

Autism Spectrum Disorder

Distributed By:

Maine Parent Federation
PO Box 2067
Augusta, Maine 04338

1-800-870-7746 (Maine Only)
207-588-1933

Email: parentconnect@mpf.org
Online community: www.startingpointsforme.org

Original: 01/2000
Updated:07/2015

Autism Spectrum Disorder
Maine Parent Federation



Information Disclaimer

The purpose of the information packet is to provide individuals with reader friendly information. We believe that a good overview is a realistic one. For this reason we have included a variety of information that may include the more difficult characteristics of a diagnosis or topic along with medical, educational and best practice information.

All information contained in this packet is for general knowledge, personal education and enrichment purposes. It is not intended to be a substitute for professional advice. For specific advice, diagnosis and treatment you should consult with a qualified professional.

When this packet was developed, Maine Parent Federation made every effort to ensure that the information contained in this packet was accurate, current and reliable. Packets are reviewed and updated periodically as changes occur.

09/2011

Disclaimer

The contents of this Information Packet was developed under a grant from the US Department of Education, #H328M110002. However, those contents do not necessarily represent the policy of the US Department of Education, and you should not assume endorsement by the Federal Government. Project Officer, Marsha Goldberg.



Autism Spectrum Disorder

Table of Content

	Page #
Autism Spectrum Disorder	3
Treatment Options	10
Asperger's Syndrome	13
Autism	15
Asperger Syndrome	16
Pervasive Developmental Disorders	18
State Resources	19
National Resources	20
Library Materials	21

Autism Spectrum Disorder

Autism Spectrum Disorder

Used with permission by: Center for Parent Information and Resources
Website Address: www.parentcenterhub.org

Ryan's Story

Ryan is a healthy, active two-year-old, but his parents are concerned because he doesn't seem to be doing the same things that his older sister did at this age. He's not really talking, yet; although sometimes, he repeats, over and over, words that he hears others say. He doesn't use words to communicate, though. It seems he just enjoys the sounds of them. Ryan spends a lot of time playing by himself. He has a few favorite toys, mostly cars, or anything with wheels on it! And sometimes, he spins himself around as fast as he does the wheels on his cars. Ryan's parents are really concerned, as he's started throwing a tantrum whenever his routine has the smallest change. More and more, his parents feel stressed, not knowing what might trigger Ryan's next upset.

Often, it seems Ryan doesn't notice or care if his family or anyone else is around. His parents just don't know how to reach their little boy, who seems so rigid and far too set in his ways for his tender young age. After talking with their family doctor, Ryan's parents call the Early Intervention office in their community and make an appointment to have Ryan evaluated.

When the time comes, Ryan is seen by several professionals who play with him, watch him, and ask his parents a lot of questions. When they're all done, Ryan is diagnosed with autism, one of the five disorders listed under an umbrella category of "Pervasive Developmental Disorders"—a category that's often referred to as simply the "autism spectrum."

As painful as this is for his parents to learn, the early intervention staff encourage them to learn more about the autism spectrum. By getting an early diagnosis and beginning treatment, Ryan has the best chance to grow and develop. Of course, there's a long road ahead, but his parents take comfort in knowing that they aren't alone and they're getting Ryan the help he needs.

What are the Characteristics of Autism Spectrum Disorders?

Each of the disorders on the autism spectrum is a neurological disorder that affects a child's ability to communicate, understand language, play, and relate to others. They share some or all of the following characteristics, which can vary from mild to severe:

- Communication problems (for example, with the use or comprehension of language);
- Difficulty relating to people, things, and events;
- Playing with toys and objects in unusual ways;
- Difficulty adjusting to changes in routine or to familiar surroundings; and
- Repetitive body movements or behaviors. ⁽¹⁾

These characteristics are typically evident before the age of three.

Autism Spectrum Disorder

Children with autism or one of the other disorders on the autism spectrum can differ considerably with respect to their abilities, intelligence, and behavior. Some children don't talk at all. Others use language where phrases or conversations are repeated. Children with the most advanced language skills tend to talk about a limited range of topics and to have a hard time understanding abstract concepts. Repetitive play and limited social skills are also evident. Other common symptoms of a disorder on the autism spectrum can include unusual and sometimes uncontrolled reactions to sensory information—for instance, to loud noises, bright lights, and certain textures of food or fabrics.

What are the Specific Disorders on the Autism Spectrum?

There are five disorders classified under the umbrella category officially known as Pervasive Developmental Disorders, or PDD. As shown below, these are:

- autism;
- Asperger syndrome;
- Rett syndrome;
- childhood disintegrative disorder; and
- Pervasive Developmental Disorder Not Otherwise Specified (often referred to as PDDNOS). ⁽²⁾

Although there are subtle differences and degrees of severity between these five conditions, the treatment and educational needs of a child with any of these disorders will be very similar. For that reason, the term “autism spectrum disorders”—or ASDs, as they are sometimes called—is used quite often now and is actually expected to become the official term to be used in the future (see the section below called “A Look at ASD Diagnoses in the Future”). ⁽³⁾

The five conditions are defined in the *Diagnostic and Statistical Manual, Fourth Edition, Text Revision* (DSM-IV-TR) of the American Psychiatric Society (2000). This is also the manual used to diagnose autism and its associated disorders, as well as a wide variety of other disabilities.

At the moment, according to the 2000 edition of the DSM-IV, a diagnosis of autistic disorder (or “classic” autism) is made when a child displays 6 or more of 12 symptoms across three major areas:

- **social interaction** (such as the inability to establish or maintain relationships with peers appropriate to the level of the child's development,
- **communication** (such as the absence of language or delays in its development), and
- **behavior** (such as repetitive preoccupation with one or more areas of interest in a way that is abnormal in its intensity or focus).

When children display similar behaviors but do not meet the specific criteria for autistic disorder, they may be diagnosed as having one of the other disorders on the spectrum—Aspergers, Rett's, childhood disintegrative disorder, or PDDNOS. PDDNOS (Pervasive Developmental Disorder Not Otherwise Specified) is the least specific diagnosis and typically means that a child has displayed the least specific of autistic-like symptoms or behaviors and has not met the criteria for any of the other disorders.

Autism Spectrum Disorder

Terminology used with autism spectrum disorders can be a bit confusing, especially the use of PDD and PDDNOS to refer to two different things that are similar and intertwined. Still, it's important to remember that, regardless of the specific diagnosis, treatments will be similar.

How Common are ASDs?

According to the National Institute of Mental Health (NIMH) and the Centers for Disease Control and Prevention (CDC), some form of autism affects 2 – 6 of every 1,000 children, with the most recent statistic being 1 in 110.⁽⁴⁾ ASDs are four times more common in boys than in girls, although Rett Syndrome has only been diagnosed in girls.⁽⁵⁾

What Causes an ASD?

The causes of autism and the other disorders on the spectrum are not known. Researchers are currently studying such areas as neurological damage and chemical imbalances within the brain. These disorders are not due, however, to psychological factors or, as has been widely reported in the press, to childhood vaccines.⁽⁶⁾

A Look at ASD Diagnoses in the Future

In early 2010, the American Psychiatric Association released draft revisions to its Diagnostic and Statistical Manual of Mental Disorders (DSM-5) and invited comments from both professionals and the general public. The final and official fifth revision of the DSM is expected to be published in May 2013.⁽⁷⁾

When published, the DSM-5 is expected to affect how autism and associated disorders are diagnosed. Among the proposed revisions are:

- changing the name of the diagnostic category to Autism Spectrum Disorders;
- including Asperger Syndrome, Childhood Disintegrative Disorder, and PDDNOS under the diagnosis of Autism Spectrum Disorders, rather than defining them separately and a bit differently, as is now the case;
- removing Rett Syndrome from the DSM entirely (and, thus, from the autism spectrum).⁽⁸⁾

All this is to say...stay tuned. The criteria for diagnoses of ASDs are in the process of changing.

Is There Help Available?

Yes, there's a lot of help available, beginning with the free evaluation of the child. The nation's special education law, the Individuals with Disabilities Education Act (IDEA), requires that all children suspected of having a disability be evaluated without cost to their parents to determine if they do have a disability and, because of the disability, need special services under IDEA. Those special services are:

- [*Early intervention*](#) | A system of services to support infants and toddlers with disabilities (before their 3rd birthday) and their families.
- [*Special education and related services*](#) | Services available through the public school system for school-aged children, including preschoolers (ages 3-21).

Autism Spectrum Disorder

Under IDEA, children with a disorder on the autism spectrum are usually found eligible for services under the category of “autism.” In the fall of 2005, more than 160,000 school-aged children (3-21) received special education and related services in the public schools under the “autism” category. ⁽⁹⁾

IDEA specifically defines “autism” as follows:

.....a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, that adversely affects a child’s educational performance.

A child who shows the characteristics of autism after age 3 could be diagnosed as having autism if the criteria above are satisfied. [34 CFR §300.8(c)(1)]

Other characteristics often associated with autism are engaging in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences. The term autism does not apply if the child’s educational performance is adversely affected primarily because the child has an emotional disturbance, as defined in IDEA.

To have a child evaluated to see if he or she has a disability, including one on the autism spectrum, or to access early intervention services for a child up to his or her 3rd birthday, we recommend asking your pediatrician or a local hospital’s maternity ward for a referral to early intervention. Either should be able to put you in contact with the early intervention program in your community.

To have a school-aged child evaluated for an ASD or to access special education services for a school-aged child, we recommend getting in touch with your local public school system. Calling the elementary school in your neighborhood is an excellent place to start.

What about School?

Early diagnosis and intervention are very important for children with an ASD. As we’ve mentioned, under IDEA children with an ASD may be eligible for early intervention services (birth to 3) and an educational program appropriate to their individual needs.

In addition to academic instruction, special education programs for students with ASDs focus on improving communication, social, academic, behavioral, and daily living skills. Behavior and communication problems that interfere with learning often require the assistance of a professional who is particularly knowledgeable in the autism field to develop and help implement a plan which can be carried out at home and school.

The classroom environment should be structured so that the program is consistent and predictable. Students with an ASD learn better and are less confused when information is presented visually as well as verbally. Interaction with nondisabled peers is also important, for these students provide models of appropriate language, social, and behavioral skills. Consistency and continuity are very important for children with an ASD, and parents should always be involved in the development of their child’s program, so that learning activities, experiences, and approaches will be most effective and can be carried over into the home and community.

Autism Spectrum Disorder

With educational programs designed to meet a student's individual needs and specialized adult support services in employment and living arrangements, many children and adults with a disability on the autism spectrum grow to live, work, and participate fully in their communities.

Tips for Parents

Learn about autism spectrum disorders—especially the specific disorder of your child. The more you know, the more you can help yourself and your child. Your state's Parent Training and Information Center (PTI) can be very helpful. [Find your PTI here on CPIR's website](#). We've also listed organizations at the end of this fact sheet that can help you become knowledgeable about your child's disorder.

Be mindful to interact with and teach your child in ways that are most likely to get a positive response. Learn what is likely to trigger a melt-down for your child, so you can try to minimize them. Remember, the earliest years are the toughest, but it does get better!

Learn from professionals and other parents how to meet your child's special needs, but remember your son or daughter is first and foremost a child; life does not need to become a never-ending round of therapies.

If you weren't born loving highly structured, consistent schedules and routines, ask for help from other parents and professionals on how to make it second nature for you. Behavior, communication, and social skills can all be areas of concern for a child with autism and experience tells us that maintaining a solid, loving, and structured approach in caring for your child, can help greatly.

Learn about assistive technology (AT) that can help your child. This may include a simple picture communication board to help your child express needs and desires, or may be as sophisticated as an augmentative communication device.

Work with professionals in early intervention or in your child's school to develop an IFSP or an IEP that reflects your child's needs and abilities. Be sure to include related services, supplementary aids and services, AT, and a positive behavioral support plan, if needed.

Be patient and stay optimistic. Your child, like every child, has a whole lifetime to learn and grow.

Tips for Teachers

Learn more about the autism spectrum. Check out the research on [effective instructional interventions](#) and behavior on CPIR's website. The organizations listed in this publication can also help.

Make sure directions are given step-by-step, verbally, visually, and by providing physical supports or prompts, as needed by the student. Students with autism spectrum disorders often have trouble interpreting facial expressions, body language, and tone of voice. Be as concrete and explicit as possible in your instructions and feedback to the student.

Find out what the student's strengths and interests are and emphasize them. Tap into those avenues and create opportunities for success. Give positive feedback and lots of opportunities for practice.

Autism Spectrum Disorder

Build opportunities for the student to have social and collaborative interactions throughout the regular school day. Provide support, structure, and lots of feedback.

If behavior is a significant issue for the student, seek help from expert professionals (including parents) to understand the meanings of the behaviors and to develop a unified, positive approach to resolving them.

Have consistent routines and schedules. When you know a change in routine will occur (e.g., a field trip or assembly) prepare the student by telling him or her what is going to be different and what to expect or do.

Work together with the student's parents and other school personnel to create and implement an educational plan tailored to meet the student's needs. Regularly share information about how the student is doing at school and at home.

Organizations: Your Gateway to Information, Connection, and Research

For incredible amounts of information on ASDs, visit the organizations listed below.

Autism Society of America
1.800.3AUTISM (1.800.328.8476)
<http://www.autism-society.org/>

Autism Speaks
888-AUTISM2 (288-4762)
<http://www.autismspeaks.org/>

OASIS @ MAPP
Online Asperger Syndrome Information and Support (OASIS) and MAAP Services for Autism and Asperger Syndrome.
<http://www.aspergersyndrome.org>

Exploring Autism
Information in English and Spanish.
<http://www.exploringautism.org/>

Autism Collaboration
<http://www.autism.org/>

National Autism Center
1.877.313.3833
<http://www.nationalautismcenter.org/index.php>

Interactive Autism Network
<http://www.ianproject.org/>

OAR | Organization for Autism Research
<http://www.researchautism.org/>

Autism Spectrum Disorder

CDC | Centers for Disease Control and Prevention
Information in English and Spanish.
www.cdc.gov/ncbddd/autism/index.html

First Signs
<http://www.firstsigns.org>

References

- 1 | Autism Society of America. (2008). *About autism*. Available online at: www.autism-society.org
- 2 | American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders fourth edition, text revision (DSM-IV-TR)*. Arlington, VA: Author.
- 3 | American Psychiatric Association. (2010). *DSM-5 proposed revisions include new category of autism spectrum disorders* (press release). Available online at: www.dsm5.org/Newsroom/Documents/Autism%20Release%20FINAL%202010.05.pdf
- 4 | Centers for Disease Control and Prevention (CDC). (2009). *Autism spectrum disorders: Data and statistics*. Available online at: www.cdc.gov/ncbddd/autism/data.html
- 5 | Centers for Disease Control and Prevention (CDC). (2009). *Autism spectrum disorders: Research*. Available online at: www.cdc.gov/ncbddd/autism/research.html
- 6 | Centers for Disease Control and Prevention (CDC). (2009). *Concerns about autism: CDC statement on autism and thimerosal*. Available online at: www.cdc.gov/vaccinesafety/Concerns/Autism/Index.html
- 7 | American Psychiatric Association. (2009). *DSM-5 publication date moved to May 2013* (press release). Available at: www.dsm5.org/Newsroom/Documents/09-65%20DSM%20Timeline.pdf
- 8 | American Psychiatric Association. (2010). *Proposed revision: Autistic disorder*. Available online at: www.dsm5.org/ProposedRevisions/Pages/proposedrevision.aspx?rid=94#
- 9 | U.S. Department of Education. (2007). *27th annual report to Congress on the implementation of the Individuals with Disabilities Education Act, 2005* (Vol. 2). Washington, DC: Author.

Autism Spectrum Disorder

Treatment Options

Used with permission by the Autism Society
Website: www.autism-society.org

Just decades ago, many people with autism were placed in institutions. Professionals were less educated about autism than they are today, and specific services and supports were largely non-existent. **The picture is much clearer now.** With appropriate services and supports, training and information, children on the autism spectrum will grow, learn and flourish, even if at a different developmental rate than others.

While there is no known cure for autism, there are treatment and education approaches that can address some of the challenges associated with the condition. Intervention can help to lessen disruptive behaviors, and education can teach self-help skills for greater independence. **But just as there is no one symptom or behavior that identifies people with autism, there is no single treatment that will be effective for everyone on the spectrum.** Individuals can use the positive aspects of their condition to their benefit, but treatment must begin as early as possible and focus on the individual's unique strengths, weaknesses and needs.

Throughout the history of the Autism Society, parents and professionals have been confounded by conflicting messages regarding which treatment options are appropriate for children and adults on the autism spectrum. As each person responds to treatment differently, [we cannot endorse any one treatment or program](#). Families should educate themselves about all options and choose what they feel is in the best interest of their child and family, based on their experience and what resources are available.

This section provides an overview of many available approaches, not specific treatment recommendations. Keep in mind that the word “treatment” is used in a very limited sense. While typically used for children under age three, the approaches described here can be included in an educational program for older children as well.

It is important to match a child's potential and specific needs with treatments or strategies that are likely to help him/her reach established goals and greatest potential. The Autism Society does not want to give the impression that parents or professionals will select just one treatment from a list. A search for appropriate treatment must be paired with the knowledge that all treatment approaches are not equal – what works for one will not work for all. **The basis a treatment plan should come from a thorough evaluation of the child's strengths and weaknesses.**

Nonmedical Interventions

The dramatic increase in the number of people identified with ASD has focused attention on the types of interventions that can lead to opportunities for a high quality of life. These teaching strategies can introduce new behaviors or reduce inappropriate actions, often using the principles of behavior reinforcement. Nonmedical interventions frequently address one specific issue at a time – for example, teaching a student to focus on homework – and can yield results in those specific areas as well as more general improvement in functioning.

The Texas Statewide Leadership for Autism Training has compiled the [Texas Autism Resource Guide for Effective Teaching \(TARGET\)](#), which provides information on interventions for people with ASD. Recognizing the diversity of those with ASD, TARGET exercises a pragmatic approach to evidence-based practices:

Autism Spectrum Disorder

“The best measure of effectiveness of an intervention is whether it is effective for a particular individual. It is of utmost importance to collect and analyze data when using interventions with a student with autism. If an intervention results in positive change for a particular student and you, as an educational professional, have data to support that, then the intervention is evidence-based for that student.”

A report by for military families the Ohio State University Project Team includes a [comparison chart](#) (created by Brenda Smith Myles, Ph.D.) outlining and describing the evidence-based practices developed by the [Centers for Medicare & Medicaid Services](#), the [National Autism Center](#) and the [National Professional Development Center on ASD](#).

For more information about interventions, try [Autism Source](#), the Autism Society’s national contact center and database. Autism Source can connect you to service providers in your area and supply information to help you in choosing an intervention or therapy.

Related Approaches

While early educational intervention is key to improving the lives of people with ASD, some parents and professionals believe other treatment approaches play an important role in improving communication skills and reducing behavioral symptoms associated with autism. These complementary therapies might include music, art or animal therapy, among many others, and might be undertaken on an individual basis or through an educational program.

All of these therapies can help by increasing communication skills, developing social interaction and providing a sense of accomplishment. They can provide a non-threatening way for a child on the autism spectrum to develop a positive relationship with a therapist in a safe environment. They can also be productive hobbies in their own right!

Art and music are particularly useful in sensory integration, providing tactile, visual and auditory stimulation. Music therapy is good for speech development and language comprehension. Songs can be used to teach language and increase the ability to put words together. Art therapy provides a nonverbal, symbolic way means of self-expression, and can develop fine motor skills.

Animal therapy might include working with dogs, horseback riding or swimming with dolphins. These animals can provide soothing sensory stimulation, a point of focus and opportunities to learn about behavior and communication. Therapeutic riding programs provide both physical and emotional benefits, improving coordination and motor development while creating a sense of well-being and increasing self-confidence. Dolphin therapy was first used in the 1970s by psychologist David Nathanson, who believed interactions with dolphins would improve a child’s attention, enhancing cognition.

Again, as with all other therapy or treatment approaches, it is important to gather information and make an informed decision to choose a reputable, effective therapy. Keep in mind, however, that little scientific research has been conducted on most complementary therapies. They must be judged by their results on a person-by-person basis.

Autism Spectrum Disorder

Use [Autism Source](#) to find therapies and other services near you.

Evaluating Options

After identifying available treatments, interventions, therapies and other services, you'll need to choose which ones are best for your child. Here are some considerations to help you make your decision:

- Do you adhere to the Autism Society's [Priorities of Professional Conduct](#)?
- What is the purpose of this theory/practice?
- What do I have to do to benefit from the theory/practice, and what are its lasting effects?
- What is the status of this theory/practice relative to controlled (scientific) investigation, and does it include a reference list of publications?
- For how long must my child be involved in this theory/practice to benefit from it?
- Is there any physical or psychological harm this theory/practice could do to my child?
- What are the personal costs of time and money that I will have to endure, and can I be reimbursed for these expenses?
- How do I know that the costs of this theory/practice are fair and reasonable?
- Are the theoreticians or practitioners competently and appropriately trained and prepared to implement the provisions of the theory or practice? How is their competence assured?
- What steps will be taken to protect my privacy?
- Are there any legal actions, current or past, against promoters, consumers or practitioners of the theory/practice?
- How will the effects of this theory/practice be evaluated?
- By choosing this theory/practice, what alternatives (proven or unproven) am I not pursuing?
- Does this approach mesh with my child's overall program?
- Who has this theory positively benefited, and under what conditions?

The [National Institute of Mental Health](#) suggests the following list of questions to ask when planning a treatment program:

- How successful has the program been for other children?
- How many children have gone on to placement in a regular school and how have they performed?
- Do staff members have training and experience in working with children with autism?
- How are activities planned and organized?
- Are there predictable daily schedules and routines?
- How much individual attention will my child receive?
- How is progress measured? Will my child's behavior be closely observed and recorded?
- Will my child be given tasks and rewards that are personally motivating?
- Is the environment designed to minimize distractions?
- Will the program prepare me to continue the therapy at home?
- What is the cost, time commitment, and location of the program?

Autism Spectrum Disorder

Asperger's Syndrome

Used with permission by the Autism Society
Website: www.autism-society.org

History

Asperger's syndrome (also known as Asperger's Disorder) was first described in the 1940s by Viennese pediatrician Hans Asperger, who observed autism-like behaviors and difficulties with social and communication skills in boys who had normal intelligence and language development. Many professionals felt Asperger's syndrome was simply a milder form of autism and used the term "high-functioning autism" to describe these individuals. Uta Frith, a professor at the Institute of Cognitive Neuroscience of University College London and editor of *Autism and Asperger Syndrome*, describes individuals with Asperger's as "having a dash of autism."

Asperger's Disorder was added to the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)* in 1994 as a separate disorder from autism. However, there are still many professionals who consider Asperger's Disorder a less severe form of autism. In 2013, the *DSM-5* replaced Autistic Disorder, Asperger's Disorder and other pervasive developmental disorders with the umbrella diagnosis of [autism spectrum disorder](#).

Characteristics

What distinguishes Asperger's Disorder from classic autism are its less severe symptoms and the absence of language delays. Children with Asperger's Disorder may be only mildly affected, and they frequently have good language and cognitive skills. To the untrained observer, a child with Asperger's Disorder may just seem like a neurotypical child behaving differently.

Children with autism are frequently viewed as aloof and uninterested in others. This is not the case with Asperger's Disorder. Individuals with Asperger's Disorder usually want to fit in and have interaction with others, but often they don't know how to do it. They may be socially awkward, not understand conventional social rules or show a lack of empathy. They may have limited eye contact, seem unengaged in a conversation and not understand the use of gestures or sarcasm.

Their interests in a particular subject may border on the obsessive. Children with Asperger's Disorder often like to collect categories of things, such as rocks or bottle caps. They may be proficient in knowledge categories of information, such as baseball statistics or Latin names of flowers. They may have good rote memory skills but struggle with abstract concepts.

One of the major differences between Asperger's Disorder and autism is that, by definition, there is no speech delay in Asperger's. In fact, children with Asperger's Disorder frequently have good language skills; they simply use language in different ways. Speech patterns may be unusual, lack inflection or have a rhythmic nature, or may be formal, but too loud or high-pitched. Children with Asperger's Disorder may not understand the subtleties of language, such as irony and humor, or they may not understand the give-and-take nature of a conversation.

Autism Spectrum Disorder

Another distinction between Asperger's Disorder and autism concerns cognitive ability. While some individuals with autism have intellectual disabilities, by definition, a person with Asperger's Disorder cannot have a "clinically significant" cognitive delay, and most possess average to above-average intelligence.

While motor difficulties are not a specific criterion for Asperger's, children with Asperger's Disorder frequently have motor skill delays and may appear clumsy or awkward.

Diagnosis

Diagnosis of Asperger's Disorder has increased in recent years, although it is unclear whether it is more prevalent or more professionals are detecting it. When Asperger's and autism were considered separate disorders under the *DSM-IV*, the symptoms for Asperger's Disorder were the same as those listed for autism; however, children with Asperger's do not have delays in the area of communication and language. In fact, to be diagnosed with Asperger's, a child must have normal language development as well as normal intelligence. The *DSM-IV* criteria for Asperger's specified that the individual must have "severe and sustained impairment in social interaction, and the development of restricted, repetitive patterns of behavior, interests and activities that must cause clinically significant impairment in social, occupational or other important areas of functioning."

The first step to diagnosis is an assessment, including a developmental history and observation. This should be done by medical professionals experienced with autism and other PDDs. Early diagnosis is also important as children with Asperger's Disorder who are diagnosed and treated early in life have an increased chance of being successful in school and eventually living independently.

Autism Spectrum Disorder

Autism

Used with permission by the National Institute of Neurological Disorders and Stroke
Website: www.ninds.nih.gov/

What is Autism?

Autistic disorder (sometimes called autism or classical ASD) is the most common condition in a group of developmental disorders known as the autism spectrum disorders (ASDs).

Autistic children have difficulties with social interaction, display problems with verbal and nonverbal communication, and exhibit repetitive behaviors or narrow, obsessive interests. These behaviors can range in impact from mild to disabling. Autism varies widely in its severity and symptoms and may go unrecognized, especially in mildly affected children or when more debilitating handicaps mask it. Scientists aren't certain what causes autism, but it's likely that both genetics and environment play a role.

Is there any treatment?

There is no cure for autism. Therapies and behavioral interventions are designed to remedy specific symptoms and can bring about substantial improvement. The ideal treatment plan coordinates therapies and interventions that meet the specific needs of individual children. Treatment options include educational/behavioral interventions, medications, and other therapies. Most professionals agree that the earlier the intervention, the better.

What is the prognosis?

For many children, autism symptoms improve with treatment and with age. Some children with autism grow up to lead normal or near-normal lives. Children whose language skills regress early in life, usually before the age of 3, appear to be at risk of developing epilepsy or seizure-like brain activity. During adolescence, some children with autism may become depressed or experience behavioral problems. Parents of these children should be ready to adjust treatment for their child as needed. People with an ASD usually continue to need services and support as they get older but many are able to work successfully and live independently or within a supportive environment.

What research is being done?

The National Institute of Neurological Disorders and Stroke (NINDS) conducts research in its laboratories at the National Institutes of Health (NIH) and also supports additional research through grants to major medical institutions across the country. As part of the Children's Health Act of 2000, the NINDS and three sister institutes have formed the NIH Autism Coordinating Committee to expand, intensify, and coordinate NIH's autism research. As part of the Children's Health Act of 2000, the NINDS and three sister institutes have formed the [NIH Autism Coordinating Committee](#) to expand, intensify, and coordinate NIH's autism research. Eight dedicated research centers across the country have been established as "Centers of Excellence in Autism Research" to bring together researchers and the resources they need. The Centers are conducting basic and clinical research, including investigations into causes, diagnosis, early detection, prevention, and treatment of autism.

Autism Spectrum Disorder

Asperger Syndrome

Used with permission by the National Institute of Neurological Disorders and Stroke
Website: www.ninds.nih.gov/

What is Asperger Syndrome?

Asperger syndrome (AS) is a developmental disorder. It is an autism spectrum disorder (ASD), one of a distinct group of neurological conditions characterized by a greater or lesser degree of impairment in language and communication skills, as well as repetitive or restrictive patterns of thought and behavior. Other ASDs include: classic autism, Rett syndrome, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified (usually referred to as PDD-NOS). Unlike children with autism, children with AS retain their early language skills.

The most distinguishing symptom of AS is a child's obsessive interest in a single object or topic to the exclusion of any other. Children with AS want to know everything about their topic of interest and their conversations with others will be about little else. Their expertise, high level of vocabulary, and formal speech patterns make them seem like little professors. Other characteristics of AS include repetitive routines or rituals; peculiarities in speech and language; socially and emotionally inappropriate behavior and the inability to interact successfully with peers; problems with non-verbal communication; and clumsy and uncoordinated motor movements.

Children with AS are isolated because of their poor social skills and narrow interests. They may approach other people, but make normal conversation impossible by inappropriate or eccentric behavior, or by wanting only to talk about their singular interest. Children with AS usually have a history of developmental delays in motor skills such as pedaling a bike, catching a ball, or climbing outdoor play equipment. They are often awkward and poorly coordinated with a walk that can appear either stilted or bouncy.

Is there any treatment?

The ideal treatment for AS coordinates therapies that address the three core symptoms of the disorder: poor communication skills, obsessive or repetitive routines, and physical clumsiness. There is no single best treatment package for all children with AS, but most professionals agree that the earlier the intervention, the better.

An effective treatment program builds on the child's interests, offers a predictable schedule, teaches tasks as a series of simple steps, actively engages the child's attention in highly structured activities, and provides regular reinforcement of behavior. It may include social skills training, cognitive behavioral therapy, medication for co-existing conditions, and other measures.

What is the prognosis?

With effective treatment, children with AS can learn to cope with their disabilities, but they may still find social situations and personal relationships challenging. Many adults with AS are able to work successfully in mainstream jobs, although they may continue to need encouragement and moral support to maintain an independent life.

Autism Spectrum Disorder

What research is being done?

Many of the Institutes at the NIH, including the NINDS, are sponsoring research to understand what causes AS and how it can be effectively treated. One study is using functional magnetic resonance imaging (fMRI) to show how abnormalities in particular areas of the brain cause changes in brain function that result in the symptoms of AS and other ASDs. Other studies include a clinical trial testing the effectiveness of an anti-depressant in individuals with AS and HFA who exhibit high levels of obsessive/ritualistic behavior and a long-range study to collect and analyze DNA samples from a large group of children with AS and HFA and their families to identify genes and genetic interactions that are linked to AS and HFA.

Autism Spectrum Disorder

Pervasive Developmental Disorders

Used with permission by the National Institute of Neurological Disorders and Stroke
Website: www.ninds.nih.gov/

What are Pervasive Developmental Disorders?

The diagnostic category of pervasive developmental disorders (PDD) refers to a group of disorders characterized by delays in the development of socialization and communication skills. Parents may note symptoms as early as infancy, although the typical age of onset is before 3 years of age. Symptoms may include problems with using and understanding language; difficulty relating to people, objects, and events; unusual play with toys and other objects; difficulty with changes in routine or familiar surroundings, and repetitive body movements or behavior patterns. Autism (a developmental brain disorder characterized by impaired social interaction and communication skills, and a limited range of activities and interests) is the most characteristic and best studied PDD. Other types of PDD include Asperger's Syndrome, Childhood Disintegrative Disorder, and Rett's Syndrome. Children with PDD vary widely in abilities, intelligence, and behaviors. Some children do not speak at all, others speak in limited phrases or conversations, and some have relatively normal language development. Repetitive play skills and limited social skills are generally evident. Unusual responses to sensory information, such as loud noises and lights, are also common.

Is there any treatment?

There is no known cure for PDD. Medications are used to address specific behavioral problems; therapy for children with PDD should be specialized according to need. Some children with PDD benefit from specialized classrooms in which the class size is small and instruction is given on a one-to-one basis. Others function well in standard special education classes or regular classes with additional support.

What is the prognosis?

Early intervention including appropriate and specialized educational programs and support services plays a critical role in improving the outcome of individuals with PDD. PDD is not fatal and does not affect normal life expectancy.

What research is being done?

The NINDS conducts and supports research on developmental disabilities, including PDD. Much of this research focuses on understanding the neurological basis of PDD and on developing techniques to diagnose, treat, prevent, and ultimately cure this and similar disorders.

Autism Spectrum Disorder

State Resources

Autism Society of Maine

72B Main Street

Winthrop, ME 04364

Phone Number: 1-800-273-5200

Website: <http://www.asmonline.org>

Maine Autism Institute for Education and Research

Website: <http://umaine.edu/autisminstitute/resources/>

Child Development Services

Phone: 1-877-770—8883

Website: <http://www.maine.gov/doe/cds/>

Maine Department of Education

23 State House Station

Augusta, ME 04333-0023

Voice: (207) 624-6600

Website: <http://maine.gov/doe/specialed>

Center for Community Inclusion and Disability Studies

225 Western Avenue

Augusta, Maine 04330

Phone: 207.623.3925 (V)

877.475.4800 (V)

207.629.5429 (Fax)

TTY users call Maine Relay 711

Website: <http://ccids.umaine.edu>

Maine Developmental Disabilities Council

225 Western Avenue, Suite 4

Augusta, ME 04330

Phone: 207-287-4213

Toll-free: 1-800-244-3990

Website: <http://www.maineddc.org>

Autism Spectrum Disorder

National Resources

National Autism Resource & Information Center

1825 K Street NW, Suite 1200
Washington, DC 20006

National Information and Referral Call Center

Phone: Toll Free: 855-8Autism (1-855-828-8476)

Website: <http://autismnow.org>

American Academy of Child and Adolescent Psychiatry

3615 Wisconsin Ave., NW
Washington, DC 20016-3007
Phone: 202-966-7300
Fax: 202-966-2891
Website: www.aacap.org

Autism Society of America

7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814-3067
Phone: 301-657-0881 or 800-3AUTISM
Website: www.autism-society.org

Wrightslaw

Website: www.wrightslaw.com

Center for Parent Information and Resources

Website Address: www.parentcenterhub.org

Association for behavior Analysis (ABA)

Website: www.abainternational.org

Association for Positive Behavioral Support (APBS)

Website: www.apbs.org

Autism Spectrum Disorder

Maine Parent Federation Lending Library

Library Procedures

The MPF Library is a valuable resource to families and professionals in Maine. The success of the library is greatly determined by the quality and availability of the materials we offer. To help us maintain our library, we ask that you follow these guidelines.

How to Request Materials

Call: 1-800-870-7746
or 207-588-1933

E-mail: dnewcombe@mpf.org
Fax: 207-588-1938

Write: MPF Library
P O Box 2067
Augusta, Maine 04338

Visit: 484 Maine Avenue, Suite 2D
Farmingdale, Maine 04344
Hours: 8:30 - 4:30 Mon. – Fri.

Library Policy

The complete library list is available in print or online at www.startingpointsforme.org.

You may borrow two materials at a time. You are responsible for the cost of return postage.

Materials will be mailed out on the day you request them if they are available.

Materials are loaned for a three-week period. If you need materials longer and call to check with us, we may be able to extend the due date if no one is waiting for them.

If materials are more than one week late we will ask you for a \$5 late fee donation payable to the MPF Library for every week the material is overdue. A reminder card will be mailed during the first week that materials are overdue.

We keep a waiting list for materials that are already on loan when you request them. You can ask that your name be added to the waiting list and materials will be mailed to you when they become available.

About the Library List

The library list is arranged by topic then listed alphabetically by title. Materials are not cross-referenced, so each title appears only once and you may have to check other sections.

*** Please remember - we are always adding new materials and updating the library list.**

Autism Spectrum Disorder

The following materials on **Autism Spectrum Disorder** are available from our lending library:

A Picture's Worth: PECS & Other Visual Communication Strategies in Autism by Andy Bondy, Ph.D. and Lori Frost, M.S. (Book) An easy-to-understand guide presenting the Picture Exchange Communication System to help children express needs and desires.

All Cats Have Asperger Syndrome by Kathy Hoopmann (Book)
Touching, insightful, humorous, this book evokes the joys and challenges of raising a child who is different.

Andy and His Yellow Frisbee by Mary Thompson (Children's Book)
This heartwarming story introduces young readers to autism.

Asperger Syndrome in Adolescence by Liane Holliday Willey (Book) Living with the ups and downs and all the things in between.

Asperger Syndrome by Tony Atwood (Book) Detailed discussions of the problems people with the syndrome will encounter and practical suggestions to help.

Asperger Syndrome – Crossing the Bridge by Liane Holliday & Dr. Tony Atwood (Video) Presents Asperger syndrome through the eyes of an adult diagnosed with the disorder.

Autism is a World a CNN Documentary (DVD) In Sue Rubin's own words, this DVD takes viewers on a journey into her mind, her daily world, and her life with autism.

Autism Through the Lifespan by David Holmes, Ed.D. (Book) The Eden Model – Presents an in-depth model for providing lifelong services for children and adults with autism.

Born on a Blue Day by Daniel Tammet (Book) A guide to the extraordinary mind of an autistic savant by the person himself, Daniel Tammet.

Born on the Wrong Planet by Erika Hammerschmidt (Book) The author recounts her struggles during her journey through life with Asperger's Syndrome.

Children with Autism by Michael Powers, Psy.D. (Book)
A parents guide that provides information about children with autism.

The Complete Guide to Asperger's Syndrome by Tony Atwood (Book) A good mix of research information, first person reports and clinical information in an easy-to-read, non-technical format.

Fragile Success by Virginia Walker Sperry (Book) A view of autism and all its variations – follow the story of ten children with autism from childhood to adulthood.

Getting the Best for Your Child with Autism by Bryna Siegel, Ph.D. (Book) A must-have resource for families dealing with autism spectrum disorders, offers step-by-step help for parents.

Autism Spectrum Disorder

Guns A'Blazing by Jeffrey Cohen (Book) Explains how parents of children on the Autism Spectrum and schools can work together to pave a path to academic success.

I Need Help with School! by Rebecca Moyes (Book) A guide for parents of children with Autism and Asperger Syndrome that will help demystify special education laws and help parents understand their legal rights and the rights of their child.

Joey & Sam by Ilana Katz & Edward Ritvo, MD (Children's Book)
A story about autism, family, and a brother's love.

A Mind Apart by Pater Szatmari, MD (Book) This book takes you on a voyage through the world of children and young adults with autism and Asperger syndrome.

Mind/Body Techniques for Asperger's Syndrome by Ron Rubio (Book) Offers exercises (with photographs) for people who experience difficulty with balance, gait, coordination, and sensory integration.

My Child Has Autism by Clarrissa Willis, Ph.D. (Book) Explains Autism in simple terms, discusses the major characteristics associated with Autism, and offers strategies to help children at home, in school, and in the community.

My Friend with Autism by Beverly Bishop (Children's Book) A book to help provide young children and their parents with information about their friends who have Autism Spectrum Disorder.

A Parent's Guide to Asperger Syndrome & High Functioning Autism by Ozonoff, Dawson & McPartland (Book) How to meet the challenges and help your child thrive.

Pervasive Development Disorder: An Altered Perspective by Barbara Quinn & Anthony Malone (Book) Provides realistic and practical information brought to life by the stories of families in which even the simplest of events is frighteningly complex.

Pretending to be Normal by Liane Holliday Willey (Book) This autobiography will allow others to understand the world as perceived by a person with Asperger Syndrome.

Reaching Out, Joining In by Mary Jane Weiss, Ph.D. and Sandra Harris, Ph.D. (Book)
This book shows ways to teach social skills to young children with autism.

Reweaving the Autistic Tapestry, Autism, Asperger Syndrome and ADHD by Lisa Blakemore-Brown (Book) Demonstrates how a deeper understanding of the complexity of human development can lead to more appropriate early intervention and treatment plans for children who manifest complex symptoms.

Right From the Start: Behavioral Intervention for Young Children with Autism by Sandra Harris, Ph.D. & Mary Jane Weiss, Ph.D. (Book)
Explains how the teaching method known as intensive behavioral intervention can benefit young children with autism and related disorders.

Autism Spectrum Disorder

Straight Talk About Autism by The Attainment Company, Inc. (Video)
Features interviews, explores new ideas and provides crucial survival tips.

Ten Things Every Child with Autism Wishes You Knew by Ellen Notbohm (Book) This book defines the top 10 characteristics that illuminate the minds and hearts of children.

Understanding Asperger's Produced by Larry Welkowitz, Ph.D. & Linda Baker, Ph.D. (Video)

Who Took My Shoe by Karen Emigh (Children's Book) Written by the mother of a son with Autism Spectrum Disorder, helps children understand the who, what, when questions.

A Will of His Own by Kelly Harland (Book) Harland gives an intimate, sometimes humorous look at a family in the process of unveiling the mysteries of Autism.

This is a partial list of the materials we have available on Autism Spectrum Disorders. To view the complete library list, visit our website at www.mpf.org.

Rev.7/2015