Autism Spectrum Disorder

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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.

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Autism Spectrum Disorder

What is autism spectrum disorder?

Autism spectrum disorder (ASD) refers to a group of complex neurodevelopment disorders characterized by repetitive and characteristic patterns of behavior and difficulties with social communication and interaction. The symptoms are present from early childhood and affect daily functioning.

The term “spectrum” refers to the wide range of symptoms, skills, and levels of disability in functioning that can occur in people with ASD. Some children and adults with ASD are fully able to perform all activities of daily living while others require substantial support to perform basic activities. The Diagnostic and Statistical Manual of Mental Disorders (DSM-5, published in 2013) includes Asperger syndrome, childhood disintegrative disorder, and pervasive developmental disorders not otherwise specified (PDD-NOS) as part of ASD rather than as separate disorders. A diagnosis of ASD includes an assessment of intellectual disability and language impairment.

ASD occurs in every racial and ethnic group, and across all socioeconomic levels. However, boys are significantly more likely to develop ASD than girls. The latest analysis from the Centers for Disease Control and Prevention estimates that 1 in 68 children has ASD.

What are some common signs of ASD?

Even as infants, children with ASD may seem different, especially when compared to other children their own age. They may become overly focused on certain objects, rarely make eye contact, and fail to engage in typical babbling with their parents. In other cases, children may develop normally until the second or even third year of life, but then start to withdraw and become indifferent to social engagement.

The severity of ASD can vary greatly and is based on the degree to which social communication, insistence of sameness of activities and surroundings, and repetitive patterns of behavior affect the daily functioning of the individual.

Social impairment and communication difficulties

Many people with ASD find social interactions difficult. The mutual give-and-take nature of typical communication and interaction is often particularly challenging. Children with ASD may fail to respond to their names, avoid eye contact with other people, and only interact with others to achieve specific goals. Often children with ASD do not understand how to play or engage with other children and may prefer to be alone. People with ASD may find it difficult to understand other people’s feelings or talk about their own feelings.

People with ASD may have very different verbal abilities ranging from no speech at all to speech that is fluent, but awkward and inappropriate. Some children with ASD may have delayed speech and language skills, may
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repeat phrases, and give unrelated answers to questions. In addition, people with ASD can have a hard time using and understanding non-verbal cues such as gestures, body language, or tone of voice. For example, young children with ASD might not understand what it means to wave goodbye. People with ASD may also speak in flat, robot-like or a sing-song voice about a narrow range of favorite topics, with little regard for the interests of the person to whom they are speaking.

Repetitive and characteristic behaviors

Many children with ASD engage in repetitive movements or unusual behaviors such as flapping their arms, rocking from side to side, or twirling. They may become preoccupied with parts of objects like the wheels on a toy truck. Children may also become obsessively interested in a particular topic such as airplanes or memorizing train schedules. Many people with ASD seem to thrive so much on routine that changes to the daily patterns of life — like an unexpected stop on the way home from school — can be very challenging. Some children may even get angry or have emotional outbursts, especially when placed in a new or overly stimulating environment.

What disorders are related to ASD?

Certain known genetic disorders are associated with an increased risk for autism, including Fragile X syndrome (which causes intellectual disability) and tuberous sclerosis (which causes benign tumors to grow in the brain and other vital organs) — each of which results from a mutation in a single, but different, gene. Recently, researchers have discovered other genetic mutations in children diagnosed with autism, including some that have not yet been designated as named syndromes. While each of these disorders is rare, in aggregate, they may account for 20 percent or more of all autism cases.

People with ASD also have a higher than average risk of having epilepsy. Children whose language skills regress early in life — before age 3 — appear to have a risk of developing epilepsy or seizure-like brain activity. About 20 to 30 percent of children with ASD develop epilepsy by the time they reach adulthood. Additionally, people with both ASD and intellectual disability have the greatest risk of developing seizure disorder.

How is ASD diagnosed?

ASD symptoms can vary greatly from person to person depending on the severity of the disorder. Symptoms may even go unrecognized for young children who have mild ASD or less debilitating handicaps.

Autism spectrum disorder is diagnosed by clinicians based on symptoms, signs, and testing according to the Diagnostic and Statistical Manual of Mental Disorders-V, a guide created by the American Psychiatric Association used to diagnose mental disorders. Children should be screened for developmental delays during periodic checkups and specifically for autism at 18- and 24-month well-child visits.

Very early indicators that require evaluation by an expert include:

- no babbling or pointing by age 1
- no single words by age 16 months or two-word phrases by age 2
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- no response to name
- loss of language or social skills previously acquired
- poor eye contact
- excessive lining up of toys or objects
- no smiling or social responsiveness

Later indicators include:

- impaired ability to make friends with peers
- impaired ability to initiate or sustain a conversation with others
- absence or impairment of imaginative and social play
- repetitive or unusual use of language
- abnormally intense or focused interest
- preoccupation with certain objects or subjects
- inflexible adherence to specific routines or rituals

If screening instruments indicate the possibility of ASD, a more comprehensive evaluation is usually indicated. A comprehensive evaluation requires a multidisciplinary team, including a psychologist, neurologist, psychiatrist, speech therapist, and other professionals who diagnose and treat children with ASD. The team members will conduct a thorough neurological assessment and in-depth cognitive and language testing. Because hearing problems can cause behaviors that could be mistaken for ASD, children with delayed speech development should also have their hearing tested.

What causes ASD?

Scientists believe that both genetics and environment likely play a role in ASD. There is great concern that rates of autism have been increasing in recent decades without full explanation as to why. Researchers have identified a number of genes associated with the disorder. Imaging studies of people with ASD have found differences in the development of several regions of the brain. Studies suggest that ASD could be a result of disruptions in normal brain growth very early in development. These disruptions may be the result of defects in genes that control brain development and regulate how brain cells communicate with each other. Autism is more common in children born prematurely. Environmental factors may also play a role in gene function and development, but no specific environmental causes have yet been identified. The theory that parental practices are responsible for ASD has long been disproved. Multiple studies have shown that vaccination to prevent childhood infectious diseases does not increase the risk of autism in the population.
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What role do genes play?
Twin and family studies strongly suggest that some people have a genetic predisposition to autism. Identical twin studies show that if one twin is affected, then the other will be affected between 36 to 95 percent of the time. There are a number of studies in progress to determine the specific genetic factors associated with the development of ASD. In families with one child with ASD, the risk of having a second child with the disorder also increases. Many of the genes found to be associated with autism are involved in the function of the chemical connections between brain neurons (synapses). Researchers are looking for clues about which genes contribute to increased susceptibility. In some cases, parents and other relatives of a child with ASD show mild impairments in social communication skills or engage in repetitive behaviors. Evidence also suggests that emotional disorders such as bipolar disorder and schizophrenia occur more frequently than average in the families of people with ASD.

In addition to genetic variations that are inherited and are present in nearly all of a person’s cells, recent research has also shown that de novo, or spontaneous, gene mutations can influence the risk of developing autism spectrum disorder. De novo mutations are changes in sequences of deoxyribonucleic acid or DNA, the hereditary material in humans, which can occur spontaneously in a parent’s sperm or egg cell or during fertilization. The mutation then occurs in each cell as the fertilized egg divides. These mutations may affect single genes or they may be changes called copy number variations, in which stretches of DNA containing multiple genes are deleted or duplicated. Recent studies have shown that people with ASD tend to have more copy number de novo gene mutations than those without the disorder, suggesting that for some the risk of developing ASD is not the result of mutations in individual genes but rather spontaneous coding mutations across many genes. De novo mutations may explain genetic disorders in which an affected child has the mutation in each cell but the parents do not and there is no family pattern to the disorder. Autism risk also increases in children born to older parents. There is still much research to be done to determine the potential role of environmental factors on spontaneous mutations and how that influences ASD risk.

Do symptoms of autism change over time?
For many children, symptoms improve with age and behavioral treatment. During adolescence, some children with ASD may become depressed or experience behavioral problems, and their treatment may need some modification as they transition to adulthood. People with ASD usually continue to need services and supports as they get older, but depending on severity of the disorder, people with ASD may be able to work successfully and live independently or within a supportive environment.

How is autism treated?
There is no cure for ASD. Therapies and behavioral interventions are designed to remedy specific symptoms and can substantially improve those symptoms. The ideal treatment plan coordinates therapies and interventions that meet the specific needs of the individual. Most health care professionals agree that the earlier the intervention, the better.

Educational/behavioral interventions: Early behavioral/educational interventions have been very successful in many children with ASD. In these interventions therapists use highly structured and intensive skill-oriented training sessions to help children develop social and language skills, such as applied behavioral analysis, which encourages positive behaviors and discourages negative ones. In addition, family counseling for the parents and
siblings of children with ASD often helps families cope with the particular challenges of living with a child with ASD.

**Medications:** While medication can’t cure ASD or even treat its main symptoms, there are some that can help with related symptoms such as anxiety, depression, and obsessive-compulsive disorder. Antipsychotic medications are used to treat severe behavioral problems. Seizures can be treated with one or more anticonvulsant drugs. Medication used to treat people with attention deficit disorder can be used effectively to help decrease impulsivity and hyperactivity in people with ASD. Parents, caregivers, and people with autism should use caution before adopting any unproven treatments.

**What research is being done?**

The mission of the National Institute of Neurological Disorders and Stroke (NINDS) is to seek fundamental knowledge about the brain and nervous system and to use that knowledge to reduce the burden of neurological disease. The NINDS is a component of the National Institutes of Health (NIH), the leading supporter of biomedical research in the world. NINDS and several other NIH Institutes and Centers support research on autism spectrum disorder.

Nearly 20 years ago the NIH formed the Autism Coordinating Committee (NIH/ACC) to enhance the quality, pace, and coordination of efforts at the NIH to find a cure for autism. The NIH/ACC has been instrumental in promoting research to understand and advance ASD. The NIH/ACC also participates in the broader Federal Interagency Autism Coordinating Committee (IACC), composed of representatives from various U.S. Department of Health and Human Services agencies, the Department of Education, and other governmental organizations, as well as public members, including individuals with ASD and representatives of patient advocacy organizations. One responsibility of the IACC is to develop a strategic plan for ASD research, which guides research programs supported by NIH and other participating organizations.

NINDS and several other NIH institutes support autism research through the Autism Centers of Excellence (ACE), a trans-NIH initiative that supports large-scale multidisciplinary studies on ASD, with the goal of determining the causes of autism and finding new treatments. NINDS currently supports an ACE network focused on ASD and tuberous sclerosis complex (TSC). ASD occurs in approximately half of TSC patients. In particular, the ACE investigators are studying whether certain brain imaging and activity measures in infants diagnosed with TSC can predict the development of ASD. Such biomarkers could aid in understanding how and why ASD occurs in some children but not others, and help to identify patients who might benefit from early intervention. Other ACE centers and networks are investigating early brain development and functioning; genetic and non-genetic risk factors, including neurological, physical, behavioral, and environmental factors present in the prenatal period and early infancy; and potential therapies.

NINDS funds additional research aimed at better understanding the factors that lead to ASD, including other studies on genetic disorders associated with ASD, such as TSC, Fragile X Syndrome, Phelan-McDermid syndrome (which features such autism-like symptoms as intellectual disability, developmental delays, and problems with developing functional language), and Rett syndrome (a disorder that almost exclusively affects girls and is characterized by slowing development, intellectual disability, and loss of functional use of the hands). Many of these studies use animal models to determine how specific known mutations affect cellular and developmental processes in the brain, yielding insights relevant to understanding ASD due to other causes and discovering new targets for treatments.
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NINDS researchers are studying aspects of brain function and development that are altered in people with ASD. For example, NINDS-funded researchers are investigating the formation and function of neuronal synapses, the sites of communication between neurons, which may not properly operate in ASD and neurodevelopmental disorders. Other studies use brain imaging in people with and without ASD to identify differences in brain connectivity and activity patterns associated with features of ASD. Researchers hope that understanding these alterations can help identify new opportunities for therapeutic interventions. Additional NINDS researchers are studying the relationship between epilepsy and autism.

Through the National Center for Advancing Translational Sciences (NCATS) Rare Disease Clinical Research Network (RDCKR), NINDS and other NIH Institutes and Centers support a research consortium focused on three rare genetic syndromes associated with ASD and intellectual disability, including TSC and syndromes involving mutations in the genes SHANK3 (Phelan-McDermid syndrome) and PTEN. The goals of the consortium are to understand shared mechanisms across these syndromes, which may suggest common approaches to their treatment.

NINDS supports autism spectrum disorder research through clinical trials at medical centers across the United States to better our knowledge about ASD treatment and care. Information about participating in clinical studies can be found at the “NIH Clinical Trials and You” website at www.nih.gov/health/clinicaltrials. Additional studies can be found at www.clinicaltrials.gov. People should talk to their doctor before enrolling in a clinical trial.

More information about research on ASD supported by NINDS and other NIH Institutes and Centers can be found using NIH RePORTER (projectreporter.nih.gov), a searchable database of current and past research projects supported by NIH and other federal agencies. RePORTER also includes links to publications and resources from these projects.

Where can I get more information?

For more information on neurological disorders or research programs funded by the National Institute of Neurological Disorders and Stroke, contact the Institute’s Brain Resources and Information Network (BRAIN) at:

BRAIN
P.O. Box 5801
Bethesda, MD 20824
800-352-9424
http://ninds.nih.gov

Information also is available from the following organizations:

Centers for Disease Control and Prevention (CDC)
U.S. Department of Health and Human Services
1600 Clifton Road
Atlanta, GA 30333
inquiry@cdc.gov
https://www.cdc.gov/
Tel: 800-311-3435; 404-639-3311; 404-639-3543
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National Institute of Child Health and Human Development (NICHD)
National Institutes of Health, DHHS
31 Center Drive, Rm. 2A32 MSC 2425
Bethesda, MD 20892-2425
http://www.nichd.nih.gov
Tel: 301-496-5133
Fax: 301-496-7101

National Institute on Deafness and Other Communication Disorders (NIDCD)
National Institutes of Health, DHHS
31 Center Drive, MSC 2320
Bethesda, MD 20892-2320
nidcdinfo@nidcd.nih.gov
http://www.nidcd.nih.gov
Tel: 301-496-7243; 800-241-1044; 800-241-1055 (TTY)

National Institute of Environmental Health Sciences (NIEHS)
National Institutes of Health, DHHS
111 T.W. Alexander Drive
Research Triangle Park, NC 27709
webcenter@niehs.nih.gov
http://www.niehs.nih.gov
Tel: 919-541-3345

National Institute of Mental Health (NIMH)
National Institutes of Health, DHHS
6001 Executive Blvd. Rm. 8184, MSC 9663
Bethesda, MD 20892-9663
nimhinfo@nih.gov
http://www.nimh.nih.gov
Tel: 301-443-4513; 866-415-8051; 301-443-8431 (TTY)
Fax: 301-443-4279

Association for Science in Autism Treatment
P.O. Box 1447
Hoboken, NJ 07030
info@asatonline.org
http://www.asatonline.org

Autism National Committee (AUTCOM)
P.O. Box 429
Forest Knolls, CA 94933
http://www.autcom.org
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Autism Network International (ANI)
P.O. Box 35448
Syracuse, NY 13235-5448
jisincl@syru.edu
http://www.autismnetworkinternational.org

Autism Research Institute (ARI)
4182 Adams Avenue
San Diego, CA 92116
director@autism.com
http://www.autismresearchinstitute.com
Tel: 619-281-7165; 866-366-3361
Fax: 619-563-6840

Autism Science Foundation
28 West 39th Street
Suite 502
New York, NY 10018
contactus@autismsciencefoundation.org
http://www.autismsciencefoundation.org
Tel: 212-391-3913
Fax: 212-228-3557

Autism Society of America
4340 East-West Highway
Suite 350
Bethesda, MD 20814
http://www.autism-society.org
Tel: 301-657-0881; 800-3AUTISM (328-8476)
Fax: 301-657-0869

Autism Speaks, Inc.
1 East 33rd Street
4th Floor
New York, NY 10016
contactus@autismspeaks.org
http://www.autismspeaks.org
Tel: 212-252-8584; 888-288-4762
Fax: 212-252-8676

MAAP Services for Autism, Asperger Syndrome, and PDD
P.O. Box 524
Crown Point, IN 46308
info@aspergerssyndrome.org
http://www.aspergerssyndrome.org
Tel: 219-662-1311
Fax: 219-662-1315
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What is Autism?

Autism Society
Website: www.autism-society.org

Signs and Symptoms

The characteristic behaviors of autism spectrum disorder may be apparent in infancy (18 to 24 months), but they usually become clearer during early childhood (24 months to 6 years).

As part of a well-baby or well-child visit, your child’s doctor should perform a “developmental screening,” asking specific questions about your baby’s progress. The National Institute of Child Health and Human Development (NICHD) lists five behaviors that warrant further evaluation:

- Does not babble or coo by 12 months
- Does not gesture (point, wave, grasp) by 12 months
- Does not say single words by 16 months
- Does not say two-word phrases on his or her own by 24 months
- Has any loss of any language or social skill at any age

Any of these five “red flags” does not mean your child has autism. But because the disorder’s symptoms vary so widely, a child showing these behaviors should be evaluated by a multidisciplinary team. This team might include a neurologist, psychologist, developmental pediatrician, speech/language therapist, learning consultant or other professionals who are knowledgeable about autism.

For more information, visit the Infants and Toddlers page or the CDC’s “Learn the Signs. Act Early” program.

Diagnosis

When parents or support providers become concerned that their child is not following a typical developmental course, they turn to experts, including psychologists, educators and medical professionals, for a diagnosis.

At first glance, some people with autism may appear to have an intellectual disability, sensory processing issues, or problems with hearing or vision. To complicate matters further, these conditions can co-occur with autism. However, it is important to distinguish autism from other conditions, as an accurate and early autism diagnosis can provide the basis for an appropriate educational and treatment program.

Other medical conditions or syndromes, such as sensory processing disorder, can present symptoms that are confusingly similar to autism’s. This is known as differential diagnosis.

There are many differences between a medical diagnosis and an educational determination, or school evaluation, of a disability. A medical diagnosis is made by a physician based on an assessment of symptoms and diagnostic tests. A medical diagnosis of autism spectrum disorder, for instance, is most frequently made by
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a physician according to the Diagnostic and Statistical Manual (DSM-5, released 2013) of the American Psychological Association. This manual guides physicians in diagnosing autism spectrum disorder according to a specific number of symptoms.

A brief observation in a single setting cannot present a true picture of someone’s abilities and behaviors. The person’s developmental history and input from parents, caregivers and/or teachers are important components of an accurate diagnosis.

An educational determination is made by a multidisciplinary evaluation team of various school professionals. The evaluation results are reviewed by a team of qualified professionals and the parents to determine whether a student qualifies for special education and related services under the Individuals with Disabilities Education Act (IDEA) (Hawkins, 2009).

Medical Diagnosis

There are no medical tests for diagnosing autism. An accurate diagnosis must be based on observation of the individual’s communication, social interaction, and his or her activities and interests.

Because many of the behaviors associated with autism are common to other disorders, some medical tests can be performed in order to identify other causes or diagnoses. People with autism often have symptoms of various co-occurring mental, behavioral and physical conditions.

Medical professionals who may have experience with autism and other neurodevelopmental disorders include pediatricians (especially developmental pediatricians), neurologists (specifically pediatric neurologists), and child and adolescent psychiatrists. Not every one of these professionals has experience with autism, so parents and caregivers should seek recommendations of knowledgeable professionals in their area from:

- their local Autism Society affiliate
- autism support groups
- people who have children or other family members with autism
- their primary-care provider

A skilled practitioner can begin the assessment; the evaluation itself can vary depending on the professional administering it, the age of the person being assessed, the severity of his or her symptoms, and local available resources.

For example, if a very young child (1-3 years old) is showing significant developmental delays, a primary-care practitioner may refer the family to a psychologist, pediatric neurologist or developmental pediatrician for a diagnostic assessment. Read this guide from the Autism Advocate to learn more.

An initial medical assessment typically includes:

- a medical history of the mother’s pregnancy
- developmental milestones
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- eating and sleeping habits
- coordination
- stomach and bowel functioning
- sensory challenges

- allergies
- medical illnesses, including ear infections and seizures
- any family history of developmental disorders
- any family history of genetic and metabolic disorders
- parents’ and the child’s exposure to environmental toxins
- a thorough physical exam
- routine lab tests

While there is no one behavioral or communications test that can detect autism, several screening instruments are now being used in diagnosing it.

School Evaluation

The first step in obtaining special education services is for your child to be evaluated. The evaluation can be done when your child is first suspected of having a disability (pre-placement evaluation) or when your child’s level of functioning changes in one or more areas (re-evaluation). There are two ways in which a child can be evaluated under the Individuals with Disabilities Education Act:

• The parent can request an evaluation by calling or writing the director of special education or the principal of the child’s school.

If you call, put your request in writing as well, keeping a copy for yourself. This should be part of your routine communication with anyone concerning your child’s education. Follow up on all telephone calls with a letter summarizing the conversation. This way, the other party has the opportunity to make corrections to any misunderstood information, and you have a paper trail in case of a disagreement with the school system.

• The school system may determine that an evaluation is necessary. If so, they must receive written permission from the parent before conducting the evaluation.

An evaluation should be conducted by a multidisciplinary team or group, which must include at least one teacher or other specialist with specific knowledge in the area of the suspected disability. IDEA mandates that no single procedure can be used as the sole criterion for determining an appropriate education program. The law also requires that the child be assessed in all areas related to the suspected disability, including but not limited to health, vision, hearing, communication abilities, motor skills, and social and/or emotional status.
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If the parents disagree with the results of the evaluation, they may choose to obtain an independent evaluation at public or private expense. You may request a list of professionals that meet state requirements from your school, or you can choose one on your own. If the professional chosen meets appropriate criteria set up by the state, then the school must consider his/her evaluation in developing an IEP.

Re-Evaluation

The above standards also apply for a child who already receives special education services. A re-evaluation must take place at least every three years. It may, however, be conducted more often if the parent or a teacher makes a written request. An evaluation may also focus on a specific area of concern. A re-evaluation of all areas of suspected need is necessary if parents feel their child is not meeting the short-term objectives of his/her current IEP.

Parents who feel their child’s placement should be changed need to have a basis for the request. For example, a child may be exhibiting new problem behaviors. It may be necessary to reassess his/her placement or develop new behavior techniques to address this area. As a first step, an evaluation by a specialist familiar with ASD behaviors could be requested. The IEP can then be changed to reflect the results of the evaluation.

For example, a child may have an annual goal to increase her language production and comprehension skills, but is not meeting the objectives developed in her IEP for this goal. The parent may wish to request a re-evaluation with a speech therapist who is knowledgeable about autism. It may be determined from the results that an increase in the weekly number of hours of therapy is necessary.

A re-evaluation of all areas of suspected need may come prior to the scheduled annual IEP meeting. If the child has made significant progress since the last evaluation, the treatment, placement and therapy recommendations may no longer be applicable. A re-evaluation addressing all areas would become the basis for a more appropriate IEP.

Parents may suggest that professionals with knowledge of autism be present at the school for these evaluations. The school does not have to use the suggested professional, but may appreciate the assistance in finding a qualified person. As explained above, if the parents disagree with the school’s evaluation, they do have a right to acquire an independent evaluation.

The evaluation (school or independent) should become the basis for writing the child’s IEP. The IEP must be prepared and agreed upon before placement decisions are made, rather than written after the fact to fit the placement decision.

Differential Diagnosis

Some conditions may have symptoms similar to autism; therefore, professionals must be diligent when determining a diagnosis and its treatment.
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Following is a list of related syndromes/disorders that manifest behaviors similar to those of autism and/or are more prevalent in individuals with autism:

**Congenital Rubella Syndrome:** Helen Keller National Center for Deaf-Blind Youths and Adults

**Cornelia deLange Syndrome:** Cornelia deLange Syndrome Foundation

**Down Syndrome:** National Down Syndrome Society

**Fragile X Syndrome:** National Fragile X Foundation

**Klüver-Bucy Syndrome:** National Institute of Neurological Disorders and Stroke

**Landau-Kleffner Syndrome:** National Institute of Neurological Disorders and Stroke

**Lesch-Nyhan Syndrome:** Lesch-Nyhan Disease network

**Untreated Phenylketonuria (PKU):** National PKU Alliance

**Prader-Willi Syndrome:** Prader-Willi Syndrome Association

**Rett Syndrome:** International Rett Syndrome Foundation

**Tourette Syndrome:** Tourette Syndrome Association

**Tuberous Sclerosis:** Tuberous Sclerosis Alliance

**Williams Syndrome:** Williams Syndrome Association

Although autism is commonly thought of as a mental health disorder, it is a whole-body condition and can manifest through a number of physical symptoms and characteristics.

**Related Conditions**

• **Allergies/ Immune System:** Many individuals with autism also suffer immune system deficiencies or immune dysregulation. Within the autism spectrum population, there are groups that will experience rashes, allergic sensitivities, gastrointestinal, ear and other infections as a result. Immune deficiencies and/or immune dysregulation make a person with autism more vulnerable to infection, chronic inflammation and autoimmune reactions, most frequently in the brain and gastrointestinal tract (Jepson, 2007).
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-Chronic Constipation and/or Diarrhea: Medical literature states that about 47 percent of adults on the spectrum and 45 percent of children with autism have gastrointestinal symptoms. Diarrhea is most common, abdominal pain is cited next most frequently, and constipation is reported slightly less. Constipation in autism is usually not hard, impacted stools, but the slow passage of stools with long gaps in between, and loose stools when they do come.

-Low IQ: Research studies have frequently used inappropriate IQ tests, such as verbal tests with nonverbal children, and in some cases have estimated children’s intelligence level without any objective evidence. Tests that do not require language skills, such as the Test of Nonverbal Intelligence (TONI), can offer more accurate information about the person.

-Low Muscle Tone: About 30 percent of children with autism have moderate to severe loss of muscle tone, which can limit their gross and fine motor skills.

-Pain: Some people with autism have very high pain thresholds (insensitivity to pain), while others have very low pain thresholds. There are interventions, such as sensory integration therapy, designed to help normalize their senses.

-Pica: About 30 percent of children with autism have moderate to severe pica, which means they eat non-food items such as paint, sand, dirt, paper, etc. Pica can be dangerous as ingesting these inedible substances can cause choking, digestive problems, parasitic infections and other illnesses.

-Seizures: It is estimated that around 30 percent of people with autism develop epilepsy, some in early childhood and others as they go through hormone level changes in puberty. Suspected seizures should be confirmed by electroencephalogram (EEG) and treated with prescribed anticonvulsant medications.

-Sensory Processing Disorder: Many people with autism have sensory processing disorder (formerly known as sensory integration disorder), which involves unusual sensitivities to sounds, sights, touch, taste and smells. High-pitched intermittent sounds, such as fire alarms or school bells, may be painful to these children. Scratchy fabrics and clothing tags may also be intolerable, and some children have visual sensitivities, such as to the flickering of fluorescent lights.

-Sleep Problems: Many individuals with autism have sleep problems. Night waking may be due to gastrointestinal issues, allergies, environmental intolerances, seizures or the effects of medications. Other potential causes are sleep apnea (pauses in breathing when the airway becomes obstructed during sleep), sleep terrors or confusional arousals. Children with sensory processing difficulties may have more problems falling asleep and increased periods of night waking. The Autism Society offers a guide on sleep problems and strategies for solving them.

Hearing and Visual Impairments

Children with a dual diagnosis of autism and a sensory impairment face many possible paths. If the child is born deaf/hard of hearing or blind/visually impaired, that diagnosis is usually made early on, and autism behaviors may be mistaken for a reaction to the sensory loss. Conversely, if a child with autism has progressive hearing and visual impairments, his or her adaptation to the sensory loss may be misunderstood as a behavior.
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of autism. For more information, visit the Nebraska Center for the Education of Children who are Blind or Visually Impaired or this article about autism and deafness.

About 30 percent of children receiving education related to deafness/hard of hearing and blindness/visual impairment are also identified as having autism. Every child should be able to enter his/her education program in the best aural and visual health possible, and should be monitored and tested to ensure continued health and care. For more in-depth information on hearing and vision screenings for people with autism, see this article from the Autism Advocate.

Families can feel overwhelmed and isolated while searching for information. An Autism Society subgroup, the Autism Network For Individuals Deaf/Hard Of Hearing and Blind/Visually Impaired, holds its annual meeting at the Autism Society’s National Conference every July. The network, which has worldwide family and professional membership, provides links to other families and researchers through the Autism Research Institute.

DSM-5

The American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders, most recently released as the DSM-5 in 2013, is used by many organizations, individuals and government to diagnosis psychiatric disorders such as autism.

The DSM-5 redefined autism. Its predecessor, the DSM-IV-TR, included five Pervasive Developmental Disorders (PDDs): Autistic Disorder, Asperger’s Disorder, Rett’s Disorder, Childhood Disintegrative Disorder and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS).

In the DSM-5, Autistic Disorder, Asperger’s Disorder and PDD-NOS are replaced by the diagnosis of Autism Spectrum Disorder. Additionally, the DSM-5 also reduces social-related elements of autism into social communication impairment and repetitive/restricted behaviors, though the labels of Asperger’s and PDD-NOS are still in common use.

Those who worked on the DSM-5 repeated many times that no one who already had a diagnosis of autism will be impacted by these changes. However, it is possible that the government and other program providers might choose to re-diagnose their beneficiaries under the new definition to determine whether they are still considered to be living with autism for purposes of receiving services.

We applaud the National Institute of Mental Health and its director Dr. Tom Insel, who has chosen not to place so much weight on the DSM-5 diagnosis categories. NIMH will not use DSM categories as the “gold standard” and will begin moving away from an exclusive focus on symptom-based categories.

The Autism Society strongly urges every government unit and service provider not to reduce or eliminate services to people who were already getting services. In addition, we encourage them to fully understand and appreciate that a person who might not be defined as living with autism under the new DSM-5 criteria might still need a helping hand.
Autism Spectrum Disorder

Screening Instruments

Early identification is associated with dramatically better outcomes for people with autism. The earlier a child is diagnosed, the earlier he or she can begin benefiting from early intervention treatment and education.

The Centers for Disease Control and Prevention’s National Center on Birth Defects and Developmental Disabilities (NCBDD) recommends that all children be screened for autism by their family pediatrician three times by the age of three — at nine, 18, and 24 or 30 months. Treatment should start when an autism diagnosis is suspected, rather than when a formal diagnosis is made.

The advantages of early intervention cannot be overemphasized. Children who receive intensive therapy can make tremendous strides in their overall functioning.

The NCBDD provides a wealth of information on the early signs of autism through its “Learn the Signs. Act Early” initiative.

While there is no one behavioral or communications test that can detect autism, several screening instruments have been developed for use in diagnosing it. For detailed information about these instruments and the research behind them, see this guide from the Texas Statewide Leadership for Autism Training.
Autism Spectrum Disorder

State Resources

Autism Society of Maine
72B Main Street
Winthrop, ME 04364
Phone Number: 1-800-273-5200
Website: www.asmonline.org

Maine Autism Institute for Education and Research
5766 Shibles Hall
Orono, ME 04469
Tel: 207.581.2352
Website: https://umaine.edu/autisminstitute/resources/

Autism Speaks Maine
Website: www.autismspeaks.org/resource-guide/state/ME

Child Development Services
The Child Development Services system is an Intermediate Educational Unit that provides both Early Intervention (birth through two years) and Free Appropriate Public Education (for ages three through five years) under the supervision of the Maine Department of Education. The CDS system ensures the provision of special education rules, federal and state regulations statewide, through a network of regional sites
Referral Line: 1-877-770-8883
Website: www.main.gov/doi/cds/

Maine Department of Education - Special Services
The Office of Special Services is responsible for the state’s oversight and support for the delivery of all special education services provided in Maine under the federal Individuals with Disabilities Education Act (IDEA). This includes early intervention services to eligible children age birth to under age three and their families, provided under IDEA, Part C, and Free Appropriate Public Education to eligible children age three to 20, provided under IDEA, Part B. The Office of Special Services is also responsible for meeting the state’s responsibilities under IDEA.
Phone: 624-6600
Website: www.main.gov/doi/specialed/

Disability Rights Maine
24 Stone St, Ste. 204
Augusta, ME 04330
800.452.1948 (V/TTY)
207.626.2774 (V/TTY)
207.621.1419 (FAX)
advocate@drme.org
Website: http://drme.org/
Autism Spectrum Disorder

National Resources

**National Institute of Neurological Disorders and Stroke**  
Website: [www.ninds.nih.gov](http://www.ninds.nih.gov)

**Autism Research Institute**  
Website: [www.autism.com/index.asp](http://www.autism.com/index.asp)

**Autism Society of America**  
Website: [www.autism-society.org/](http://www.autism-society.org/)

**Autism Speaks**  
Website: [www.autismspeaks.org](http://www.autismspeaks.org)

**Center for Disease Control: Learn the Signs**  
Website: [www.cdc.gov/ncbddd/actearly/index.html](http://www.cdc.gov/ncbddd/actearly/index.html)
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
Farmirgdale, Maine 04344
Hours: 8:30-4:30, Mon.–Fri.

Library Policy:

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

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

Materials are loaned for a 3 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.

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 want to check other sections.

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

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

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<thead>
<tr>
<th>Title</th>
<th>Author(s)</th>
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<tr>
<td>1001 Great Ideas for Teaching &amp; Raising Children w/ Autism or</td>
<td>Ellen Notbohm &amp; Veronica Zysk</td>
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<td>101 Tips for Parents of Children with Autism</td>
<td>Arnold Miller and Theresa Smith</td>
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<tr>
<td>All Cats Have Asperger Syndrome</td>
<td>Kathy Hoopmann</td>
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<td>Andy and His Yellow Frisbee</td>
<td>Mary Thompson</td>
<td>Children's Book</td>
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<td>Aquamarine Blue 5</td>
<td>Dawn Prince Hughes</td>
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<tr>
<td>Asperger Syndrome - Crossing the Bridge</td>
<td>Liane Holliday Willey &amp; Dr. Tony Atwood</td>
<td>Video</td>
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<tr>
<td>Asperger Syndrome in Adolescence</td>
<td>Liane Holliday Willey</td>
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<tr>
<td>Asperger Syndrome: A Different Mind</td>
<td>Narrated by Simon Baron-Cohen</td>
<td>DVD</td>
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</table>
## Asperger's Syndrome

**Tony Atwood**  
**Book**  
223 Pages  
Detailed discussions of the problems people with the syndrome will encounter and practical suggestions to help.

## Autism is a World

**CNN Documentary**  
**DVD**  
40 Mins.  
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

**David Holmes, Ed.D.**  
**Book**  
383 Pages  
The Eden Model - Presents an in-depth model for providing lifelong services for children and adults with Autism.

## Behavior Support for Students with ASD: Practical Help for 10 Common

**Debra Leach**  
**Book**  
245 Pages  
This practical, user-friendly guide will help you understand and develop comprehensive individualized interventions based on the unique challenges of each student.

## Born on a Blue Day

**By Daniel Tammet**  
**Book**  
237 Pages  
A guide into the extraordinary mind of an autistic savant by the person himself, Daniel Tammet.

## Born on the Wrong Planet

**Erika Hammerschmidt**  
**Book**  
198 Pages  
The author recounts her struggles during her journey through life with Asperger's Syndrome.

## Chasing the Rabbit: A Dad's Life Raising a Son on the Spectrum

**Derek Volk with Dylan Volk**  
**Book**  
265 Pages  
This colorful book is peppered with anecdotes as Derek shares his experiences raising a son on the Autism Spectrum.

## Children with Autism - Diagnosis and Interventions

**Trevathen, Aitken, Papoudi & Robarts**  
**Book**  
348 Pages  
Understanding Autism and normal infant development.

## Complete Guide to Asperger’s Syndrome, The

**Tony Atwood**  
**Book**  
397 Pages  
A good mix of research information, first person reports and clinical information in an easy-to-read, nontechnical format.
Fragile Success
Virginia Walker Sperry  Book  242 Pages
A view of Autism in all its variations - follow the story of ten children with Autism from childhood to adulthood.

Functional Behavior Assessment for People with Autism
Beth Glasberg, Ph.D. & Robert LaRue, Ph.D.  Book  171 Pages
Making sense of seemingly senseless behavior - shows how to use FBAs to unlock an unwanted behavior's purpose and change it and much more.

Getting the Best for Your Child with Autism
Bryna Siegel, Ph.D  Book  277 Pages
A must-have resource for families dealing with Autism Spectrum Disorders, offers step-by-step help for parents.

Guns A’ Blazing
Jeffrey Cohen  Book  209 Pages
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!
Rebecca A. Moyes  Book  191 Pages
A guide for parents of children with Autism and Asperger's syndrome, offers info. on 504 plans, IEPs, and much more.

Ian’s Walk
Laurie Lears  Children’s Book
A story about Autism and feelings.

Joey and Sam
Illana Katz & Edward Ritvo, M.D.  Children’s Book
A storybook about Autism, a family, and a brother's love.

Making Our Way
A Production of MPBN  DVD
This documentary on Autism seeks to demystify Autism and examines a broad spectrum of experiences and successes. Features an interview with Temple Grandin.

Mind Apart, A
Peter Szatmari, MD  Book  209 Pages
This book takes you on a voyage through the world of children and young adults with Autism and Asperger’s syndrome.
Mind/Body Techniques for Asperger’s Syndrome
Ron Rubio  
Book  
150 Pages
Offers exercises (with photographs) for people who experience difficulty with balance, gait, coordination and sensory integration.

My Child Has Autism
Clarissa Willis, Ph.D.  
Book  
160 Pages
Explain 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
Beverly Bishop  
Children’s Book  
30 Pages
A book to help provide young children and their parents with information about their friends who have Autism Spectrum Disorder.

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

Parenting a Child with Asperger Syndrome
Brenda Boyd  
Book  
202 Pages
Brenda, who’s son has AS, offers 200 tips and strategies for parents and teachers that will have a positive effect and help you understand ‘Planet Asperger’.

Parenting a Teen or Young Adult with Asperger Syndrome
Brenda Boyd  
Book  
240 Pages
Brenda, who’s son has AS, offers 325 ideas, insights, tips, and parenting strategies, full of down-to-earth and up-to-date advice.

Pervasive Developmental Disorder - An Altered Perspective
Barbara Quinn & Anthony Malone  
Book  
157 Pages
Written for parents, the author provides realistic and practical information brought to life by the stories of families.

Picture’s Worth, A : PECS & Other Visual Comm. Strategies in Autism
Andy Bondy, Ph.D. & Lori Frost, M.S.,  
Book  
155 Pages
Easy-to-understand guide presenting the Picture Exchange Communication System to help children express needs & desires.

Playing It Right!
Rachel Bareket  
Book  
101 Pages
Social skills activities for parents and teachers of young children with Autism Spectrum Disorders, including Asperger Syndrome and Autism.
<table>
<thead>
<tr>
<th>Title</th>
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<tr>
<td>Pretending to be Normal</td>
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<tr>
<td>Liane Holliday Willey</td>
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<tr>
<td>This autobiography will allow others to understand the world as perceived by a person with Asperger's Syndrome.</td>
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<td>Reaching Out, Joining In</td>
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<td>Mary Jane Weiss, Ph.D., BCBA &amp; Sandra</td>
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<td>This book shows ways to teach social skills to young children with Autism.</td>
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<tr>
<td>Reweaving the Autistic Tapestry</td>
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<tr>
<td>Lisa Blakemore-Brown</td>
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<td>This book offers an in-depth look at the links between ADHD and Autism Spectrum Disorders.</td>
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<td>Right From the Start - Behavioral Intervention for Young Children</td>
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<td>Sandra Harris, Ph.D. &amp; Mary Jane Weiss, Ph.</td>
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<tr>
<td>Explains how the teaching method known as intensive behavioral intervention can benefit young children with Autism &amp; related disorders.</td>
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<td>Straight Talk About Autism</td>
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<td>Attainment Company, Inc.</td>
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<tr>
<td>Features interviews, explores new ideas and provides crucial survival tips.</td>
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<tr>
<td>Ten Things Every Child With Autism Wishes You Knew</td>
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<tr>
<td>Ellen Notbohm</td>
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<td>This book defines the top 10 characteristics that illuminate the minds and hearts of children with Autism.</td>
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<td>The Autism Playbook for Teens</td>
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<tr>
<td>Irene McHenry, Ph.D. &amp; Carol Moog, Ph.D.</td>
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<tr>
<td>Imagination-based mindfulness activities to calm yourself, build independence, and connect with others.</td>
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<tr>
<td>Treasure Chest of Behavioral Strategies for Individuals with Autism, A</td>
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<td>Beth Fouse Ph.D. &amp; Maria Wheeler, M.Ed.</td>
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<td>A comprehensive, easy-to-understand book full of practical tools for behavioral strategies, intervention strategies and case examples.</td>
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<td>Understanding Asperger's</td>
<td>Video</td>
<td>29</td>
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<tr>
<td>Produced by Larry Welkowitz, Ph.D. &amp; Linda Baker, Ph.D., Keene State College, Keene, NH</td>
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</tbody>
</table>
Who Took My Shoe?
Karen Emigh  
Children's Book  
19 Pages
Written by the mother of a son with Autism Spectrum Disorder, helps children understand the who, what, and when questions.

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