents%20guide.pdf>.

³“Navigating the Maze of Medical Research.” *JAMA*. Vol. 280, no. 3, pg. 306, 1998.

⁴“Medical Research: Finding the Best Information.” *JAMA*. Vol. 284, no. 10, pg. 301, 2000.

¹Gina Kolata. “Searching for Clarity: A Primer on Medical Studies.” *The New York Times*. September 30, 2008.



EVERYDAY STRATEGIES TO USE AT HOME AND SCHOOL

CENTER FOR AUTISM SPECTRUM DISORDERS, CHILDREN'S NATIONAL MEDICAL CENTER

BACKGROUND INFORMATION

- Autism spectrum disorders (ASDs) are complex neurological disorders marked by social impairment, communication difficulties, and restricted and repetitive behaviors and interests.
- Children with ASDs commonly exhibit difficult behaviors because of differences in the physical structure of their brains, not because they are being willfully noncompliant. A child's skills may vary significantly from day to day or hour to hour; negative behaviors will generally become more severe when the child is overloaded or stressed.
- ASDs are developmental disorders: What is easy or difficult for a child will change as the child learns and grows.
- ASDs are caused by biological factors, not by bad parenting.
- There is no "cure" for autism, although early intervention and appropriate educational and environmental supports can be highly effective. Small changes in daily practices and routines can lead to big improvements in behavior.

OVERALL PRINCIPLES

- **Build on the child's strengths** to increase both self-esteem and the efficacy of interventions. Common strengths of children with ASDs include: memorizing, noticing details, thinking logically, visualizing problems and understanding visual information, maintaining focus on interesting activities, following clear rules, and behaving with honesty and integrity.
- **Praise the child:** Recognize how hard the child with an ASD is working to live in a neurotypical world. Be sure to celebrate every effort, success, and sign of progress; value effort and intentions over results. Every day, praise the child three times more often than you give commands and corrections. If you can make the ratio 4:1 or 5:1 of praise to command/correction, even better!
- **Provide structured motivation:** Integrate a points system that rewards expected behavior into the daily routine. Points should be awarded and counted frequently throughout the day; bonus points should be given for extra effort. Points should be redeemed frequently for something the child finds highly motivating (e.g. computer time).
- **Have clear expectations:** Like all children, children with ASDs usually are eager to please the adults in their lives. Have consistent, clear expectations so the child with an ASD can successfully understand and meet goals. Explicitly explain and post rules, schedules, and checklists for daily routines.
- **Provide visual supports:** Children with ASDs respond remarkably well to seeing rather than hearing information, particularly when they are upset. Create visual schedules, visual rating scales, choice boards, and flowcharts yourself, and show them to the child frequently throughout the day. Parents can create visual supports at home: Write down options on a piece of paper, draw stick figures on a white board, or create a visual schedule out of free clip art in a simple drawing or word processing computer program. See the "Visual Supports" article in this book for more information.
- **Foster independence:** When the child no longer needs your prompts or a visual support, gradually remove them. Give the child choices, and encourage him/her to work things out independently when this is realistic. Emphasize personal hygiene, professional dress, time management, tolerance for boring tasks, and limits on talking about special interests, especially for older children and adolescents.
- **Be aware of your own feelings:** Seek out support for yourself so you can be at your best for your child: Caring for someone who has an ASD is intensely rewarding but can also be highly stressful. Use your own (inevitable) frustration as a warning that you need to change strategies or take a break. Be calm, flexible, and positive. Use clear language with few figures of speech. If the child processes language slowly, slow down yourself and wait for the child to respond.

STRATEGIES FOR ADDRESSING SPECIFIC CHALLENGES

Common Challenges	Support Strategies
<p><i>Social Challenges</i></p> <ul style="list-style-type: none"> • Lack of understanding of social cues and subtleties • Difficulty engaging in reciprocal conversation and play • Tendency to speak bluntly; difficulty assessing impact of words on others • Naïve, vulnerable to bullying • Wants friends but does not know how to “fit in” socially 	<ul style="list-style-type: none"> • Children with ASDs are generally poor observational learners. Explicitly teach the child social rules, and how context can entirely change social rules. • At school, pair the child with a socially skilled, tolerant peer “buddy” who will act as a long-term social tutor and trusted ally for the child in the classroom as well as during unstructured times at school. At the beginning of the buddy relationship, assign the pair to structured tasks at which the child is confident. • Appreciate that social interactions, particularly in unstructured settings like lunch and recess, are very taxing for the child. • For older, highly verbal children, process social situations out loud (e.g. “he didn’t mean to bump into you; it was an accident”; “why do you think she’s upset?”). • Recognize that the child is a likely target for bullying, which can have devastating psychosocial consequences. Providing typically developing peers with straightforward, accurate information about autism reduces the likelihood of bullying.
<p>Universal application of social rules to all situations</p>	<p>Realize that the child may not understand that what is acceptable behavior among peers is unacceptable in the classroom.</p>
<p>Focus on single topic of interest that may not be of interest to others</p>	<p>Consider using the special interest as a motivating factor at school. Incorporate the special interest into activities that are difficult, if this helps the child to focus on the difficult activity.</p>
<p>Literal interpretation of others’ words. Difficulty understanding social nuances such as sarcasm, metaphor, allegory, and rhetorical questions</p>	<p>Explain and avoid the use of slang and idioms, particularly when the child is upset. Provide extra support when teaching allegorical stories.</p>
<p>Echolalia – may repeat last words heard without regard for meaning; may repeat memorized lines from television shows, etc. in appropriate or inappropriate contexts</p>	<p>Help peers understand that the child is not copying them to annoy them. Respect “scripted” language as a strategy the child uses to overcome communication difficulties or anxiety.</p>
<p>Poor judge of personal space – may stand too close to other children</p>	<p>If appropriate, do a class activity with a visual aid (e.g. hula hoops) to help children visualize the concept of personal space. Understand that the child does not bump other children intentionally.</p>
<p>Abnormal vocal inflection and eye contact</p>	<p>Realize that the child’s lack of eye contact or abnormal intonation does not imply guilt or disrespect. Do not force child to look someone in the eye.</p>
<p>Inappropriate facial expressions or gestures</p>	<p>Help the child name his/her emotions (e.g. “you’re laughing, but I think you feel angry right now”). Use a “feelings thermometer” or other visual aid to help child become more aware of his/her own emotions.</p>
<p>Difficulty interpreting others’ nonverbal communication cues</p>	<p>Interpret body language for the child (e.g. “she slammed down her paper because she is angry”). Communicate all information verbally with the child (e.g. “I am proud of you/really serious”).</p>

Common Challenges, cont'd.	Support Strategies, cont'd.
<i>Cognition Challenges</i>	
Difficulty with transitions and changes in routine	Create a clear visual schedule that is always accessible to the child. Give two minute warnings before transitions. Make all transitions predictable and explicit. Forewarn child of any changes to routine. Remind the child that small changes (e.g. a substitute teacher) do not impact the remainder of the routine.
Poor organizational skills and attention	Minimize distractions. Use written planners and organizers, and strong school-home communication systems. Create visual representations of information whenever possible.
Concrete, literal, rigid thinking	Draw a flowchart of potential choices and outcomes before starting the activity so the child can visualize the possible paths the activity could take.
Rigid problem-solving strategies; difficulty shifting to a new strategy	Have child identify his/her goal and several alternative strategies before starting the activity.
Difficulty generalizing and applying learned knowledge and skills across different situations, settings, and people	First teach a new skill through explicit short rules, recipes, checklists and routines. After child has practiced the skill in a familiar environment, apply the skill to a novel routine or material. Do not assume mastery until the child has demonstrated the skill in a group. Expect the child to show reduced performance in larger groups and less structured settings.
Difficulty processing auditory information, particularly when upset or excited	Rather than only talking to the child, write down information and choices for the child. Drawing a quick flowchart of potential choices and consequences, or writing a few words down on a dedicated white board at the child's desk, can often help "get through" to an upset child.
<ul style="list-style-type: none"> • Difficulty managing stress and regulating emotions • Increased risk of depression and anxiety disorders 	Allow the child ample extra time; avoid rushing the child. Designate a quiet corner of the classroom to which the child can voluntarily withdraw when s/he is feeling overwhelmed. Include "down time" in the child's schedule. Frequently praise the child's successes at keeping control. If necessary, keep a log to identify triggers and warning signs that occur before misbehavior; modify the environment as appropriate. Watch carefully for symptoms of depression and anxiety (irritability, depressed mood, increased acting out, bodily symptoms like stomachaches and headaches).

Common Challenges, cont'd.	Support Strategies, cont'd.
<i>Cognition Challenges, cont'd.</i>	
Tantrums and “meltdowns”	<p>When a tantrum is approaching:</p> <ul style="list-style-type: none"> • Warn the child that you think s/he is about to lose control. • Try to de-escalate the situation by distracting, soothing, or ignoring the child. • Collaborate with the child to help him regain control: write the child’s options down so the child doesn’t have to process auditory information; whisper to the child; invite the child to calm down in a quiet corner. <p>During the tantrum:</p> <ul style="list-style-type: none"> • Ensure safety. • Notice your own feelings. Stop and walk away yourself if you feel angry (tantrums are contagious!). Don’t take the tantrum personally (it’s not your fault). • Use few words: the child can process very little language during a tantrum. • Don’t force compliance: wait until after the child is calm to resolve the issue. • Don’t give in: if the child benefits from a tantrum, he will have tantrums more often in the future. <p>Long-term strategies for use when the child is calm:</p> <ul style="list-style-type: none"> • Help the child practice self-calming techniques (“taking space” in a quiet corner, taking deep breaths, visualizing a calming image, etc.). • Help the child build perspective-taking skills (e.g. practice identifying the conflicting perspectives of peers, or of characters in movies and books). • Help the child build problem-solving skills (e.g. practice writing down alternatives, or drawing flowcharts of actions and consequences).
<i>Sensory and Motor Challenges</i>	
Over- or under-sensitivity to different sensory stimuli, including pain and hunger	Child may require special accommodation. Help child verbalize his/her sensory experience (e.g. “I think you may be upset because those lights are very bright/because you are hungry”).
Difficulty with fine-motor skills, such as handwriting	Child may require special accommodation. Recognize that the child may resist handwriting because it is uncomfortable and draining.

ADDITIONAL RESOURCES

- Organization for Autism Research. *Life Journey Through Autism: An Educator’s Guide*. 2004. Available online at http://www.researchautism.org/resources/OAR_EducatorsGuide.pdf.
- Autism Society of America. *Building our Future: Educating Students on the Autism Spectrum*. 2006. Available online at <http://www.autism-society.org/site/DocServer/buildingourfuture06.pdf?docID=4201>
- Autism Speaks. “General Strategies for Intervention.” *School and Community Tool Kit*. Available online at http://www.autismspeaks.org/community/family_services/school_kit_general_strategies.php.
- TEACCH Autism Program, University of North Carolina Department of Psychiatry. “Information on Autism: Educational Approaches.” Available online at: www.teacch.com/highfunction.html.
- Williams, Karen. “Understanding the student with Asperger’s syndrome: A guide for teachers.” Available online at: www.udel.edu/bkirby/asperger/karen_williams_guidelines.html.

Behavioral Challenges

What kinds of behavioral challenges might we face with our child?

Children with autism spectrum disorders (ASDs) have a hard time relating and communicating with other people. Many also have unusual ways of learning, paying attention, or reacting to different feelings. These qualities can cause behavioral challenges. For example, children with ASDs may have a hard time telling their parents what they want or need and may throw a tantrum instead. They may become very upset when there is a change in their routine. They may hurt people's feelings by seeming not to listen or refusing to play with another child. Each child's behavior is unique. Learning behavioral principles can help you to increase your child's good behavior and reduce problem behaviors.

What should we know about behavioral principles?

Basic behavioral principles can help explain how children with and without ASDs learn. Typically, behaviors occur in response to events in the environment as well as emotions.

Some examples of problem behaviors include

- Throwing a tantrum instead of using words to get attention, to get something the child wants, or to avoid doing something the child does not want to do
- Nail biting because it has become a habit
- Rocking back and forth or hand clapping for self-stimulation when bored or to tune out too much outside stimulation
- Tics, hyperactivity, and night waking in response to biological conditions

Some behaviors start out for one reason, and then keep happening because they take on new meaning. For instance, a child who first bangs his head because of ear pain may continue to head bang with tantrums.

Talk to your child's doctor, a school behavior specialist, or a psychologist if your child has these or other behaviors (such as hand flapping or self-injury) that are problematic. The reasons that behaviors occur can be different for each child.

What can we do to improve behavior?

You can increase your child's good behavior and decrease problem behavior by taking consistent action. That means trying to always have the same response.

1. Reward the child's good behavior.

You can increase behaviors you want from your child by positive reinforcement or praise/reward when a desired behavior occurs. Teaching a child how to behave in a positive fashion is the most important part of any behavioral plan. Most children learn language by receiving a reward, such as praise, for saying a word or sentence. It might take a while for your child's behavior to change because you will need to teach her what behaviors are pleasing to you.

Rewards vary from child to child. Smiles, praise, and earning privileges are all examples of rewards. One way to use rewards is by having a star or sticker chart where a child gets a star or sticker for good behavior. When the child earns enough stars or stickers, she can trade them in for a reward. It is not the same as bribing.

2. Have your child earn privileges for desired behaviors and withhold them for undesired behaviors.

Working for reinforcement helps teach new behaviors. One way to decrease behaviors you do not want from your child is to take away things your child likes, such as TV, when your child engages in behaviors you do not want him to do. You can also have your child earn TV time by periods of desired behavior. Time-out is an example of removing a child from activities as a response to undesired behaviors. It will only work if "time in" is positive. Teaching your child behaviors you want will help him know behaviors you do not want. Sometimes children act up because they find the class- or adult-directed behavior stressful. They act up because time-out may be a relief. If that seems to be the case, it is important to figure out what is stressful for the child about the adult-directed activity.

Time-out for younger children needs to happen as soon as they do something wrong. The amount of time a child is in time-out should depend on his understanding. A guide is 30 seconds to 1 minute per year of mental age.

If you put your child in time-out, make sure he is safe. Tell your child why he is in time-out, and as soon as time-out is over, lead your child to a good behavior that you can reward. He needs to learn how you want him to behave.

3. Have consequences for undesired behaviors.

Although many families punish children when they have undesired behaviors, this approach is not endorsed. Spanking your child and other physical punishment may teach your child to use violence with anger. What is considered punishment varies from child to child. It can include consequences such as making a child write 100 times, “I will not chew gum in class,” to cleaning up a mess made during a tantrum.

How can we better understand behavioral problems?

Think about your child’s behavior using the ABC method.

- A** = Antecedent, or what happened before your child’s behavior
- B** = Behavior, or what your child did
- C** = Consequence, or what happened after your child’s behavior

This can help you to think about why the behavior happened so you can prevent it in the future. The goal is to avoid situations that can lead to problem behavior and to reinforce good behaviors so they continue. A simple chart can help you keep track of your child’s behavior so you can figure out why it is happening. It might look like the following:

Date and Time of Behavior	Antecedent	Behavior	Consequence
Sample: Monday 8:00–8:15 am	Told to turn off TV	“No” and tantrum	I turned off TV and took him to school bus after he stopped.

Schools can also help you understand behaviors. You can ask your child’s school about a functional behavioral analysis and plan if your child is having behavioral problems in school. This analysis looks at your child’s specific behaviors and when they occur. It should help you to find out what might influence problem behaviors and identify ways to change them. Many families benefit from input from a behavioral health professional to better understand their child’s behavior and develop a plan to help.

Resources

Harris SL, Weiss MJ. *Right from the Start: Behavioral Intervention for Young Children with Autism*. 2nd ed. Bethesda, MD: Woodbine House; 2007

Myles BS, Southwick J. *Asperger Syndrome and Difficult Moments: Practical Solutions for Tantrums, Rage, and Meltdowns*. 2nd rev ed. Shawnee Mission, KS: Autism Asperger Publishing; 2005

Phelan TW. *1-2-3 Magic: Effective Discipline for Children 2-12*. 3rd ed. Glen Ellyn, IL: Parent Magic, Inc; 2003

The information contained in this publication should not be used as a substitute for the medical care and advice of your pediatrician. There may be variations in treatment that your pediatrician may recommend based on individual facts and circumstances.

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DEDICATED TO THE HEALTH OF ALL CHILDREN™

Visual-Spatial Supports for Children with Autism or PDD

The following is a list of some ways that you can use visual-spatial supports to increase your child's understanding, independence, confidence, and abilities. This list can be used as a menu that describes some basic strategies that you can use if you are having difficulty helping your child in a specific area. You can choose the strategies that you think are appropriate for your child's ability level, interest, and needs. You may need to change various aspects of the strategies listed below in order to create a better fit between the strategies and the specific situation. Since we cannot describe every possible strategy and situation, you may also want to use this list to give you ideas for creating new ways to use visual-spatial supports.

1. Give Information about Environment (routines and changes)

- Object/picture prompts give information about what is just about to happen. Before demands are made on child to start a new activity or routine, show child an object representing that activity and say a word, for example show child her blanket and say "nap time" before taking the child to her room for a nap.
- Picture or word schedules give an overview of what will happen and when there will be changes. Put a series of pictures together with velcro or drawn in to help child understand what is going to happen. For some children who have difficulty when changes occur in their day, a schedule of daily activities could be constructed with pictures of breakfast, getting ready for school, the school bus, etc.) Then the child can rely on the schedule to tell him what will happen. If there is no school on one day, then the pictures of school can be taken down in front of the child and replaced with some other activity. In this way, the child can gain information about changes that he may not understand from just verbal information. Another example may be if a child continually gets upset when running errands with his parent because of all the changes, he could be given a list of pictures of where he is going to go, in what order (grocery store and then gas station and then the post office) and then perhaps with a picture of McDonalds or some other reward at the end of the errands.
- draw child's attention to naturally occurring visual prompts such as when the table is set, dinner will happen soon.

2. Transitions

Establish routines in transitions that incorporate objects or pictures that help the child anticipate when an activity is going to end (see Time), when a transition is going to occur, and what new activity is going to start. (See handout if interested)

3. Directions

Decrease verbalization and Increase visualization to help child understand directions by using the following:

- Use gestures -- pretend to put on a coat while saying "go get your coat"
- Physical prompts -- turn child in direction of coat as you say "go get your coat"
- Visual tools (objects and pictures) -- show child picture of a coat when you say "go get your coat" and allow them to hold the picture on the way to their coat.
Create parent communication book with pictures that symbolize frequent directions and use these pictures when giving directions

4. Increasing Children's Attention (see handout)

- helping child understand "start" and "finish"
- helping to remember the steps in a task
- helping to remember the rewards for completing the task

5. Choosing:

- Increase use of visuals with pictures and objects while giving child choice, such as holding up cartons of juice and milk when asking "do you want juice or milk?"
- Use choice boards with pictures of what activities or items are available to help children to remember and understand what is available.

6. Information About Time

- Use clocks, cooking timers, sand clocks, and naturally occurring cues to increase child's ability to anticipate when things will end. Make sure the child understands how to tell when the activity will be over and this will depend on developmental level, e.g. putting a red dot on the stationary and rotating part of a cooking timer and telling the child, "when the dots are together, nap is finished." You may need to practice doing short activities and stopping as soon as the dots are together. By knowing when an activity is over, children can increase their ability to stick with the activity.
- Use Pictures or other cues to draw child's attention to the beginning of a specific situation. Children may not be picking up on environmental cues, so they may need more obvious cues (e.g. nap time starts when you give child her blanket or doll). For children with basic communication skills this principle can be used to draw their attention to subtle social situations such as waiting time, independent play time etc.

7. Procedures and Tasks

- Organize sequence of tasks by lining up the objects used during the task in left to right order. Put an object at the very end that is a reward or reminds child of reward for completing the task. Show child each object before each step in task. This can help children anticipate what is coming next. Later, children can use the cues to help remind them of what step they need to do next. This can help them become more independent at performing the task. For example, set out the toothbrush, then the toothpaste, then a cup of water, then a book (if reading a book is the reward).

- For children that can use pictures, put up pictures that show sequences of tasks that the child is learning how to do, such as getting ready for school, washing hands, using the toilet. . Later, children can learn to go and gather the materials together themselves. Remember to include the reward as the last step in task. It may be helpful to keep all the materials for some tasks in a separate box with a picture of the activity on top.
- At first these prompts will help your child understand what is going on and decrease anxiety as you guide them through the routine, later these prompts will increase your child's ability to complete the tasks independently.

8. Learning Concepts

- For children who have some basic communication abilities, early concepts to start with are "no, yes, start, finish."
- Introduce the idea of the international "no" sign (a line through a circle) to remind a child she may not go into a specific cabinet, may not touch certain items, or of pictures of unacceptable behavior.
- - Use "no" to teach the concept of "not available" such as when juice is all gone, say "no more juice" and take the picture of juice off refrigerator and put it away, cover it up, or put a "no" circle with a slash around it.

9. Learning Social Skills

(for children who have basic communication skills)

- Make pictures of the behavior and it's consequence (e.g. picture of child breaking crayons = picture of crayons with a big circle around it with a slash through it, picture of a child coloring with crayons). Its best if you give children information on what they are not suppose to do, that you give information about what the child is suppose to do at the same time. Often children with autism have difficulty generating positive alternatives on their own.
- Use Cognitive Picture Rehearsal (from the Groden Center) to teach a social or skill based behavior. Create a "cartoon" that uses pictures and very basic words that include a) pictures and descriptions of antecedent situations that help child identify when to use the target behavior (e.g. sitting at table, juice in front of him, cup in front of him), b) pictures of the target behavior, (e.g. child pours juice into cup), c) pictures of reward (e.g. child has smile, "he is a big boy", he drinks the juice).
- For children with good verbal skills and basic reading skills, use Social Stories (developed by Carol Grey) that are longer and more complex than the cartoons described above to help children learn about social skills and routines.
- Also for developmentally older children you can also help them to identify behavior choices by providing them with word or picture lists such as:
 - go to room
 - it's too noisy wear earphones
 - go swing

Using Photographs to Teach Language Skills

by Carolyn A. Weiner, M.A., C.C.C.

You can use photographs at home to help your child learn three important language skills:

- Using symbols to communicate
- How to sort into categories
- Using words to express thoughts and feelings

Using Photographs to Learn About Symbols

To use language to communicate, children must learn to understand and use symbols. A symbol is a sign that represents something else. For example, the letters of the alphabet represent sounds. The word "dog" stands for a group of four-legged animals.

Photographs can be used to help children develop symbolic communication skills. For most children, the earliest communication is done by pointing and using other gestures that do not require symbols. For children delayed in language development, this gestural level may cover a span of several years. Some children will remain "stuck" at this level. Using symbols to communicate is too *abstract* for them.

Your child may go to the refrigerator and point to request juice. The child may have difficulty understanding that you would get the juice if the child said "juice." In this situation, you can take a photograph of the juice container and tape it on the refrigerator. Each time your child points at the refrigerator, you can lift the child's finger to the photograph and say "juice." If there are two possible items of interest, you could put both photographs on the refrigerator and ask which one the child wants.

By pointing to the photograph, your child will be using a symbol to communicate. You can then move the photograph to a small communication wallet that your child can wear or carry in a pocket.

Your child can then use photographs in the wallet to communicate. By using photographs in this way, you clearly demonstrate the advantage of symbols over gestures. The object doesn't have to be present in order to say something about it. Your child, for example, can point to the

photograph of "juice" while you're riding in the car. This would mean, "Can I have some juice when I get home?" This is a productive means of communication that can be a basis for using language. Using the word "juice" is the next step, as your child learns to replace photographs with simple words.

Using Photographs to Develop Sorting Skills

An important language-based skill is the ability to classify or sort events and objects. Schools rely on this skill to teach many subjects including:

- Reading — (Let's find all the words that start with this sound.)
- Math — (Circle every picture with two animals.)
- Science — (Find the animals that change color in the winter.)

Parents can use photographs to help develop classification skills at any language level using these activities:

1. Make up category photo albums with your child. The albums can include very simple categories (things I like, things I don't like); intermediate categories (yellow things, round things, food, animals); or advanced ones (items associated with Africa, objects made of wood). Add photos to the category albums on a regular basis. Your child's albums do not need to be expensive. Just use colored construction paper and looseleaf binders.
2. Identify categories to which photos belong. Cooperate with your child to take a variety of photos around the house. Make lists of different ways the photos could be categorized. For example: food, furniture, clothing, Mom's things, hard things, and small appliances. Discuss which items belong to different categories.
3. Take photos of items in a category. Select just one category for the week or month. Ask your child to take as many photos in that category as possible.

Using Photographs to Develop Communication Skills

One of the most difficult tasks for language learners of all ages is expressing their own ideas in words. As a result, children rely on things in their environment as "props" to help them get their point across. This works out well when children want to talk about things that are present (as when requesting an object by pointing to it). However, a child cannot rely on pointing when talking about objects that are not present, or events that have happened in the past.

In order to help your child learn to talk about things not immediately present in the environment, use photographs to:

1. Talk about memorable events.

Take photographs of memorable events, such as school parties and family get-togethers. Talk about the photos with your child. Discuss the occasion—the setting, the people and emotions involved, and the sequence of events that occurred. Keep your language slightly above your child's language level, whether it is single words or longer sentences. Use words such as "yesterday," "last Halloween," and "last week." The pictures will help your child "see" what you mean.

2. Talk about the sequence of an activity.

Take sequences of three to four photos showing a school activity or a frequent household routine. The activities could be completing a worksheet at school or having an evening meal at home. Mix the photos up and put them back into order with your child. Talk about events at both your child's language level and slightly above. Use words such as "first," "last," "next," "before," and "after."

3. Encourage discussion of topics important to your child.

When appropriate, allow your child to take a camera to school or to a special event. Let your child take pictures around the house. Discuss your child's photos. A child with communication difficulties can learn to use a camera as a welcome helper in the communication process. By using your child's photographs, you know the child will be interested in a discussion. In talking about the photos, you can demonstrate how to put ideas and words together. Your child will then be equipped to show the pictures to someone else and to use more words the next time.

4. Facilitate home/school interaction.

Invite your child's teacher to take photos and send them home. Encourage your child to tell you about the photos. This lets your child know that school is important to you. It also gives your child an opportunity to demonstrate newly-learned communication skills. The child will have to communicate effectively to tell you about things that you are not familiar with.

5. Provide practice in learning language skills.

Keep in mind that, unlike an experience which occurs once, photographs can be reviewed and discussed repeatedly. This repetition offers your child the opportunity to continue to learn new language skills while reinforcing already-learned ones.

Vocabulary

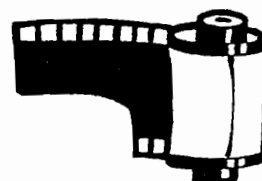
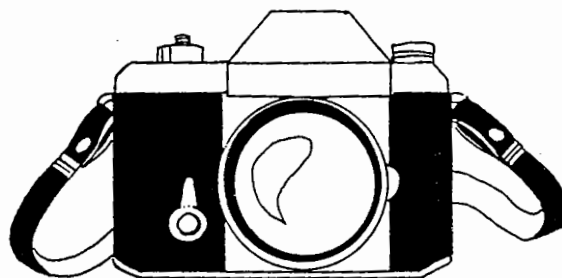
Abstract—Relating to ideas, symbols, and relationships rather than concrete objects.

Classify—To sort into groups with common characteristics.

Symbol—A sign that stands for or represents something else.

Refer to:

- 2.1 Language Development
- 3.7 Learning About Time and Space
- 4.3 Association Skills
- 5.0 Section: Home Activities for Speech and Language Development
- 7.1 Help Your Child Use Gesture to Communicate
- 8.3 Pre-Reading Skills





VISUAL SUPPORTS FOR CHILDREN AND ADOLESCENTS WITH AUTISM SPECTRUM DISORDERS

CENTER FOR AUTISM SPECTRUM DISORDERS, CHILDREN'S NATIONAL MEDICAL CENTER

Understanding information presented visually is often an area of strength for children and adolescents with autism spectrum disorders (ASDs). Visual information can be particularly helpful for children who have language disorders and/or difficulty processing auditory information. Special educators and clinicians have devised visual strategies to assist children's functioning at home and at school. This handout describes several of these strategies.

Color photographs of the actual items mentioned in a visual support (e.g. the child's toothbrush) are easiest to understand. Adults sometimes take digital photographs of the child's environment and include these in the support. Some children are able to interpret line drawings like "picture symbols" (used by speech and language pathologists, available for free at dotolearn.com [click on "Picture Cards"]). When necessary, pages can be laminated using self-adhesive laminating sheets (available at office supply stores), clear Contact Paper, or a professional laminating machine, and written on with transparency or dry erase markers.






I. VISUAL SCHEDULES

Children and adolescents with ASDs typically respond well to having a regular, predictable routine that they understand. A visual schedule is a written or pictorial representation of a schedule that a child can refer to throughout the day (Figures 1 and 2). Parents and teachers can make visual schedules for a particular routine (e.g. brushing teeth), part of the day (e.g. the morning routine), the whole day, or the week, depending on the child's needs. Posting the schedule in the child's environment, and including a laminated copy in the child's backpack, at his/her desk, or in a frequently used notebook can help ensure the child has access to the schedule whenever he/she is feeling uncertain.








Figure 1. A visual schedule illustrating an afternoon routine, using photographs of the child's environment.

Figure 2. A visual schedule illustrating a school day using clip art.

Max's Afternoon Schedule

3:30 – Get home from school. Snack.	
4:00 – Homework	
4:30 – Playtime	
6:00 – Dinner	
7:30 – Bedtime	

Max's School Schedule

Arrival	
Math	
Snack	
Special (PE, art, or music)	
Lunch	
Reading	
Dismissal	

Parents and teachers should think carefully about including times on the schedule, as some children with ASDs are careful timekeepers who are upset by minor changes. Depending on the child, the schedule could include disclaimers like “about” or “approximately,” or omit times entirely. If there will be a change in the schedule, tell the child well in advance if possible. Emphasize the things that will remain the same in the schedule (for example, “There’s no school on Monday, but you’ll still have PE on Tuesday and art on Wednesday”). If part of the schedule will vary from day to day or has not yet been decided, include a “?” or a generic term in the schedule. For example, a weekend schedule might begin “get dressed, eat breakfast, ?, come home for lunch,” etc., with the “?” representing an outing that will change from week to week.

Some parents and teachers use the laminated, Velcro-backed picture technique described below in Section II to create a simplified visual schedule board. The schedule board contains three squares where pictures for past (“Finished”), current (“Now”), and future (“Next”) activities are attached. When it is time to transition to a new activity, children help move the “Next” picture to “Now,” add a new “Next” picture, etc. This type of visual schedule is useful for children who have difficulty with transitions, and whose language skills are still emerging.

II. CHOICE BOARDS

A choice board is a visual representation of a child’s options for a particular choice, like what to have for snack or what to do during free play time. Parents and teachers can laminate photographs or picture symbols, and put Velcro on the back of each picture. They can then create a “choice board” by putting squares of Velcro on a piece of poster board. The child can show his/her choice by attaching a picture to the choice board. For example, parents can provide pictures of foods so a child can show what s/he wants for snack. Many examples are available online (search the internet for “choice boards”).

III. FLOWCHARTS

Flowcharts can be a powerful tool for helping children and adolescents with ASDs visualize the potential consequences of their choices. Flowcharts can be made with words or pictures, depending on the skills of the child (*Figures 3 and 4*). Some parents and teachers find it helpful to keep a white board or pad of paper handy so they can quickly sketch out a child’s options as needed throughout the day. Others create laminated flowcharts incorporating a child’s interests to reinforce important concepts.

Figure 3. A flowchart illustrating the consequences of hitting. Such flowcharts can be customized to incorporate the child’s special interests (e.g. by showing a favorite cartoon character “walking away”).

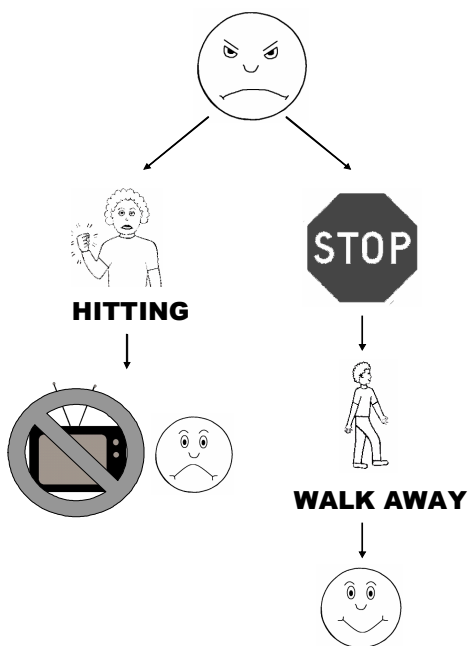
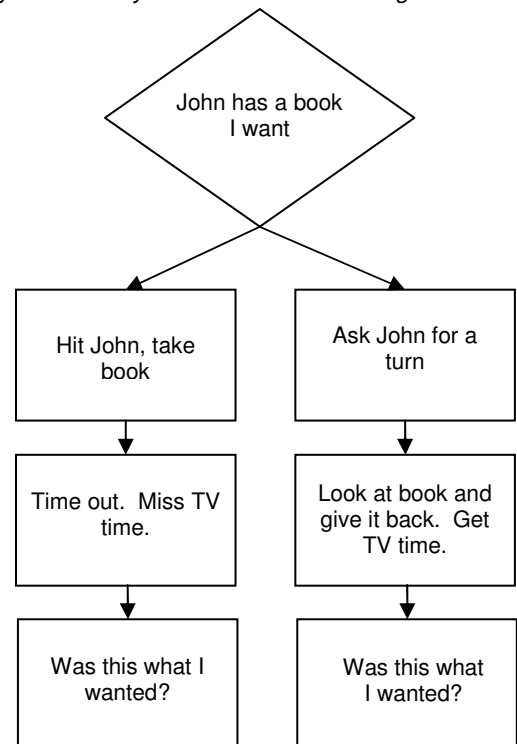


Figure 4. A flowchart using words to show the consequences of hitting. Similar flowcharts could be quickly sketched by adults as needed throughout the day.



IV. TABLES

Children with ASDs generally have great difficulty understanding other people’s perspectives. This can make others’ behavior seem absolutely baffling to the child, and can lead to frustration and behavioral problems. Drawing a table illustrating two conflicting perspectives and possible compromises can help defuse a situation and coach perspective taking skills (Figure 5).

Figure 5. A table illustrating ways to compromise between conflicting perspectives. Such tables can be used to coach perspective taking skills.

Dad wants/feels...	I want/feel...	Possible compromises...
for me to clean my room	to watch tv	<ul style="list-style-type: none"> clean my room first, then watch an extra 10 minutes of tv watch my favorite show now, then clean my room quickly. If I don't clean up quickly I can't watch any tv tomorrow

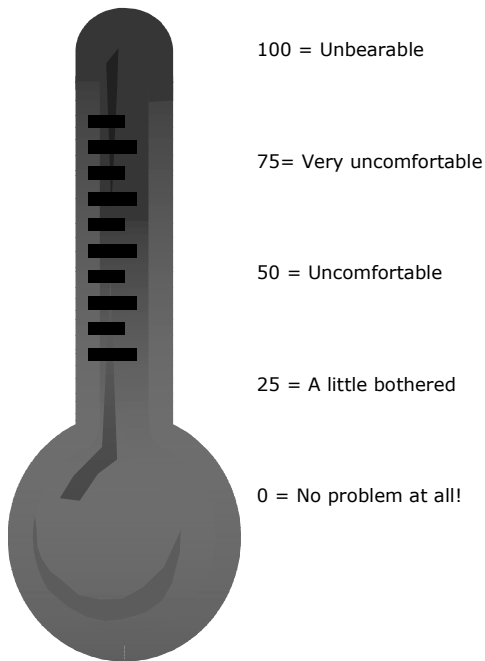
V. THERMOMETERS AND RATING SCALES

Children with ASDs often have trouble gauging and communicating the intensity of their own emotional and physical experiences, making it difficult for them to respond appropriately. Thermometers and ratings scales are intended to give children tools for gaining insight into how they are currently feeling (Figures 6 and 7). Ideally, immediately after using these self-assessment tools, children are helped to cope with the feelings they have identified. For example, after recognizing that she is angry, a child should be reminded of her “cooling off” strategy so she does not escalate further.

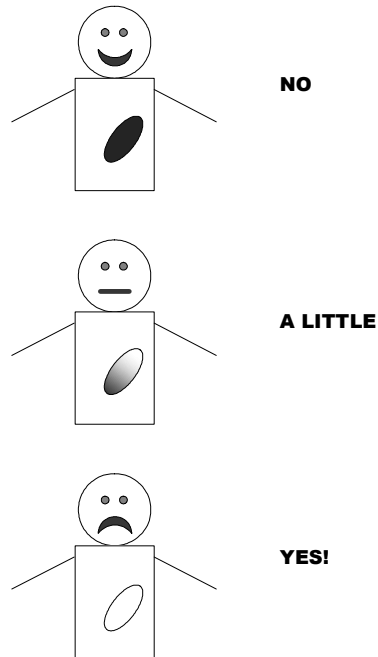
Figure 6. A visual rating scale on which a child can indicate how intense his/her negative feelings are. For younger children, a simplified scale of 1 to 5 can be used.

Figure 7. A visual rating scale on which a child can indicate how hungry s/he is.

Recognizing Your Uncomfortable Feelings Using a Feelings Thermometer



Are You Hungry?



ADDITIONAL INFORMATION

- The University of Florida Center for Autism and Related Disorders 16 minute video, “Making and Using Visual Supports” (<http://www.card.ufl.edu/video.htm>) provides an excellent practical introduction.
- The website dotolearn.com has many free resources including picture symbols and schedule templates.

SOCIAL LANGUAGE USE (PRAGMATICS)

BY THE AMERICAN SPEECH-LANGUAGE-HEARING ASSOCIATION

You have invited your friend over for dinner. Your child sees your friend reach for some cookies and says, "Better not take those, or you'll get even bigger." You're embarrassed that your child could speak so rudely. However, you should consider that your child may not know how to use language appropriately in social situations and did not mean harm by the comment.

An individual may say words clearly and use long, complex sentences with correct grammar, but still have a communication problem - if he or she has not mastered the rules for social language known as **pragmatics**. Adults may also have difficulty with pragmatics, for example, as a result of a brain injury or stroke.

Pragmatics involve three major communication skills:

- **Using language** for different purposes, such as
 - greeting (e.g., hello, goodbye)
 - informing (e.g., I'm going to get a cookie)
 - demanding (e.g., Give me a cookie)
 - promising (e.g., I'm going to get you a cookie)
 - requesting (e.g., I would like a cookie, please)
- **Changing language** according to the needs of a listener or situation, such as
 - talking differently to a baby than to an adult
 - giving background information to an unfamiliar listener
 - speaking differently in a classroom than on a playground
- **Following rules** for conversations and storytelling, such as
 - taking turns in conversation
 - introducing topics of conversation
 - staying on topic
 - rephrasing when misunderstood
 - how to use verbal and nonverbal signals
 - how close to stand to someone when speaking
 - how to use facial expressions and eye contact

These rules may vary across cultures and within cultures. It is important to understand the rules of your communication partner.

An individual with pragmatic problems may:

- say inappropriate or unrelated things during conversations
- tell stories in a disorganized way
- have little variety in language use

It is not unusual for children to have pragmatic problems in only a few situations. However, if problems in social language use occur often and seem inappropriate considering the child's age, a pragmatic disorder may exist. Pragmatic disorders often coexist with other language problems such as vocabulary development or grammar. Pragmatic problems can lower social acceptance. Peers may avoid having conversations with an individual with a pragmatic disorder.

Reprinted with permission from "Social Language Use (Pragmatics)." Available from the website of the American Speech-Language-Hearing Association:
www.asha.org/public/speech/development/Pragmatics.htm.

PRAGMATIC LANGUAGE TIPS

BY THE AMERICAN SPEECH-LANGUAGE-HEARING ASSOCIATION

Parents, caregivers, families, and teachers can help individuals use language appropriately in social situations (*pragmatics*). Some general suggestions to help develop skills in three major pragmatic areas are listed below.

Using Language for Different Purposes

- **Ask questions** or make suggestions to use language for different purposes:

Desired Language Function	Suggested Question or Comment
Comment	"What did you do?" "Tell me about..."
Request	"Tell your friend..." "What do you want?"
Question	"Ask me"

- **Respond to the intended message** rather than correcting the pronunciation or grammar. Be sure to provide an appropriate model in your own speech. For example, if an individual says, "That's how it doesn't go," respond, "You're right. That's not how it goes."
- **Take advantage of naturally occurring situations.** For example, practice greetings at the beginning of a day, or have the individual ask peers what they want to eat for dinner or request necessary materials to complete a project.

Changing Language for Different Listeners or Situations

- **Role-play conversations.** Pretend to talk to different people in different situations. For example, set up a situation (or use one that occurs during the course of a day) in which the individual has to explain the same thing to different people, such as teaching the rules of a game, or how to make a cake. Model how the person should talk to a child versus an adult, or a family member versus a friend of the family.
- **Encourage the use of persuasion.** For example, ask the person what he or she would say to convince family members or loved ones to let him or her do something. Discuss different ways to present a message:
 - Polite ("Please may I go to the party?") versus impolite ("You better let me go")
 - Indirect ("That music is loud") versus direct ("Turn off the radio")
 - Discuss why some requests would be more persuasive than others

Conversation and Storytelling Skills

- **Comment on the topic** of conversation before introducing a new topic. Add related information to encourage talking more about a particular topic.
- **Provide visual cues** such as pictures, objects, or a story outline to help tell a story in sequence.
- **Encourage rephrasing** or revising an unclear word or sentence. Provide an appropriate revision by asking, "Did you mean ?"
- **Show how nonverbal signals are important** to communication. For example, talk about what happens when a facial expression does not match the emotion expressed in a verbal message (e.g., using angry words while smiling).

Reprinted with permission from "Pragmatic Language Tips." Available from the website of the American Speech-Language-Hearing Association:
www.asha.org/public/speech/development/PragmaticLanguageTips.htm.

Using Language to Get Results

by M. Ann Marquis, M.S., C.C.C.

Why do children communicate?
To get what they want!

Nonverbal Communication

The first step in influencing others is to get their attention. Before children learn to talk, parents respond to gestures, cries, or even sounds like grunts and moans. For example, pointing to a cookie is good communication for the child who can't say "cookie."

Children first learn to influence others by using nonverbal communication. A baby's cry, for example, is a request (or demand) for attention. It can bring a parent from another room. Crying is often a successful way to influence others.

Nonverbal communication, like speech, must be learned by trial and error and by getting results. Nonverbal communication is successful when parents do what children want them to do. Children often use the following nonverbal behaviors:

Child's Behavior	Child's Goal
Long sound	Asking for people, objects, animals
Abrupt, short sound	Getting attention
Look, grasp, point to people or objects	Getting person, object
Cry	Seeking comfort or food
Shakes head	Rejecting food, object, person

Verbal Communication

By the time children approach two years, the use of nonverbal communication should be giving way to using words. Words are much more effective. Instead of just pointing to a desired cookie, the child says "cookie." As the child develops more language, the pointing usually disappears because it is easier to just say "cookie."

Children who have difficulty learning language may continue to use nonverbal communication. They will fall back on gestures and sounds if their verbal requests are not understood.

If using language is difficult for your child and whining, crying, and gestures get results, there is little reason to talk. Children talk in order to get what they want. If your child can get a cookie by pointing to it, there really is no need to say "cookie." How can parents encourage children who prefer not to talk? Here is an example:

Child's Behavior	Parent's Language
1. Points at cookie.	"What do you want?"
2. Continues to point, and grunts.	"Do you want a cookie? Tell me cookie."
3. Says "tu."	"Yes, cookie. Here's your cookie."

In this sequence, the parent required an attempt at saying "cookie" before fulfilling the request. If the child could actually say "cookie," the parent would have asked for the correct word before delivering the cookie. Did you notice that the parent used the word "cookie" four times? By using the word in several different sentences it was clear which word was appropriate.

From Words to Conversation

The next stage for children who are learning to control their environment is to combine words. Just as you expected your child to say words instead of pointing, soon you can expect "orange juice" instead of "juice." In any stage of development, parents can help children control their lives by using language.

Children with language problems often need help labeling things and people. Words like "this" or "that," "here" or "there" are common in our language. But they have no meaning unless you know what your child is referring to. For example, a request like "I want that" is confusing if you don't know what "that" is. Whenever your child's communication is confusing, ask, "What do you want?"

How can you encourage conversation? Do things together with your child. Talk about what you're doing. Create new situations for conversations. Everything you do together is worth talking about. Take turns when talking. Use short sentences. Use language that is only slightly more difficult than your child uses. Tell your

child the words for objects or people that the child does not know.

Learning to Say "No"

Saying "no" is one of the most important concepts your child will learn. The ability to refuse, deny, and disagree helps children to control their environment in a straightforward way. Your child probably expressed "no" before learning to talk by pushing things away. Rejection of certain foods is a common occurrence in most families. These rejections are important around two years of age, when children start wanting to do things for themselves. This desire for independence is an important step of development.

How you respond when your child says "no" will determine whether the behavior will be used again. When your child does not like an object or person, tell the child you understand. Accepting your child's reasonable rejection of an object, food, or person will help the child become better at controlling the world.

How can parents help children use language to influence the world they live in?

1. When your child starts a conversation, give the child your full attention.
2. Depending on your child's language level, require that your child attempt sounds, words, or sentences. Ask your speech clinician what is reasonable to expect.
3. Show that you understand the word or phrase your child is attempting. Then fulfill the request if appropriate.

4. Pause after speaking. This gives your child a chance to continue the conversation.
5. Help your child put feelings, actions, and desires into words.
6. Encourage your child to give and take directions.
7. Help your child to use language to make choices.
8. Allow your child to verbally disagree.
9. Teach your child to greet people.
10. Play games with your child, especially games like "playing house." Your child can pretend to be a parent and practice telling you what to do.
11. Give your child choices like "Do you want soup or a sandwich for lunch?"
12. Set a good example for your child. Model clear, assertive communication.

Vocabulary

Nonverbal communication—Communicating without words, using gestures, facial expressions, body language, or tone of voice.

Model—To provide an example of good speech or other behavior; to demonstrate a desired response.

Refer to:

- 4.1 Learning New Words
- 4.6 How Children Use Language to Satisfy Needs
- 4.8 Help Your Child Learn to Ask and Answer Questions



PSYCHIATRIC MEDICATIONS

CENTER FOR AUTISM SPECTRUM DISORDERS, CHILDREN'S NATIONAL MEDICAL CENTER

Children and adolescents with autism spectrum disorders (ASDs) are best served by an individualized, multidisciplinary approach including behavioral, educational, speech and language, and/or other interventions. Some children also benefit from an evaluation by a child and adolescent psychiatrist, who can diagnose and treat thinking, feeling, and behavioral problems with medications and/or psychotherapy. Child and adolescent psychiatrists can provide additional support, and help parents decide whether the child should receive psychiatric medication in addition to the child's other therapies.

Consider an appointment with a child and adolescent psychiatrist if you have concerns about your child's:^{1,2}

- **Physical aggression or threats of self-harm:** You are afraid that your child's behavior could present a danger to himself/herself or other people.
- **Severe tantrums:** You find yourself calling your pediatrician for help more often because your child is losing control; your child's verbal outbursts frequently escalate to uncontrollable screaming and/or physical aggression.
- **Severe worry or anxiety:** In children, worries often appear as physical symptoms (stomachaches or headaches) or behaviors (reluctance to go to school or take part in normal activities, trouble eating and sleeping, etc.).
- **Mood problems:** These can include irritability, sadness, reduced interest, elation, or severe mood swings.
- **Academic difficulty:** Your child's grades are falling, or s/he is having trouble keeping up at school.
- **Attention and/or hyperactivity issues:** Your child has fidgeting and activity beyond what is normal for his/her age, or significant difficulty paying attention at school, that is interfering with his/her functioning.
- **Sleeping or eating difficulty:** You are concerned because your child gets too little, too much, or disrupted sleep; has nightmares; or has had a significant increase or decrease in appetite or weight.
- **Acting out:** Your child gets in severe trouble at school or home for fighting, using alcohol or drugs, shoplifting, etc.
- **Unusual movements:** Your child has unintentional, sudden, repetitive movements like facial grimaces, eye blinking, head jerking, sniffing, or throat clearing.
- **Other adults' concerns:** Other trusted adults in the child's life, like teachers and grandparents, have noticed a significant worsening of your child's functioning.
- **Overall functioning:** Everyday life is a huge struggle; you aren't sure how long you can go on like this.

Following are some of the psychiatric medications most often prescribed to children and adolescents:

<i>Type of Medication</i>	<i>Common Uses</i>	<i>Examples</i>
Attention deficit hyperactivity disorder medications	Attention problems, distractibility, hyperactivity	Ritalin/Concerta/Daytrana/ Focalin (methylphenidate) Strattera (atomoxetine)
Neuroleptics (also called antipsychotics)	Small doses are used to treat irritability, tantrums, aggression, and unstable mood in children with ASDs. Also used to treat tics (involuntary movements or verbal outbursts), disorganized thinking, hallucinations, and delusions.	Risperdal (risperidone) Abilify (aripiprazole) Seroquel (quetiapine) Geodon (Ziprasidone)
Antidepressants	Depression, irritability, anxiety, some repetitive behaviors	Prozac (fluoxetine) Zoloft (sertraline) Lexapro (escitalopram) Celexa (citalopram)
Mood stabilizers/ anticonvulsants	Unstable mood, seizures (epilepsy), migraine headaches	Depakote (valproic acid) Lamictal (lamotrigene) Lithium
Anxiolytics	Anxiety	Buspar (buspirone) Ativan (lorazepam)
Sedatives	Severe sleep problems (used for limited periods of time in addition to behavioral interventions)	Benadryl (diphenhydramine) Catapres (clonidine) Desyrel (trazodone)

Questions to ask if your child is prescribed a psychiatric medication:³

- What is known about the use of this medication in children with symptoms similar to my child's?
- If the medication works well, what behavior changes will we see, and when?
- What side effects and drug interactions might occur, and how should we manage them?
- When and how should we take the medication? What should we do if we miss a dose?
- What information should we bring to our next appointment so we can evaluate whether the medication is working?
- Who will monitor my child's progress and adjust dosing? How often will we be seen for follow-up appointments?
- How long will my child be on this medication? How will we decide when to discontinue the medication?

Additional Resources:

¹American Academy of Child and Adolescent Psychiatry. "Facts for Families."
aacap.org/cs/root/facts_for_families/facts_for_families_numerical_list

²Amato, J. "Red flags: When to take your child with autism to a psychiatrist." Interactive Autism Network. 2007.
www.iancommunity.org/cs/therapies_treatments/child_psychiatry_and_autism

³Schall, Carol. "A Consumer's Guide to Monitoring Psychotropic Medication in Individuals with Autism Spectrum Disorders." *Focus on Autism and Other Developmental Disabilities*. 17 (4): 229-235, winter 2002.

Sleep Problems

What should we know about sleep problems?

Sleep problems are common in children with and without autism spectrum disorders (ASDs). One third to one half of children with ASDs have sleep problems. This can lead to daytime problems with paying attention, being irritable, and displaying more repetitive behaviors. The amount of nighttime sleep needed by preschoolers in general is typically 10 to 13 hours. It decreases with age to 8 to 11 hours by 13 years.

What are some reasons for sleep problems?

Children with ASDs may have many reasons for sleep problems. The causes may be medical, behavioral, or both. Medical reasons for sleep problems may include allergies, breathing problems, and gastrointestinal reflux (stomach discomfort). Medications can also affect sleep.

Sleep normally has cycles with different brain wave patterns. These patterns may be different in some people with autism. Typical sleep patterns include lighter sleep and dreaming later in the night. That is when night waking often happens. The hormone melatonin is made by the brain to control sleep. Some scientific studies have shown that people with ASDs may not have the same amount or action of this hormone.

Some sleep problems include

- Trouble falling asleep. Children may have a hard time falling asleep if there is a lot of activity in the household, if they eat foods with caffeine, or if they are hyperactive. It may be that they do not connect bedtime with falling asleep or that they want to be with the family.
- Night waking. Children who wake up in the middle of the night may stay awake if they don't know how to fall back to sleep alone or they don't understand that nighttime is for sleeping. They may stay awake because they are used to getting food, attention, or other reinforcement when they wake up. Some children wake up when soiled or wet.

- Early waking. Children may wake up early because of abnormal sleep cycling or melatonin production or because of problems with falling back to sleep when they wake up. They may also wake up early because their sleep needs have been met.
- Nightmares, sleep terrors, sleepwalking. These occur in the first few hours of the sleep cycle in children with or without ASDs and are related to brain activity during sleep.

How are sleep problems assessed?

Your child's doctor can do a general physical exam and history of health and sleep problems. Try to keep a sleep diary for a while to help the doctor understand your child's sleep habits. The doctor may also run lab tests if the history or physical exam suggests medical reasons for the sleep problems.

What can we do to help our child sleep better?

Studies have shown that behavioral strategies help more than medication to improve sleep problems. Some basic suggestions include

First step: Sleep schedule (Use for 2 weeks.)

Set a regular time for going to bed and getting up for the day. Start a relaxing routine leading up to bedtime. Try to do this the same way each night. Make sure your child's bedroom is set up for sleep. It should be quiet and dark, without TV or music on. The rest of the household should be quiet at bedtime. Make sure your child knows that the bed and bedtime are for sleep only, not for play or time-out. This sleep hygiene step sometimes works all by itself to help sleep problems, but other steps may be needed.

Next step: Ignoring problem behavior

If sleep problems continue after setting up a good sleeping area and routine for your child, you may want to add the step of ignoring sleep protests. When leaving your child in the bedroom, say "good night" and praise your child for going to bed. Then check in at times you have decided on and ignore protests between checks. Increase the time between checks during the night and over the next several days. When checking, briefly look in the bedroom. If your child is awake, tell him to go to sleep, and then leave.

It is important that all caregivers are consistent in this step. Protests may get worse for 2 to 3 days, but you must do this in the same way for 2 weeks. Families may need ongoing support to carry this out, especially if parents and other caregivers disagree with ignoring protests.

Another potential step: Medication

Your child's doctor may suggest prescription or over-the-counter medications to be used along with behavioral training.

Other behavioral approaches to night waking and delayed sleep onset should be discussed with your pediatrician if you have used the approach described previously in a consistent fashion for 2 weeks and your child still has disturbed sleep. There are other behavioral interventions that can be used. Particularly difficult problems will need consultation from a sleep expert.

Resources

Durand VM. *Sleep Better! A Guide to Improving Sleep for Children with Special Needs*. Baltimore, MD: Paul E. Brookes Publishing Co; 1997

Ferber R. *Solve Your Child's Sleep Problems: New, Revised, and Expanded Edition*. New York, NY: Fireside; 2006

The information contained in this publication should not be used as a substitute for the medical care and advice of your pediatrician. There may be variations in treatment that your pediatrician may recommend based on individual facts and circumstances.

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Published as part of *AUTISM: Caring for Children With Autism Spectrum Disorders: A Resource Toolkit for Clinicians*.

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DEDICATED TO THE HEALTH OF ALL CHILDREN™

Transition to Adulthood: The Ultimate Outcome

Moving into adulthood can be a difficult and scary time for any young person. For youth with autism spectrum disorders (ASDs) and their families, this time can cause great anxiety. But planning early for this change can reduce stress and uncertainty—and even make this a time of excitement.

When should we start planning for the transition?

The Individuals With Disabilities Education Act requires a child's Individualized Education Program (IEP) to include a transition plan by age 16 years. Families are strongly encouraged to start planning and setting long-term goals when the child is 14 years old.

What are some areas of our youth's life that should be included in a transition plan?

A plan for transition should include goals for your youth as he becomes an adult. Be sure to get input from your youth on his desires and goals. The plan should address health care, employment options, community participation, and continuing education. Also consider social situations (friends, hobbies, interests); financial planning; long-term care; community, state, and federal resources; and sibling support.

How do we get started with planning?

You may want to start by writing a list of questions to discuss with everyone involved in the transition plan. Actively involve your youth in developing these questions. Siblings and friends should be included when appropriate. Example questions include

- What does your youth like to do? What are her dreams?
- What can your youth do? What are her strengths?
- What does your youth need to explore?
- What does your youth need to learn to reach her goals?
- What are some future education goals?
- How do you and your youth feel about getting a job?
- Where can your youth go to find a job?
- What transportation is available?
- Where will your youth live?
- Where will your youth get health insurance?

- Are supports needed to encourage friendships?
- Do people in the community know your youth?
- Are supports needed to structure time for recreation?
- Does your youth have any interests or hobbies?
- Does your youth have a system for communicating that works well? What strategies are needed to enhance her communication?

The answers to these questions will help you form goals for your youth. And those goals will lead you in putting together action steps to help your youth develop the skills she needs to enter the adult world.

What are some developmental issues we should consider?

When planning for your teen's future, think about his learning skills. This is important when planning for independence and employment. For example, is your young adult a slow learner? Does he have a learning disability? For individuals who have trouble speaking, it is important that they have a way to communicate. Young adults with sensory problems must also have a way to cope with new sights, sounds, and smells they may face in the workplace or community.

What should we know to get ready for educational transition?

If your child has an IEP, plans for transition will be added to it. This transition plan will identify the services that your teen needs to prepare for life after school. For instance, job skills training may be provided to help your young adult get ready for employment. Your school system may work with other agencies to give the support your teen requires. Some teens do not get special education services and instead have a 504 plan. If so, you will want to think about adding some supports that will help your teen develop skills for adulthood.

What should we know to get ready for health care transition?

The American Academy of Pediatrics recommends that families have a health care transition plan before a child is 14 years old. Work with your teen's doctor to make a plan for the health-related skills your young adult will need, how your child will gain those skills, and the timing of transition to adult health care services. Check with your current health insurance plan to find out about extended coverage after your child turns 18.

Where can we get help with transition planning?

Many people will help with your youth's transition plan. These include your doctor or other health care worker, school employees, family members, trusted friends (circle of support), and community agencies. Each of them can help you better understand how to plan for transition and guide you in making decisions. Your state's vocational rehabilitation office and the US Social Security Administration are also helpful sources of information. To find the contact information for your state's vocational rehabilitation office, visit www.jan.wvu.edu/sbses/vocrehab.htm. Information for the US Social Security Administration can be found at www.ssa.gov.

What predicts adult outcomes?

People with ASDs who have good learning and language skills are more likely to have more education or work in the community. But independent of the child's ability, good planning makes it possible for young people with ASDs to work toward goals that will allow them to participate fully in their communities. To improve adult outcomes for people with ASDs, parents can also continue to advocate for community living options, social groups, and support services for young adults after the ages when the schools have to provide them.

Reference

American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians-American Society of Internal Medicine. A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics*. 2002;110:1304–1306

Resources

Council for Exceptional Children: www.cec.sped.org

ERIC—Educational Resources Information Center: www.eric.ed.gov

DisabilityInfo.gov—The New Freedom Initiative's Online Resource for Americans with Disabilities: www.disabilityinfo.gov

Healthy & Ready to Work National Resource Center: www.hrtw.org

National Center on Secondary Education and Transition: www.ncset.org

National Dissemination Center for Children with Disabilities: www.nichcy.org

US Social Security Administration: www.ssa.gov

The information contained in this publication should not be used as a substitute for the medical care and advice of your pediatrician. There may be variations in treatment that your pediatrician may recommend based on individual facts and circumstances.

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Adapted from the Autism Society of America: *Living with Autism*. Available at: www.autism-society.org. 800/3AUTISM (800/328-8476)

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OVERVIEW OF IDEA AND SECTION 504

CENTER FOR AUTISM SPECTRUM DISORDERS, CHILDREN'S NATIONAL MEDICAL CENTER

Although parents of children with disabilities are typically more familiar with the Individuals with Disabilities Education Act (IDEA), they should also be aware of Section 504 of the Rehabilitation Act of 1973, **as some kids with special needs do not receive services under IDEA (i.e., IEP), but are served under what is called a "504 plan."** Knowledge of both statutes, and particularly what they encompass, is often necessary when securing an appropriate education for one's child. An understanding of the provisions of these two laws and how they differ can help you and your child's school/ teachers outline the most appropriate education for your child.

IDEA

By federal law, every child with a disability is entitled to a free and appropriate public education (FAPE) that meets his individual needs. The Individuals with Disabilities Education Act (IDEA) is a federal act that governs all special education services and provides some funding to state and local education agencies. The purpose of the act is to guarantee special education and related services for those students with disabilities. **IDEA requires a school district to provide an individual education program (IEP).** The IEP's purpose is to provide 'Educational Benefit' to students who meet criteria for eligibility in any of the following distinct categories of disability:

- Intellectually Handicapped
- Learning Disabled
- Behavior Disordered
- Communication Disordered
- Other Health Impaired
- Hearing Impaired-Hard of Hearing
- Visually Impaired
- Multi-Handicapped-Deaf/Blind
- Hearing Impaired -Deaf
- Developmentally Delayed-Preschool
- Visually Impaired
- Traumatic Brain Injury
- Autism

SECTION 504

Section 504 is a civil rights law that protects the rights of individuals with disabilities in programs and activities that receive or benefit from federal financial assistance. Section 504 does not require the federal government to provide additional funding for students identified with special needs. Although it does not provide or allocate finances for qualifying children, Section 504 does outline potential consequences for noncompliance. For example, a school that is found by the Office of Civil Rights (OCR) to be out of compliance with Section 504 may lose its federal financing.

Section 504 states that schools must provide children with special needs with reasonable accommodations to those provided to their peers. In other words, it "**levels the playing field**" for children with disabling conditions, so that they may appropriately access their education. **Section 504 requires a written accommodation plan.**

A student is eligible as long he/she currently has or has had a physical or mental impairment which substantially limits a major life activity, even with the help of medication or aids/ devices. Major life activities include:

- walking
- seeing
- hearing
- speaking
- breathing
- learning
- working
- caring for One's self
- performing manual tasks

Some examples of possible 504 disabilities are:

- Attention Deficit /Hyperactivity Disorder
- Arthritis
- Asthma
- Cancer
- Communicable Diseases: HIV, TB
- Physical Disabilities
- Temporary Disabling Conditions
- Mental illness

Components of this handout were obtained from the following:

- www.idonline.org/article/Understanding_the_Differences_Between_IDEA_and_Section_504
- [Understanding the Differences Between IDEA and Section 504. Teaching Exceptional Children, v.34\(3\).](#)

IDEA VERSUS SECTION 504: EXPLORING THE DIFFERENCES

Flexibility of procedures is often considered the major difference between IDEA and Section 504. Although in many ways IDEA is oftentimes more comprehensive in terms of depth and structure (i.e., accountability), Section 504 is more comprehensive in terms of breadth.

1. Eligibility criteria and compliance regulations: For a child to be identified as eligible for services under Section 504, there are less specific procedural criteria that govern the requirements of the school personnel. Schools may offer a student assistance if a disability/ disorder impacts any of his 7 major life activities; however, they may offer less assistance and monitoring (as compared to IDEA) because there are fewer regulations by the federal government to instruct them, especially in terms of compliance/ accountability.

In contrast, a child identified for services under IDEA must meet *specific* criteria and in turn the school is then *accountable* to provide these services (at their cost). In addition, the degree of regulation is more specific in terms of measurable goals (i.e., demonstrable progress), time frames, parental participation, and formal paperwork requirements (e.g., educational goals).

2. Age of inclusion: IDEA covers children from preschool to graduation (from ages 3 to 21). Section 504 covers the lifespan.

3. Protected settings: IDEA addresses the special education of students with disabilities; whereas, Section 504 safeguards the rights of persons with disabilities in across multiple areas of their lives, including employment, public access to buildings, transportation, as well as education.

4. Identification: In order for children with disabilities to receive services under IDEA or 504, they must be identified and then determined to be eligible for assistance/services.

Under IDEA guidelines, school districts are required to identify and evaluate all children suspected of having a disability whose families reside within the district. IDEA covers all school-aged children who fall within one or more specific categories of qualifying conditions (See the handout: Overview of IEP and Section 504 for more information).

Section 504 does not require identification (e.g., Child Find) or evaluation. It covers individuals who meet the definition of qualified "handicapped" person (See the handout: Overview of IEP and Section 504 for more information).

5. Eligibility: IDEA requires that a child's disability adversely affects his/ her educational performance.

Section 504 does not require that a child need special education to qualify. Note: Students who are ineligible for services or are no longer entitled to services under IDEA may be entitled to accommodations under Section 504.

6. Evaluation:

IDEA

- Requires that a child with a disability be fully and comprehensively evaluated by a multidisciplinary team to determine what services, if any, are needed.
- Requires informed and written parental consent.
- Requires a reevaluation of the child at least once every three years, or if conditions warrant a reevaluation, or if the child's parent or teacher requests a reevaluation.
- Provides for independent evaluation at the district's expense if parents disagree with first evaluation (restrictions apply).
- Does not require reevaluation before a significant change in placement.

Section 504

- Draws on information from a variety of sources and is documented.
- Decisions about the child, evaluation data, and placement options are made by knowledgeable individuals. Such decisions do not require written consent of the parents, only that the parents are notified.
- Requires "periodic" reevaluation.

- No provisions made for independent evaluation at school's expense.
- Requires reevaluation before a significant change in placement.

7. FAPE responsibilities: (*FAPE is an acronym for Free and Appropriate Education*)

IDEA

- Requires an individualized education program (IEP).
- "Appropriate" education is defined as a program designed to provide "educational benefit" for a person with disabilities.
- Placement may be any combination of special education and general education classrooms.
- Provides related equipment and services, if required. Related services may include speech and language therapy, occupational therapy, physical therapy, counseling services, psychological services, social services, and transportation.

Section 504

- Does not require an IEP, but does require a plan.
- "Appropriate" means an education comparable to the education provided to those students who are not disabled (i.e., "leveling the playing field").
- Placement is usually in a general education classroom. Children can receive specialized instruction, related services, or accommodations within the general education classroom.
- Provides related services, if needed.

8. Due process procedures: When parents and school districts disagree about how a child with disabilities should be educated, there are procedures in place to handle these disagreements.

IDEA

- Must provide impartial hearings for parents who disagree with the identification, evaluation, or placement of the student.
- Requires written consent.
- Describes specific procedures.
- An impartial appointee selects a hearing officer.
- Provides "stay-put" provision (the student's current IEP and placement continues to be implemented) until all proceedings are resolved.
- Parents must receive ten days' notice prior to any change in placement.
- Enforced by U.S. Department of Education, Office of Special Education.

Section 504

- Must provide impartial hearings for parents who disagree with the identification, evaluation, or placement of the student.
- Does not require parental consent.
- Requires that parents have an opportunity to participate and be represented by legal counsel (details left to the discretion of the school).
- A hearing officer is usually appointed by the school.
- No "stay-put" provisions.
- Does not require that parents are notified prior to the student's change of placement, but they still must be notified.
- Enforced by U.S. Department of Education, Office of Civil Rights (OCR).

Additional information can be obtained from the following websites:

www.wrightslaw.com/advoc/articles/504_IDEA_Rosenfeld.html

www.wrightslaw.com/info/sec504.summ.rights.htm

www.idonline.org/article/6086

www.kidsource.com/kidsource/content3/ada.idea.html

www.nldline.com/iep_vs_504.htm

www.ncld.org/at-school/your-childs-rights/iep-aamp-504-plan/section-504-and-idea-comparison-chart

Components of this handout were obtained from the following:

- www.idonline.org/article/Understanding_the_Differences_Between_IDEA_and_Section_504
- [*Understanding the Differences Between IDEA and Section 504. Teaching Exceptional Children, v.34\(3\).*](#)

WHAT IS AN IEP?

(By Jan Baumel, M.S. and the National Center for Learning Disabilities (NCLD) via the website www.nclld.org, originally published: February 24, 2009)

Each public school child who receives special education and related services must have an individualized Education Program (IEP). Each IEP must be designed for one student and must be a truly individualized document. The IEP creates an opportunity for teachers, parents, school administrators, related service personnel, and students (when appropriate) to work together to improve educational results for children with disabilities.

To create an effective IEP, parents, teachers, other school staff and often the student must come together to look closely at the student's unique needs. These individuals pool knowledge and experience to design an educational program that will help the student be involved in, and progress in (as demonstrated via measurable goals), the general curriculum. The IEP guides the delivery of special education supports and services for the student with a disability.

Overview of General Steps in the Special Education Process

1. Child is identified as possibly needing special education and related services
2. Child is evaluated
3. Eligibility is decided (if the child is found eligible for services, the IEP process continues)
4. IEP meeting is scheduled
5. IEP meeting is held and the IEP is written
6. Services are provided
7. Progress is measured and reported to parents
8. IEP is reviewed
9. Child is reevaluated

Contents of the IEP

By law, the IEP must include certain information about the child and the educational program designed to meet his or her unique needs. This information covers topics such as current performance, annual (measurable) goals, special education and related services, accommodations, participation in state and district-wide tests, needed transition services, and measured progress.

Writing the IEP

A meeting to write the IEP must be held within 30 calendar days of deciding that the child is eligible for special education and related services. Each team member brings important information to the IEP meeting. Members, share their information and work together to write the child's individualized Education Program.

To help decide what special education and related services the student needs, generally the IEP team will begin by looking at the child's evaluation results, such as classroom tests, individual tests given to establish the student's eligibility, and observations by teachers, parents, paraprofessionals, related service providers, administrators, and others. This information will help the team describe the student's "present levels of education performance" in other words, how the student is currently doing in school. Knowing how the student is currently performing in school will help the team develop annual goals to address those areas where the student has an identified educational need.

The IEP team must also discuss specific information about the child.

This includes:

- The child's strengths
- The parents' ideas for enhancing their child's education
- The results of recent evaluations or reevaluations
- How the child has done on state and district-wide tests

- Depending on the needs of the child, the IEP team also needs to consider special factors, which include behavioral issues, limited proficiency in English, blindness or visual impairment, communication needs, deafness or difficulty hearing, and assistive technology.

It is important that the discussion of what the child needs are framed around how to help the child do the following:

- Advance toward the annual goals
- Be involved in the progress in the general curriculum
- Participate in extracurricular and nonacademic activities
- Be educated with and participate with other children with disabilities and non-disabled children

This information is then used to *determine and outline* the services and supports the school will provide for the child, including particular devices or services (including an intervention, accommodation, or other program modification).

After the IEP is Written

When the IEP has been written, parents must receive a copy at no cost to themselves. Everyone who will be involved in implementing the IEP or who is responsible for aspects of the child's education must have access to the document, including the child's regular education teacher(s), special education teacher(s), related service provider(s) (e.g., speech therapist), or any other service provider (e.g., paraprofessional). Each of these individuals needs to know what his/ her specific responsibilities are for carrying out the child's IEP, including accommodations, modifications, and supports that they are expected to provide.

Parents Permission

Before the school can provide a child with special education and related services for the first time, the child's parents must give their permission.

Adapted from the Guide to the Individualized Education Program by the Office of Special Education and Rehabilitative Services, U.S. Department of Education.

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IEP MEETING PLANNER

Comprehensive information about how best to prepare for the IEP process can be obtained from the National Center for Learning Disabilities: IDEA Parent Guide. Among the chapters included in this invaluable resource is an IEP planner, which can be found via the web at <http://www.nclld.org>

The following is a condensed version of this planner, which is designed to assist you in getting the most out of your child's IEP meetings:

- 1. Visit your child's classroom:** If your child is elementary age, you should consider visiting the classroom to observe how your child is performing in class, classroom conditions and routines, instructional materials being used. Classroom visits should be arranged in advance with the teacher and school officials.
- 2. Review/ organize** (preferably in a 3-ring binder) **your child's records.** Compile the following and take them with you to the IEP meeting.
 - Your child's current IEP
 - Reports of progress toward the annual goals in your child's current IEP
 - Report cards for current school year
 - Recent work samples
 - Performance on district and/or state assessments (If your child is participating in district and/or state assessments in an alternate manner, be sure to get information on how your child is performing in relative to same-grade peers, as results on alternate assessments/ out-of-level assessments do not provide information on your child's performance compared to other students at his/her grade level.)
 - Results of most recent evaluation(s) (If your child has recently received an individual evaluation, be sure to request a copy of the evaluation report prior to the IEP meeting. If you have had your child evaluated privately, it is best to share the results of the evaluation with school personnel prior to the IEP meeting.)
 - If your child has a job outside the home, bring copies of letters or reviews from supervisors.
 - Any other communications with the teacher and/or school.

NOTE: you have the right to inspect and review any education records relating to your child that are collected, maintained, or used by the school district. You may also request a copy of your child's educational records at any time.

- 3. Collect district data:** Compile the following information to help guide and inform you about your districts policies and procedures:
 - Make sure you have a copy of the current Procedural Safeguards Notice for your school district. Note: Schools are no longer required to provide a copy of this notice with each IEP meeting notice.
 - In order to make important decisions about how your child will participate in required district and/or state-wide assessments (such as those required by the No Child Left Behind Act) request complete information on those assessments, including information about the type of test, when it is administered and sample questions. Also request information about alternate assessment options and information about how participation in an alternate form of assessment might impact your child. Request state guidelines for test accommodations: This will help you determine what your child will need in order to participate in required district and/or state-wide assessments (such as those required by the No Child Left Behind) request a copy of your state's guidelines on test accommodation. Every state is required to have such guidelines. The guidelines should include information regarding any accommodation that would invalidate the scores.
 - Request a copy of your school's IEP form from your school or district special education office. Most school districts (or states) have developed IEP forms that are used to compile a student's individualized program. Become familiar with your school's form prior to the meeting so you will know what information will be included and how the IEP will be developed.
- 4. Network:** Join local chapters of parent groups that offer information about your child's specific disability. Contact your state Parent Training and Information Center for information on your state's special

education laws or regulations. Attend training and support groups that will help you understand ways to use your rights under IDEA.

5. **Request and review notice of meeting:** You should be given written notice of the proposed IEP meeting, preferably at least 10 days in advance. The notice should include the date, time, purpose of the meeting and those expected to attend. Use this meeting notice to ensure that:
 - The date and time are convenient for you and others you plan to have attend (advocate, private tutor, private evaluator)
 - If your child will turn age 16 (or older) during the period of the next IEP, or if you feel that transition planning should begin with the next IEP (regardless of your child's age), both your child and any appropriate representatives from other agencies are invited to attend.
 - All appropriate school personnel are listed as expected to be in attendance. See team excusal below for additional information.

6. **Approve or reject proposed IEP team member excusals:** Your IEP meeting notice should indicate if the school proposes to excuse a team member from attending either the entire meeting or part of the meeting.
 - It should indicate whether the member's area of curriculum or related services is: (1) not being modified or discussed in the meeting or (2) is being discussed and the member will submit written input to the parents and the team prior to the meeting. Written input from an excused member should be provided well in advance of the meeting in order to allow time for your review and acceptance. If you determine that the written input is not sufficient advise the school that you expect the member to attend the meeting
 - If you disagree with the proposal to excuse a member because you think their area of curriculum or related services *should be* discussed, inform the school that you do not agree with the proposed excusal and you expect the member to attend the meeting.
 - For best results, members of the IEP team who should not be excused under any circumstances include: (1) The district representative (knowledgeable about the availability of the school district's resources) and (2) The regular education teacher.

7. **Request alternative means of meeting attendance:** If you or others you want to attend the meeting cannot attend on the proposed date and time, you can propose alternative forms of meeting attendance such as audio conference calling or video conferencing. Be sure to make your request for such alternative meetings well in advance so the school can provide the necessary equipment.

8. **Develop your Parent Report**, which should include:
 - Your impressions of how your child is doing in school. Include both academic performance as well as social, behavioral and functional performance (include work samples and/or school reports that substantiate your comments and concerns)
 - Your child's strengths and weaknesses
 - Your comments or concerns regarding your child's attainment (or lack of attainment) of the annual goals on the current IEP
 - Your input regarding particular strategies that are or are not working for your child.
 - Your input regarding other areas such as behavior plans and/or technology that might help support your child's learning.
 - The amount of progress you want to see your child make in the coming year (progress should be adequate to allow your child to make up for significant gaps in achievement vs. same age/grade students.)
 - Any particular methodology you think would be well suited for your child given his/her particular difficulty or deficit, age, learning style. Special education and related services must be based on peer-reviewed research whenever possible.
 - If your child's IEP also includes a transition plan, include information about your child's postsecondary goals (college, vocational interests, possible career choices.)

Note: You can share your Parent Report with school personnel before or at the IEP meeting. Sharing it before the meeting will allow school personnel the opportunity to review your report and include information you have submitted in the IEP.

9. **Request IEP draft:** Many schools accomplish some advance work on developing student IEP's by doing a "draft" which will then be reviewed at the meeting. If this is the practice of your school district, request a copy of the "Draft" prior to the meeting so you have time to review it. (Note: "draft IEP" are just that – drafts to help facilitate the meeting. Completing IEPs prior to the meeting violates the IDEA. Don't be intimidated by "draft" IEPs – instead, consider it an extra opportunity to see the thinking of the IEP team members in advance. You will provide your comments and concerns about any "draft" and you should expect a final IEP to be produced at the official IEP Meeting.)
10. **Arrive early:** Arrive at least 15 minutes prior to the time your meeting is scheduled to begin. Provide any persons you have invited to attend the meeting with a copy of your child's current IEP, your Parent Report, and your suggested annual goals.
11. **Remain calm:** IEP meetings can be stressful and emotional; above all, you must be: Cooperative, Respectful, Calm, and Positive
12. **Name a note taker:** Unless you plan to tape record the meeting, you will need to take detailed notes. If note taking is hard for you to do while participating in the discussion, designate one of your invitees to be the note taker for the meeting.
13. **Request introductions:** Ask everyone at the meeting to introduce themselves and explain their role in the meeting. Have anyone you have brought to the meeting introduce themselves, and explain their relationship to your child. Be sure to record this information in your meeting notes.
14. **Review your parent report:** If you haven't shared your Parent Report with school personnel prior to the meeting, review it at this point. Your input should be incorporated into the school's information to complete your child's Present Level of Performance. (PLOP)
15. **Develop all required IEP components:** The IDEA requires several components to be a part of every IEP. Be sure that each component is discussed and included. Make sure that all agreed upon services are written in the IEP document. Keep in mind that goals have to be "measurable," as such it make take time to determine how to appropriately and effectively do this.

Note: While some services, such as accommodations, might be "standard practice" in many schools or classrooms, the IEP should reflect all special education, related services, supplemental aid; and services, modifications, accommodations (classroom and testing) that will be provided.

16. **Finalize the IEP:** You don't have to sign the IEP at this meeting. If you want to review the IEP first, ask to take it home before you sign it. Be sure your signature indicates what you intend to mean, such as attendance, agreement, partial agreement, refusal. Provide any concerns you have about the proposed IEP to the school in writing. If you object to the proposed IEP or any part of the proposal explain the reasons for your objection. Ask that your written concerns be attached to the proposed IEP.
17. **Explain changes to your child:** If your child didn't attend the IEP meeting, explain any changes that will be made to the child's current program or placement and the reasons for the changes. Don't let your child be surprised by changes agreed upon in the IEP. Knowing what to expect will help ensure success.
18. **Monitor progress:** While the school is required to provide you with regular progress reports (generally at each grading period) you can request more frequent progress reports. Progress reports should be based on objective information, not teacher opinion or observation. Work samples and performance on district or state assessments should be compared to the progress reported on the IEP progress reports. If progress reports show significant progress or a substantial lack of progress, the IEP goals(s) should be discussed and the instructional program in use should be reviewed.
19. **Meeting more than once a year:** While each student's IEP must be reviewed and updated at least annually, you can request an IEP meeting at any time. If progress is slow or other issues, such as behavior, need to be addressed, request an IEP meeting in writing.

This information has been adapted from the National Center for Learning Disabilities: IDEA Parent Guide (www.ncl.org/images/stories/Publications/AdvocacyBriefs/IDEA2004ParentGuide/Idea2004ParentGuide.pdf).

IEP MEETING CONVERSATION BARRIERS

Some of the statements made to parents at IEP Meetings are "conversation stoppers" or comments that create barriers that prevent the IEP Team from working cooperatively to develop effective special education services and supports for students with disabilities. Below are several common "conversation stoppers," some information about what may be the real issues of concern, and suggestions for how parents can respond in a forceful but respectful way so that planning for their child can move forward.

Stopper # 1: "The general education teacher could not be here today."

What is the issue?

The vast majority of children with disabilities spend most or all of their school day in general education activities or classrooms. It is essential that the general education teacher be an active IEP team member. This does not mean that parents should expect teachers to leave their classrooms for long periods of time. However, it is reasonable to expect the general education teacher to attend IEP meetings to contribute expertise in getting academic, behavioral and social goals, to advise the team about curriculum and help identify where and when adaptations and accommodation will be needed so that your child can be successful in the general classroom and have meaningful access to the general education curriculum.

Here are possible responses:

"Child is one of Miss Teacher's students and we think she is doing very well. However, I have no idea if the goals, accommodation and other supports we are suggesting are going to be helpful to Miss Teacher in adapting the curriculum and classroom activities so Child can be successful. We need to schedule another IEP Meeting so that Miss Teacher can attend for at least part of the time."

"This is the first year my child has been spending a lot of time in a general classroom. I do not want to have IEP meetings without my child's general education teacher. We can complete the main parts of the IEP and give a draft to Mr. Teacher, but then we will need to schedule another IEP Meeting that includes him so that our team is complete."

Stopper #2: "We have developed our own reading curriculum for this reading class."

What are the issues?

Unless the curriculum, which is defined as the content and the methodology used to teach that content – has been shown to have produced positive learning outcomes for all students or for students with disabilities, there are legitimate questions that parents and other IEP members must raise. Specifically, IDEA now requires that services provided to students under the IEP must be based on peer-reviewed research. Peer-reviewed research is that which has been reviewed by other education experts and can be applied to other situations, can be tested with other groups of children and can be built upon by other researchers.

Here are possible responses:

"Our job as an IEP Team is to make sure that the curriculum that is used for Child's instruction is based upon solid education research. If there is a particular curriculum used at this school or in this program, then I would like to see the research that proves that the curriculum has been successful in meeting the instruction needs of students like Maria before we can agree."

"The research on reading indicates that a reading program needs to contain several essential components – Phonemic Awareness, Phonics, Fluency, Vocabulary and Reading Comprehension – to be effective for most children. Can you provide us with independent research which shows that your reading program adequately provides each of the required components?"

Stopper #3: "Although your child has a clinical diagnosis, his education is not being adversely impacted, as noted by his overall grade level performance."

What are the issues?

The law no longer defines "educational impact" as only reflected by performance on objective academic measures. For example, educational impact also includes an inability to attend to lectures, independently complete assignments, or failing grades. Once you determine that your child's education is being impacted by

their disability, marshal the evidence. Make copies of teacher reports that document these observations and ensure that any recent evaluations clearly outline evidence of the broader education impact.

Here are possible responses:

"I understand that Child is overall performing on grade level; however, his teacher consistently reports that he is unable to independently attend to lectures and complete assignments; as such, he is clearly not able to access his education on a consistent basis. Therefore, I would like him to be provided the following supports and services."

Stopper #4: "We'll be using teacher observation to measure progress toward your child's annual IEP goal."

What is the issue?

Reporting of progress toward the achievement of each annual goal is designed to provide parents with interim reports about how their child is doing. To be accurate, such reports must be based on "objective measures." This means that there must be something besides what the teacher thinks or sees to determine progress. An objective measure might be counting the number of times your child successfully completes a class assignment, a simple weekly checklist of sight words recognized or a more formal assessment tied to your child's goals. While a structured observation by the teacher or another member of the school staff can be one way to measure progress, teacher observations cannot serve as the only measure of progress. Another issue that might be causing this conversation stopper is that the goals may not be written very well. Check to see if the goals in your child's IEP are written so they can actually be measured objectively, as well as monitored at regular (i.e., 6 month) intervals.

Possible responses are:

"It's not going to be possible for me to know if Child is making progress unless we have some objective measures written into her IEP. What other measures can we use to track her progress toward reaching these annual goals?"

"We need to think about some more formal ways of measuring Child's progress. Sometimes it takes quite a while for Child to learn new material. I need to know what assessments we are going to use to ensure that she is mastering the really important skills on this IEP".

Stopper #5: "Your child's behaviors are disrupting the classroom."

What are the issues?

Concerns about your child's behavior should not be introduced for the first time at the IEP meeting. Students benefit most when teachers and parents communicate frequently and share concerns or problems when they happen. Students with disabilities may have difficulty communicating their wants and needs, may not like "letting go" of an activity they enjoy, or may challenge adults when "beginning" an activity they don't like or have failed at in the past. Many students need help preparing for transitions throughout the day or in learning how to get positive attention from friends or teachers. Some children with special needs can engage in challenging behavior when they are upset or angry. It is very important for the IEP Team to respond to problem behaviors immediately, and to bring additional professional help to the school to do functional behavior assessments so that positive goals, interventions and support strategies can be developed for school and home.

Here are possible responses:

"Child's behavior can be disruptive at home too. But we know that when Child feels like he is communicating his wants and needs and when he is not frustrated, his behavior is much better and is not disruptive. I need the IEP Team to help everyone understand why Child has hard days sometimes and what we can do to help him improve his communication, his response to instructions and his social skills."

"Child has a lot of strengths. He loves music, he is funny and enjoys humor, and he really tries hard to do what his teachers and we expect him to do. He wants very much to be with other boys his age and socialize. Why can't we use Child's strong skills and the things he really likes to do to help him get better at handling the things that frustrate or upset him?"

Stopper #6: “Our district doesn’t put technology into the IEP.”

What are the issues?

This statement is incorrect. IDEA provides for technology services as part of students’ special education programs. What this kind of statement may communicate is that the IEP team members are not certain what type of technology is available, how to get it, or how to use it. For students with significant learning, communication, sensory, cognitive, or physical disabilities, the use of technology to assist teaching and learning can make the difference between accessing genuine opportunities for literacy and higher-level academics and a school day that is limited to low level functional, redundant activities. In this case an adaptive evaluation would be appropriate, especially for younger children. Moreover, be sure to write into the IEP technological instructional and goals that include consistent and appropriate use of the technology.

Possible responses are:

“I am sorry, but Child needs to have word prediction software to improve his written language skills. My concern is that if we do not write this into the IEP he will not get it. If you would like information on where you can find this type of software for Child, I have it at home and can send it in or call you with the information.”

Stopper #7: “We can’t give your child special education services if you don’t sign this IEP.”

What is the issue?

IDEA outlines when parents have to give written consent (or permission) for special education services. You must give written permission for your child to be evaluated to determine if your child is eligible for special education or for your child to receive special education services in the first or “initial” IEP team meeting. However, your signature on IEP documents after that “initial” IEP that you participated in developing the IEP. If you and the team disagree about some part of the IEP, it’s best to either schedule another meeting to continue to discuss the issues or simply sign your name with a sentence stating that you participated in the IEP meeting. Provide the school with a written report stating your objections and ask that it be attached to the proposed IEP.

Possible responses are:

“I am not ready to accept the entire IEP as written. I will sign that I participated in this meeting, but we will need to meet again to see if we can come up with a program that meets my child’s needs.”

“Actually, it is not necessary for me to sign the IEP document. If the school district has a policy about parents signing their child’s IEP or losing services, I would like to see a copy of that policy.”

This information has been adapted from the IEP Pop-Up tool developed by the Center on Low Incidence Disabilities, Families for Hands & Voices and TASH (<http://www.NILID.unco.edu>) and from the National Center for Learning Disabilities: IDEA Parent Guide, available at <http://www.nclld.org/images/stories/Publications/AdvocacyBriefs/IDEA2004ParentGuide/Idea2004ParentGuide.pdf>

Chart Your Own Future: How Your Individualized Education Program (IEP) Can Help

What will you be doing after high school? Where will you be working, going to school, or living? What kind of life do you want? Your transition IEP can help you answer these questions and help you live your life to the fullest.

What is an IEP? An IEP is an education program written just for you. That is why it is called “individualized.” It is based on your strengths, interests, and goals regarding education, employment, and daily living skills.

Taking an active role in developing your IEP is important. Doing so will help you:

- Gain the information, skills, and support you need to reach your future goals
- Start turning your dreams into your life
- Discover what really matters to you
- Have more control over your time and activities at school

Although you cannot control every aspect of your school education, you do have the power to make changes in your education program. As you influence major parts of your IEP, you gain more freedom and more control over what happens to you. You have a lot more power than you might think.

Three Easy Steps to Becoming Involved in Your IEP

Here are a few ideas to help you take ownership of your IEP. You may want to discuss them with a friend or family member.

1. Start thinking about what you want in life. Planning for the future is exciting. You can begin to think about what skills and interests you have now and what ones you would like to develop. As you start planning, you might consider:

- What you like to do now
- What you think you would like to be doing five years from now

- What you are good at now
- What you would like to be good at in five years
- What excites you now
- What you think will excite you five years from now

As your dreams and visions become clearer to you, talk with your family or friends about your plans. Listen to their ideas. You might want to add some of their thoughts to your plan.

2. Set one goal at a time. To make the planning process more manageable, pick one goal that is important to you. Discuss it with a relative or friend and then with your special education teacher. Have them help you break your goal into small, practical steps that you can start taking now. For example, if your goal is to continue your education, you might want to visit some colleges, technical schools, or certificate programs to see how they fit into your future dreams.

Don't worry if you feel confused while you are making decisions about your future education, employment, and housing. Everyone feels that way. It takes time and insight to figure it all out. If you are like most people, your plans will change many times as you learn more about yourself.

3. Know who can help you. Everybody needs someone who will listen to their future plans, offer suggestions, help sort through options, and find creative solutions to possible barriers. Who in your life can do that for you?

Make a list of their names, addresses, phone numbers, e-mail addresses, and descriptions of how they might be able to help you reach your goals.

For example:

- A cousin could be visited at a college you are thinking of attending.
- A neighbor might allow you to volunteer

at her daycare.

- Your older brother or sister might invite you to go apartment hunting with them.
- A family friend could show you how he runs a small lawn care business.

At your next IEP meeting, you could show your team and supporters what you've learned about your future options. You could:

- Invite everyone on your IEP team and your list of important people.
- Show pictures, a video, or a PowerPoint presentation summarizing what you did to explore possibilities.
- Invite your employer, volunteer supervisor, or friend to give his or her views at the meeting.

Learn More about Planning for Your Future

You can find out more about using your IEP to help you plan for your future by checking out these helpful resources for teens and families.

For Teens:

www.youthhood.org

This site for teens was developed by the National Center on Secondary Education and Transition (NCSET), headquartered at the University of Minnesota.

www.efoliominnnesota.com

This multimedia electronic portfolio helps you create a showcase of your education, career, and personal achievements. It's provided by the Minnesota State Colleges and Universities in partnership with state workforce and education organizations.

Wishcraft: How to Get What You Really Want by B. Sher & A. Gottlieb (2003). Ballentine Books and Random House, Inc., NY

This book is an excellent resource on planning for the future. Available at www.amazon.com.

For Families:

A Student's Guide to the IEP and Helping Students Develop Their IEPs

These helpful publications from the National Dissemination Center for Children with Disabilities (NICHCY) can be downloaded for free or purchased for a nominal fee. Available at www.nichcy.org

How Can My Child be Involved in the IEP Process?

This helpful PACER Center handout can be downloaded for free. Available online at www.pacer.org/parent/php/PHP-c77.pdf

Creating Your High School Portfolio: An Interactive School, Career, and Life Planning

Editors of JIST. (2003). JIST Publishing Inc., Indianapolis, IN

Through interactive activities, students learn to state, clarify, and explore their values, interests, abilities, and goals. The workbook helps students make informed decisions about their educational and career goals after high school. Available at www.amazon.com.

Making it Happen: Student Involvement in Education Planning, Decision Making, & Instruction by D. J. Sands & M.L. Wehmeyer, (Eds.). (1998). Baltimore: Paul H. Brookes.

While mainly for educators, this book outlines the steps that families and teachers can take to ensure active student participation in education planning and decision making. Available at either www.amazon.com or www.brookespublishing.com.

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My son/daughter has an autism spectrum disorder. Autism spectrum disorders are lifelong neurological disabilities caused by physical differences in the brain. They are not caused by poor parenting. People with autism spectrum disorders often exhibit unusual behaviors not because they are being difficult or defiant, but rather because they are just being themselves. There is no magic "cure" for autism spectrum disorders, but your understanding and attention can make a huge difference.

The following features of autism spectrum disorders present a challenge for my son/daughter at school (check all that apply):

- Delayed social skills (difficulty making friends and working in groups)
- Difficulty interpreting gestures and facial expressions (may not understand pointing, stomping foot, etc.)
- Unusual or inappropriate facial expressions (may laugh when an adult is angry at him/her)
- Avoidance of eye contact (downward gaze does *not* imply guilt or disrespect)
- Poor judge of personal space (may stand too close to other students)
- Trouble controlling emotions and anxieties
- Difficulty understanding another person's perspective, or how their own behavior affects others
- Frequent target for teasing and bullying; naïve; difficulty with pretend play
- Misinterprets friendly teasing as bullying; overreacts
- Delays in expressive language (has trouble verbalizing what s/he means)
- Delays in receptive language (has trouble understanding what is said to him/her)
- Very literal understanding of speech; difficulty with sarcasm, metaphors, innuendos, and irony
- Echolalia (may repeat last words heard without regard for meaning; may recite memorized lines from movies or television shows without intending to be disrespectful or disruptive)
- Unusually intense or restricted interest in _____ (e.g. maps, dates, coins, numbers, train schedules)
- Unusual repetitive behavior (hand flapping, rocking, reciting memorized phrases)
- Inflexibility (often gets "stuck" on a problem, can't shift to new problem-solving strategies or move on)
- Difficulty with transitions, need for sameness (e.g. slow to pack up books and move to the next class)
- Rigid adherence to rules; upset by changes in schedule (e.g. upset by a teacher's absence)
- High or low sensitivity to physical sensations (like lights, smells, tastes, tags in clothes, etc.)
- Trouble interpreting and communicating discomfort like hunger and pain
- Possible aggressive, disruptive, or self-injurious behavior; unaware of possible dangers
- Other: _____

His/her IEP accommodations include (check all that apply):

- Portable note-taking device or laptop
- Calculator
- Visual/graphic organizer
- Teacher facilitation of group or partner assignments
- Visual schedule
- Preparation for transitions
- Extended time to complete tests and assignments
- Multiple or frequent breaks for tests and assignments
- Reduce distractions to student (e.g. seating at the front of the class)
- Give written notes, outlines, and instructions
- Give short and simple directions with examples
- Give positive verbal and nonverbal reinforcement
- Other: _____

Other difficult situations and helpful strategies for my son/daughter include:

Parent Contact Information:

Cell _____ Work _____ Home _____ Email _____



PART IV: FURTHER INFORMATION

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STATE AND LOCAL RESOURCES

CENTER FOR AUTISM SPECTRUM DISORDERS, CHILDREN'S NATIONAL MEDICAL CENTER

The federal **Individuals with Disabilities Education Act (IDEA)** requires states to identify, locate, and evaluate all children with disabilities, aged birth to 21, who are in need of early intervention or special education services. Children from birth to age 3 generally are served by Early Intervention Programs mandated by Part C of IDEA, while children age 3 to 5 are served by Preschool Special Education services mandated by Part B/619 of IDEA. Each state has different eligibility requirements and lead agencies for these programs. For more information about IDEA programs for children age 5 and under see: www.childfindidea.org. Children with disabilities over age 5 are generally evaluated by the local school system.

Contact information for these IDEA-mandated programs in DC, Maryland, and Virginia, as well as other relevant state and local resources, are provided below.

MULTIPLE LOCATIONS

Autism Society of America Local Chapters

These support and advocacy groups are generally led by parent volunteers. See www.autism-society.org/site/PageServer?pagename=community_chapters to find your local chapter.

The ARC

Formerly known as the "Association for Retarded Citizens," the ARC has state and local chapters to support individuals with intellectual and developmental disabilities and their families. Go to www.thearc.org and click "Find a Chapter" in the left column.

Jewish Social Services Agency

Family Coordination programs, social skills groups, and other services for individuals with ASDs and their families. www.jssa.org.

DISTRICT OF COLUMBIA

DC IDEA program for children 0-3 years old: Infants and Toddlers with Disabilities Division

To make an intake screening appointment, contact the "Single Point of Entry" 24 hour phone line at 202-727-3665 (voice) or 202-724-7230 (fax). Fact sheets on frequently asked questions and families' rights in the early intervention system can be found at: www.osse.dc.gov/seo/cwp/view,a,1224,q,562131.asp.

DC IDEA program for children 3-5 years old: Early Stages

Early Stages is the District of Columbia's federally mandated Child Find program. Call 202-698-8037 for an intake screening appointment. www.earlystagesdc.org.

DC Quality Trust for Individuals with Disabilities

"Our vision is a city-wide system that affords individuals with developmental disabilities universal access to high quality, person-centered services and supports, regardless of the extent or severity of their needs. We will accomplish our vision through ensuring effective advocacy, monitoring, legal representation, family and advocate support, and by acting as a catalyst for positive change among all stakeholders in the District of Columbia's intellectual and developmental disabilities service system." www.dcqualitytrust.org.

Advocates for Justice and Education

"A.J.E. uses parent empowerment as a model to address grave injustices in the delivery of services to meet the most basic special education needs. AJE was formed to motivate and educate parents, and those working with parents about the laws that govern special education and related services, and the consequences of institutional negligence and/or inappropriate classification of students with special needs." www.aje-dc.org.

Children's Law Center

"Children's Law Center's Systemic Advocacy team draws on our experience representing individual children and families to advocate for laws, policies and programs that improve the lives of neglected children and children with special education and health care needs citywide." www.childrenslawcenter.org.

DC Autism Parents

Email: info@dcautismparents.org; phone: 202.271.9262; www.dcautismparents.org.

MARYLAND

Maryland IDEA program for children 0-3 years old: Infants and Toddlers Program

To make an intake screening appointment, contact the "Single Point of Entry" for your county:
http://www.msde.maryland.gov/MSDE/divisions/earlyinterv/infant_toddlers/directories/single_point_entry.htm.
Phone: 410-767-0261 or 800-535-0182.

Maryland IDEA program for children 3-5 years old: Child Find

To make an intake screening appointment, contact the local school system Child Find office from the list available at: http://mdecgateway.org/olms/data/resource/4798/LITP_LSSPtofEntry_ChildFindPhoneList.pdf.

Maryland Autism Waiver

Waiver participants are eligible for a variety of services, such as respite care, environmental modifications to their home, and family training. The waiver is currently full. The wait is currently estimated to be several years (so call now!). To be placed on the Autism Waiver Registry (a.k.a. waiting list), contact 866-417-3480. For more information on the Autism Waiver, please call the Maryland State Department of Education at 410-767-1446 or the Department of Health and Mental Hygiene at 410-767-5220.

Maryland State Department of Education Accommodations Manual

A guide to "selecting, administering, and evaluating the use of accommodations for instruction and assessment" in Maryland schools. "Accommodations" are changes in methods of testing or instruction that attempt to reduce or eliminate the effect of a student's disability on his/her academic performance; accommodations do not reduce academic expectations. Parents may find this guide useful as they prepare for their child's Individualized Education Plan (IEP) meeting. www.msde.maryland.gov/NR/rdonlyres/840EFBB6-CD7D-404E-8A77-E978F6D508AA/16337/MDAccommodationsManual_21108.pdf.

AutMont

Online listing of autism events and resources in Montgomery County. www.autmont.com.

Community Services for Autistic Adults and Children (CSAAC)

"CSAAC is a private, non-profit agency which provides direct services to children and adults with autism across the lifespan. CSAAC operates 52 community living residences for 130 residents around Montgomery County, two school sites, an after-school program, an early intervention home-based program and classroom-based preschool program." www.csaac.org

MCneeds

"MCneeds is a grassroots organization that advocates for the improvement in the quality of life for individuals with disabilities and their families in Montgomery County, Maryland. Its membership includes parents, advocates, lawyers, teachers and many others. While its focus is primarily special education, MCneeds advocates for and addresses other issues that impact the lives of individuals with disabilities." www.mcneeds.org.

The Parents' Place of Maryland

Serves families of children and young adults from birth to age 22 with all disabilities. Aims to ensure that families of children with any kind of disability or special health care need have the knowledge and assistance they need to make informed decisions that support their child's health, education, and development by providing peer support to families, and information and education to families, professionals and the community at large. Voice/TDD 410-768-9100; fax 410-768-0830; e-mail info@ppmd.org; www.ppmd.org.

Pathfinders for Autism

Referrals and information on early intervention, recreation, education and medical options in Maryland. 1-866-806-8400; www.pathfindersforautism.org.

Partnership for Extraordinary Minds

Parent organization advocating for diploma-bound Montgomery County Public School students who have ASD diagnoses. www.xminds.org.

VIRGINIA

Virginia IDEA program for children 0-3 years old: Infants and Toddlers Program

The main program website is www.infantva.org. To find your point of entry, go to 211uwgrp.org, or go to the second page of this pdf document: www.infantva.org/documents/pr-ReferralGuide.pdf.

Virginia IDEA program for children 3-5 years old: Child Find

To make an intake screening appointment, contact your local school system from the list at <https://p1pe.doe.virginia.gov/edudirectory/divisionList.do>, or try searching the internet for your school system name + Child Find (e.g. "Arlington Child Find"). Contact information for a few DC-area school districts are below:

- City of Alexandria: 703-706-4639, www.acps.k12.va.us/student-services/preschool/
- Arlington: (703) 228-6042
- Falls Church City: 703-248-5659, www.fccps.k12.va.us/md/childfind.html
- Fairfax: 571-423-4121, www.fcps.edu/dss/sei/preschool/index.htm

Parents Of Autistic Children of Northern Virginia (POAC-NoVA)

"Parents Of Autistic Children of Northern Virginia (POAC-NoVA) and its predecessor organization has worked since 1996 to improve the quality and quantity of education for students with autism within the Fairfax County Public Schools (FCPS)...POAC-NoVA also holds a monthly parent support group and information meeting to provide to parents a forum to frankly talk to other parents who have been dealing with this condition for some time. We have found that one of the best sources of information have been other parents, who truly understand how autism affects not just one child, but the entire family. We would be happy to meet you at one of these meetings."

The Parent Educational Advocacy Training Center

"Building positive futures for Virginia's children by working collaboratively with families, schools and communities in order to improve opportunities for excellence in education and success in school and community life. Our special focus is children with disabilities." 800-869-6782; www.peatc.org.

Virginia Parent Resource Centers

Resources can include lending library, workshops, parent support groups, parent newsletters, and staff who provide information and support. Find the Center for your county at: www.doe.virginia.gov/VDOE/Instruction/Sped/prc_list.pdf.

Virginia DD Waiver

Provides services including in-home residential support, respite care, and assistive technology to eligible individuals. To request a screening for the DD Waiver, contact the Virginia Department of Medical Assistance Services (VA DMAS) at 804-786-1465 or download the form from: dmas.virginia.gov/content/ltc-dd_wvr_request_for_services.htm.

Support Programs for Families

Are there support programs for children with autism spectrum disorders?

Many children with autism spectrum disorders (ASDs) are able to get support from publicly funded programs. Some examples are financial help, education, medical care, job skills training, and residential or living services. Some supports are available to all children, such as a free public education, including special education if the child is eligible. Other public benefits are based on need, such as financial need or how serious the disability is. Most children with ASDs, especially those who also have mental retardation, will qualify for these benefits.

Funding for community-based supports has risen over the past 30 years, but states put different amounts of money into these services. Some states have policies and funding to ensure that all children with disabilities, including ASDs, live in family settings. But many states still give large sums to state facilities, nursing homes, Intermediate Care Facilities for the Mentally Retarded, and other places.

What is Supplemental Security Income?

Supplemental Security Income (SSI) benefits support families who are raising children with severe disabilities at home. It is mostly for low-income families. If a child is eligible based on financial need *and* the severity of disability, the family will receive funds monthly to support the child's needs. In most states, the child will automatically become eligible for Medicaid.

What are Home and Community-Based Waiver Services?

The most common type of financial support for families is called Home and Community-Based Waiver Services (HCBWS). HCBWS funding depends on the severity of the child's disability and how it affects the family. HCBWS funding is available to all income levels. However, many states have long waiting lists—on average, 5 to 7 years. This is because unlike SSI, the family's assets are not part of deciding who is eligible. Parents must call their local HCBWS office as soon as their child is diagnosed with an ASD to get on the waiting list. Once the child receives a funded slot, a case manager works with the family on an annual service plan to choose the supports the family needs. These supports include respite (in-home, center- or camp-based), medical equipment, home remodeling for safety reasons, and other needed supports. The child usually also becomes eligible for Medicaid (again, without looking at the family income), which in itself is a great support to most families.

What is available in my state?

Because each state has different services, families must call their state or county offices of the departments of Health and Human Services, Mental Health, and Mental Retardation or the state developmental disabilities organization. Other sources of local and state information are

- Local parent groups
- Autism Society of America local chapter
- Early intervention administrators
- School district special education coordinators (Call your local school to ask.)

What is a special needs will and trust?

Some public supports (such as SSI) depend on the financial status of the family. Families risk losing these supports if a well-meaning relative gives the child with ASD money as a gift. However, supports can be protected with a special needs will and trust.

A very important part of the will is a statement that says the money a child inherits is to be used only for items and services not covered by Medicaid, SSI, or other federal funding. Not including this statement will result in the loss of federal benefits until the inheritance the child receives is spent down. In some cases, the person with autism may need to repay the government for services provided in the past. Also, siblings' shares of the inherited money may be at risk. Legal help from an experienced lawyer is needed when developing a special needs will and trust. Various nonprofit and for-profit groups can help parents. Ask your doctor for information about them.

Resources

Special Needs Advocate for Parents (SNAP): www.snapinfo.org

Special Needs Alliance: www.specialneedsalliance.com

The information contained in this publication should not be used as a substitute for the medical care and advice of your pediatrician. There may be variations in treatment that your pediatrician may recommend based on individual facts and circumstances.

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American Academy
of Pediatrics



DEDICATED TO THE HEALTH OF ALL CHILDREN™



ADDITIONAL RESOURCES

CENTER FOR AUTISM SPECTRUM DISORDERS, CHILDREN'S NATIONAL MEDICAL CENTER

The resources below are often helpful to families of children and adolescents with autism spectrum disorders. Although we do not necessarily agree with all of their ideas and techniques, we have generally found them to contain useful information.

I. BOOKS

For additional titles, see the websites of the following publishers:

- Jessica Kingsley Publishers - www.jkp.com
- Autism Asperger Publishing Company - www.asperger.net
- Future Horizons- www.FutureHorizons-autism.com
- Brookes Publishing Co. - www.brookespublishing.com

Books – General Information:

Attwood, Tony

- *Asperger Syndrome: A Guide for Parents and Professionals*

Baker, Jed

- *No More Meltdowns*
- *Preparing for Life: The Complete Guide for Transitioning to Adulthood for those with Autism and Aspergers Syndrome*

Bolick, Teresa

- *Asperger Syndrome and Adolescence: Helping Preteens & Teens Get Ready for the Real World*
- *Asperger Syndrome and Young Children: Building Skills for the Real World*

Cooper-Kahn, Joyce and Laurie Dietzel

- *Late, Lost, and Unprepared: A Parents' Guide to Helping Children with Executive Functioning*

Cumin, Val

- *Asperger's Syndrome: A Practical Guide for Teachers*

Dawson, Peg and Richard Guare

- *Smart but Scattered: The Revolutionary "Executive Skills" Approach to Helping Kids Reach Their Potential*

Duncan, Megan Moore, Jeanne Holverstott, Brenda Smith Myles, and Terri Cooper Swanson

- *Autism Spectrum Disorders: A Handbook for Parents and Professionals*

Garcia Winner, Michelle

- *Inside Out: What Makes the Person with Social Cognitive Deficits Tick?*
- *Thinking About YOU Thinking About ME, 2nd Edition*

Grandin, Temple and Barron, Sean

- *Unwritten Rules of Social Relationships*

Gray, Carol

- *The Original Social Story Book*
- *The New Social Stories*
- *Taming the Recess Jungle*
- *Comic Strip Conversations*

Grinker, Roy

- *Unstrange Minds: Remapping the World of Autism*

Gutstein, Steven

- *Autism/Aspergers: Solving the Relationship Puzzle*

Moore, Susan Thompson

- *Asperger Syndrome and the Elementary School Experience*

Myles, Brenda Smith, Diane Adreon, and Dena Gitlitz

- *Simple Strategies That Work! Helpful Hints for All Educators of Students With Asperger Syndrome, High-Functioning Autism, and Related Disabilities*

Myles, Brenda Smith and Jack Southwick

- *Asperger Syndrome And Difficult Moments: Practical Solutions For Tantrums, Rage And Meltdowns*
Myles, Brenda Smith, Melissa Trautman, and Ronda Schelvan
- *The Hidden Curriculum: Practical Solutions for Understanding Unstated Rules in Social Situations*
Notbohm, Ellen
- *Ten Things Every Child with Autism Wishes You Knew*
Offit, Paul
- *Autism's False Prophets: Bad Science, Risky Medicine, and the Search for a Cure*
Ozonoff, Sally, Dawson, Geraldine, and McPartland, James
- *A Parent's Guide to Asperger Syndrome and High-Functioning Autism: How to Meet the Challenges and Help Your Child Thrive*
Richfield, Steven
- *Parent Coaching Cards*
Rothenberg, Stephen
- *Playing with Self-Esteem*
Thompson, Travis
- *Straight Talk on Autism*
Volkmar, Fred and Wiesner, Lisa
- *A Practical Guide to Autism: What Every Parent, Family Member, and Teacher Needs to Know*
Weinfeld, Rich and Michelle Davis
- *Special Needs Advocacy Resource Book: What You Can Do Now to Advocate for Your Exceptional Child's Education*
Wheeler, Marcia
- *Toilet Training for Individuals with Autism or Other Developmental Issues*

Books – Personal Accounts and Literature

- Boyd, Brenda
 - *Parenting a Child With Asperger Syndrome: 200 Tips and Strategies*
- Grandin, Temple
 - *Thinking in Pictures, Expanded Edition: My Life with Autism*
- Haddon, Mark
 - *The Curious Incident of the Dog in the Night-Time*
- Moon, Elizabeth
 - *The Speed of Dark*
- Morrell, Maureen and Ann Palmer
 - *Parenting Across the Autism Spectrum: Unexpected Lessons We Have Learned*
- Page, Tim
 - *Parallel Play: Growing Up with Undiagnosed Asperger's*
- Robinson, John Elder
 - *Look Me in the Eye: My Life with Asperger's*
- Stork, Francisco
 - *Marcelo in the Real World*
- Willey, Liane Holliday
 - *Pretending to Be Normal: Living with Asperger's Syndrome*

Books for Children and Adolescents with ASDs, and their Siblings and Peers – General Information

- Band, Eve and Emily Hecht
 - *Autism Through a Sister's Eyes*
- Hoopmann, Kathy
 - *All Cats Have Asperger Syndrome*
- Katz, Illana
 - *Joey and Sam: A Heartwarming Storybook About Autism, A Family, and a Brother's Love*
- Larson, Elaine Marie
 - *I Am Utterly Unique: Celebrating the Strengths of Children with Asperger Syndrome and High-Functioning Autism*
- Lears, Laurie and Karen Ritz
 - *Ian's Walk: A Story About Autism*

Schnurr, Rosina

- *Asperger's Huh? A Child's Perspective*

Shally, Celeste

- *Since We're Friends: An Autism Picture Book*

Books for Children and Adolescents – Social Skills and Interventions

Baker, Jed

- *The Social Skills Picture Book: Teaching Play, Emotion, and Communication to Children with Autism*

Banks, Jane Whelen

- *Liam Wins the Game, Sometimes: A Story About Losing With Grace*

Brown, Laurie Kransy and Marc Brown

- *How to Be a Friend: A Guide to Making Friends and Keeping Them*

Huebner, Dawn

- *What to do When You Worry Too Much: A Kid's Guide to Overcoming Anxiety*
- *What to Do When Your Temper Flares: A Kid's Guide to Overcoming Problems With Anger*

Meiners, Cheri

- *Join in and Play*

Meyer, Roger

- *Asperger Syndrome Employment Workbook*

Rogers, Fred

- *First Experiences: Making Friends*

Rotner, Shelley

- *Lots of Feelings*

Winner, Michelle Garcia and Pamela Crooke

- *You Are a Social Detective*

II. WEBSITES

General Information

Advocacy Groups

Autism Society of America (www.autism-society.org) – See especially their free downloadable information sheets: click “Shop,” then “Free Downloads.”

Autism Speaks (www.autismspeaks.org) – See especially the *First 100 Days Kit* at www.autismspeaks.org/community/family_services/100_day_kit.php.

Exceptional Parent Magazine (www.eparent.com)

First Signs Video Glossary (www.firstsigns.org/asd_video_glossary/asdvg_about.htm)

Interactive Autism Network (iancommunity.org)

Online Asperger Syndrome Information and Support (aspergersyndrome.org)

Organization for Autism Research (www.researchautism.org)

Pacer Center (www.pacer.org/publications/index.asp) – See especially their handouts: Click on a topic in the table of contents, then scroll down to the “Handouts” section of that topic’s web page.

Federal Agencies and Professional Organizations

American Academy of Pediatrics (www.aap.org/healthtopics/autism.cfm)

Centers for Disease Control and Prevention (www.cdc.gov/ncbddd/autism/index.html) – See especially their vaccine safety website at www.cdc.gov/ncbddd/autism/vaccines.htm.

Federal website “connecting the disability community to information and opportunities” (Disability.gov)

Interdisciplinary Technical Assistance Program on Autism and Developmental Disabilities (www.aucd.org/itac/template/resources.cfm)

National Institute of Child Health and Human Development (www.nichd.nih.gov/health/topics/asd.cfm)

National Institute of Mental Health (www.nimh.nih.gov/health/topics/autism-spectrum-disorders-pervasive-developmental-disorders/index.shtml)

University Clinical Programs

Yale Child Study Center (info.med.yale.edu/chldstudy/autism/welcome.html)

University of Florida Center for Autism and Related Disabilities (www.card.ufl.edu)

University of North Carolina TEACCH program (www.unc.edu/depts/teacch)
University of South Dakota Autism Spectrum Disorders Handbook (www.usd.edu/medical-school/center-for-disabilities/upload/autismhandbook.pdf)

Interventions

Association for Science in Autism Treatment (www.asatonline.org/intervention/treatments_desc.htm)
Autism Science Foundation (www.autismsciencefoundation.org/home.html)
Do2Learn (www.do2learn.com) – Many free printable materials, activity suggestions, and online activities for children with disabilities.
National Information Center for Children and Youth with Disabilities (www.nichcy.org)
National Autism Center's 2009 *National Standards Report* (www.nationalautismcenter.org/affiliates/reports.php)
Picture Exchange Communication System (www.pyramidproducts.com)

Education

Elementary through High School

Council of Chief State School Officers Accommodations Manual
(www.ccsso.org/projects/SCASS/projects/assessing_special_education_students/11302.cfm) – Parents may find this guide helpful as they think about how teaching methods and school environments can be tailored to their child through the IEP.
National Academy Press' 2001 report, *Educating Children with Autism*
(www.nap.edu/catalog.php?record_id=10017)
Wright's Law (www.wrightslaw.com) – Special education law, education law, and advocacy for children and adolescents with disabilities

Postsecondary Education and Transitions to Adulthood

Danya International, Organization for Autism Research, and Southwest Autism Research and Resource Center,
Life Journey Through Autism: A Guide for Transition to Adulthood
(www.researchautism.org/resources/reading/documents/TransitionGuide.pdf)
Organization for Autism Research, *Understanding Asperger Syndrome: A Professor's Guide*
(www.researchautism.org/resources/AspergerDVDSeries.asp) – a 12-minute video available free online
TEACCH Autism Program, University of North Carolina School of Medicine, *Preparing for College: Tips for Students with HFA/Asperger's Syndrome* (www.teacch.com/college.html)
US Department of Education Office for Civil Rights, *Students with Disabilities Preparing for Postsecondary Education: Know Your Rights and Responsibilities* (www2.ed.gov/about/offices/list/ocr/transition.html)

Self-Advocacy and Personal Perspectives

Autistic Self Advocacy Network (www.autisticadvocacy.org) – “seeks to advance the principles of the disability rights movement in the world of autism”
Blogs – There are numerous thoughtful and insightful blogs written by individuals with ASDs and their families. Search the internet for “autism blog,” “autism parent blog,” etc.
Disability.gov Self-Advocacy Resources (www.disability.gov/education/student_resources/self-advocacy)
Mom-Not Otherwise Specified (momnos.blogspot.com/2010/03/on-being-hair-dryer-kid-in-toaster.html) – A mother writes about how she explained her son's autism to his elementary school aged peers

III. NEWSPAPER AND MAGAZINE ARTICLES

The Associated Press. Evidence Lacking for Special Diets in Autism. *The New York Times*. January 4, 2010. (www.nytimes.com/aponline/2010/01/04/health/AP-US-MED-Autism-Diets.html?_r=2)
Callahan, Patricia et al. “Autism Treatment: Risky Alternative Therapies Have Little Basis in Science”; “Science Hijacked to Support Alternative Therapies”; “Success Stories More Persuasive To Some than Hard Data”; “Questionable Treatments for Children.” *Chicago Tribune*. November 22, 2009. (archives.chicagotribune.com/2009/nov/22/health)
Harmon, Amy. “Finding Out: Adults and Autism; An Answer, but Not a Cure, for a Social Disorder.” *The New York Times*. April 29, 2004. (www.nytimes.com/2004/04/29/us/finding-out-adults-and-autism-an-answer-but-not-a-cure-for-a-social-disorder.html)

Konrad, Walecia. "Dealing with the Financial Burden of Autism." *The New York Times*. January 22, 2010.
(www.nytimes.com/2010/01/23/health/23patient.html?hpw)

Monday, Claudia Wallis. "New Evidence That Early Therapy Helps Autistic Kids." *Time*. November 30, 2009.
(www.time.com/time/health/article/0,8599,1943512,00.html)

IV. MOVIES

Autism: The Musical (2007). Director: Tricia Regan

Billy the Kid (2007). Director: Jennifer Venditti

Including Samuel. Director: Dan Habib (www.includingsamuel.com)

V. PRODUCTS AND TECHNOLOGY

Ablelinktech.com (Executive Function support software for PDAs; includes visual schedules and programmable, step-by-step guides for complex tasks)

ChildsWork/ChildsPlay – store.guidance-group.com (Click on "ChildsWork/ChildsPlay"; games and books addressing a range of social and emotional issues)

Model Me Kids – www.modelmekids.com (Videos teaching and demonstrating social skills)

Proloquo2go.com (Assistive communication and scheduling program for iPod Touch and iPhone)

Teacher stores – Local teacher stores, and websites like www.lakeshorelearning.com, often sell educational materials like facial expression and social skills flashcards that can be helpful for some children, particularly in the elementary grades.