

What is **AUTISM?**



What is Autism?

Autism is complex. It is a disorder that affects each child differently. However, most children have problems with communication (speaking and understanding others). The symptoms show up early in life (sometimes in infancy), but generally before three (3) years of age, and may become more noticeable as the child matures. See: <http://www.ninds.nih.gov/disorders/autism/autism.htm>

What is the difference between autism and pervasive developmental disorder—not otherwise specified (PDD-NOS) and autism spectrum disorder (ASD)?

These terms are based on a medical classification system called the Diagnostic and Statistical Manual of Mental Disorders (DSMIV).^{*1} **This classification system will change with the DSMV.**

In general, a diagnosis of

1. **Autism** is used when a child shows problems before age three in social interaction (interest and play with others), verbal and non-verbal communication (i.e., words and gestures), and shows unusual behavior and interests.
2. **PDD-NOS** is used when the child has social difficulties and the child also shows problems in either the communication area OR the behavior and interests areas. Sometimes a child may be given a diagnosis of PDD-NOS when the child is very young or has only mild problems.
3. The term **Autism Spectrum Disorders** is also used to describe children with either an autism or PDD-NOS diagnosis
However, whether your child's healthcare provider uses the term autism, autism spectrum disorder, or PDD-NOS, the general interventions your child needs will be the same.

What causes autism?

A lot of research is being conducted to try to answer this question. In most cases the cause is unknown. However in some cases autism may be due to an underlying genetic condition or underlying medical problems. It is NOT due to bad parenting.

How common is autism?

Autism is considered to be the fastest growing developmental disability diagnosis. The Centers for Disease Control and Prevention report that one in 88 children in the United States has an autism spectrum disorder and that boys are much more likely to be affected than girls. (See: <http://www.cdc.gov> for more information.)

¹The DSMV will soon be released and will change the terms somewhat

How is autism diagnosed?

The diagnosis of autism is based on a child's behaviors. Currently, there is no medical test (e.g., blood test, X-ray, MRI) that can make a diagnosis of autism. However, doctors may order genetic testing to look for a genetic cause, and they may recommend other tests or studies to help determine if conditions (such as seizures) are also present. When professionals evaluate a child to see if the child has autism or a related diagnosis, they look for difficulties in three areas: social interaction, communication, and unusual interests or behaviors.

Social Interaction: Young children with ASD

- have difficulty with the give-and-take of social interactions.
- may show poor eye contact, or may not turn when their name is called.
- may enjoy being held by their parents or engaging in active play (e.g., chase or tickle games), but are generally less interested in peers than other children.

Communication: Children with ASD can be described as

- slower to use single words and phrases.
- Not pointing to make requests or to direct a parent's attention to interesting sights or sounds.
- developing language at the expected times but then losing language skills around 18 to 24 months ("regression").

This loss of skills may include a decrease in social interest, as well as a loss of the words or phrases the child once had.

- developing language, but showing unusual patterns of speaking, such as repeating (echoing) phrases they hear people say or that they hear on television or videos. They may ask for things they want, but have great difficulty carrying on simple conversations.

Behavior and Interests: Young children with ASD

- often show unusual play interests and more repetitive behaviors. For example, they may focus on lining up or spinning objects rather than pretending to feed a doll or teddy bear.
- may also seem too attached to certain objects or insist on following particular routines.
- may repeat specific movements, such as flapping their hands, rocking, or running back and forth.



Are there other behaviors or features that go along with autism spectrum disorders?

A number of behaviors go along with autism spectrum disorders. For example, it is common for children with ASD to demonstrate a high activity level and unusual sensory behaviors. They may have a short attention span for some activities, but they are able to focus on objects that they like for very long periods of time. They may also be picky eaters and/or have difficulty sleeping. Finally, they may be oversensitive or under-sensitive to things they hear, see, touch, taste or smell. For example, a child with an ASD might not turn when his name is called, but can hear a key turning in a lock in another room.

Do all children with autism have significant developmental delays?

No. Every child with ASD is different. Some children with autism are above average or even gifted in intelligence.

Where should I start to find help?

Early intervention: Children less than three years old...

New Jersey Early Intervention System (NJEIS): For children birth to three. 1-888-653-4463. A child will qualify for services based on the degree of delay and diagnosis. A child who enters the NJEIS with appropriate documentation of a diagnosis of ASD is eligible for the system. Children who do not have a documented diagnosis of ASD prior to referral are evaluated for eligibility according to NJEIS rules, policies and procedures. The early intervention program will help families transition to school-based programs after the child turns three years old. <http://nj.gov/health/fhs/eis/policies.shtml>

Child Study Team (CST): For children over three who have not been in the early intervention program, the first step is a **referral** for a Child Study Team evaluation. The referral can be a letter written by the parent. The Child Study Team is located in each public school district. These teams can include school psychologists, school social workers, speech and language pathologists, occupational therapists and a learning disabilities teacher-consultant (LDT-C). A letter should be submitted to the supervisor of Special Education (information can be found on the district's web site). Evaluations by the CST look at how your child is doing in school. This may include identifying behavior that affects their school performance, intelligence (IQ) testing, and mental health evaluation. Sometimes other types of evaluations will have to be done (i.e., medical/health, speech, physical therapy, occupational therapy, and psychiatric, neurological and developmental-behavioral). Evaluations are paid for by the school district. When the evaluations are completed, a written report, the Individualized Education Plan (IEP), is developed if the child qualifies for special education services. www.state.nj.us/education/specialed/form/prise/prise

New Jersey Department of Health and Senior Services (NJDHSS): New Jersey has made a commitment to assist families caring for children with complex, long-term medical and developmental disabilities such as autism. The NJDHSS supports statewide referral networks that provide comprehensive diagnosis, treatment, patient and family education, and counseling for children and adults living with special child health issues such as autism. <http://www.state.nj.us/health/fhs/sch/index>

Primary Care Providers: Discuss with your pediatrician or healthcare provider your concern and ask for referrals for appropriate evaluations. Pediatricians are trained to look for red flags for autism in young children and may provide autism screening questionnaires in the office. Pediatricians will continue to follow the medical needs of your child. <http://www.aap.org/publiced/autismtoolkit.cfm>

On what areas should we focus in our intervention plan?

The Individual Family Service Plan (IFSP) or Individual Education Plan (IEP) should address the **areas that are challenging** for your child. With ASDs, this often means

- helping your child develop practical communication skills;
- expanding your child's interest in others;
- developing your child's play skills and imagination;
- decreasing problem behaviors;
- promoting overall learning and thinking skills;

Since transitions are often difficult for children with ASDs, the IFSP or IEP may also include strategies to help your child smoothly manage his or her daily schedule. Even though children with ASD share certain features, your child will have unique strengths and needs. Consequently, no two intervention plans should be identical. As the names suggest, the IFSP or IEP should be individualized and designed specifically for your child.

In addition to teachers, what other specialists should be on our intervention and follow-up team?

This depends on your child's unique developmental pattern and needs. Some of the specialists who are often very helpful in working with children with ASD include speech-language pathologists, occupational therapists, physical therapists, behavior therapists, psychologists and medical specialists. You may not need all these specialists on your team, but their roles will be briefly described here, along with links to their professional organization websites.

Speech-Language Pathologists (SLPs) are trained to identify and treat communication disorders.

- They can test and provide therapy for problems children have understanding and using language.
- They can assess and treat problems with speech (articulation and fluency).

- Some SLPs also have training and experience in treating eating disorders. This is very useful for children with ASD who may be picky eaters or have difficulty tolerating certain food tastes or textures. For more information see the American Speech and Hearing Association website at www.asha.org.

Occupational Therapists (OTs) typically focus on helping people develop fine motor skills such as holding a spoon or coloring and writing, understand information from their senses, and carry out daily living activities, such as eating, dressing, and grooming.

For young children with ASD, OT's are often helpful in

- building their play skills
- learning self-care skills
- treating sensory difficulties (i.e., the ability to tolerate different noises, textures or settings).



For more information see the American Occupational Therapy website at www.aota.org.

Physical Therapists (PTs) are trained to treat problems with movement and posture. In contrast to OT's, they tend to focus on developing gross motor skills (movements that involve the larger muscles of the arms and legs). PTs can help children with ASD who

- have problems with balance and coordination;
- have muscle problems;
- have difficulty moving about their environment and participating in play.

For more information see the American Physical Therapy Association website at www.apta.org

Behavior Therapists vary in their training backgrounds. Some will have certification through the Behavior Analyst Certification Board (BACB). Whether you are trying to locate a behavior therapist through the early intervention or school system or are looking to hire one privately, it is important to find out about their educational background and work experiences with children with ASD. Behavior therapists will likely implement a therapy called **Applied Behavior Analysis (ABA)**. While the name sounds intimidating, it is basically an organized approach to behavior change where you increase good behaviors or teach new skills by rewarding the behaviors you want to develop. There are a number of specific types of ABA (discrete trial training, pivotal response training, incidental teaching, etc.), but they all work on the same basic behavior principles. The goals of ABA are to increase positive or “good” behaviors, to teach new skills, to stop unwanted behaviors, and to help children to use these new skills at home, school, and in other settings where they play, live and work with other people. Your behavior therapist should be aware of your child’s goals and should keep records to track the progress being made.

For more information about ABA and other treatment approaches visit:

1. Parents of Autistic Children (POAC) - have free parent training – www.poac.net
2. Behavior Analyst Certification Board – www.BACB.com
3. “Treating Autism” section of the “First 100 Days Kit” which is available – www.autismspeaks.org

Social Workers can be part of a team in the school or medical setting providing early intervention services, counseling, case management, and support services. A social assessment includes observation of the child and communication with the child’s parent(s)/guardian(s). There are three levels of social work practice: certified social workers (CSW), licensed social workers (LSW) and licensed clinical social workers (LCSW). Licensed clinical social worker represents the highest-level license. <http://www.state.nj.us/oag/ca/social/swlic>

Child Psychologists are individuals with a doctorate degree in psychology who work specifically with children, dealing with such issues as relationships with parents and schoolmates, learning problems, developmental and behavioral problems. Child psychologists can provide

- specialized testing to diagnose a child with ASD;
- testing of a child’s skills (functional assessment);
- behavioral treatments and monitoring of progress for a child with autism.

Child psychologists complete a doctoral degree in psychology, and then complete additional supervised training hours. After completing these steps, a license from the state can be obtained to practice. Child psychologists often work with a team of professionals, either in a medical or educational setting. <http://www.njconsumeraffairs.gov/psy/>

Developmental-Behavioral Pediatricians are medical doctors trained to diagnose and treat a variety of developmental, learning, or behavioral problems including autism spectrum disorders. Developmental-behavioral pediatricians have completed four years of medical school, three years of residency training in pediatrics, board certification in pediatrics and additional subspecialty training in developmental-behavioral pediatrics. Some developmental-behavioral pediatricians specialize in

- testing very young children for autism;
- medications and or supplements for children with autism;
- general behavior management training for families of children with ASD.

A developmental-behavioral pediatrician can help design and follow treatment programs for children with autism. Some developmental and behavioral pediatricians are able to evaluate and treat medical and psychiatric problems in children with autism such as sleep disorders, attention difficulties, constipation and anxiety. <https://www.abp.org>

Child Neurologists are medical doctors that treat children from birth into young adulthood with disorders of the nervous system (brain, spinal cord, muscles, nerves). In many cases, child neurologists work with a team of other pediatric specialists to care for children who have more complex or serious medical issues, such as autism.

Neurologists can evaluate a child with autism when there are concerns about

- movement disorders (i.e., how a child walks or sits or speaks), epilepsy(seizures);
- headaches/migraines, sleep disorders, loss of skills, and other neurological complaints;
- whether a child does have autism;
- medications and/or supplements to treat medical disorders associated with autism.

Child neurologists complete four years of medical school and then at least one to two years of pediatric residency after three or more years of residency training in adult and child neurology. Some child neurologists secure additional fellowship training in epilepsy. <http://www.abpn.com>.

Child Psychiatrists are medical doctors who can treat the mental health issues associated with autism. A psychiatrist can prescribe medication or other treatments to handle issues such as depression and anxiety, aggression, ADD/ADHD, obsessive compulsive behavior, tic disorders, and more. Child and adolescent psychiatric training requires four years of medical school, at least three years of approved residency training in medicine, neurology and general psychiatry with adults, and two years of additional specialized training in psychiatric work with children, adolescents and their families. <http://www.aacap.org>

What treatments are effective interventions for young children with ASD?

Effective interventions start when ASD is suspected. They involve active engagement with the child for at least 25 hours per week, include one-on-one and small group teaching, incorporate parent training, have a low student to teacher ratio in classroom settings, and regularly assess the child's progress. As you are developing your child's IFSP or IEP, these are good principles to keep in mind. See the National Research Council's (2001) *Educating Children with Autism* at <http://www.nap.edu/openbook.php?isbn=0309072697> for more details.

Should I use alternative or less mainstream treatments?

When you start searching for autism-related treatments, you will find ones that have strong evidence of their effectiveness, such as the behavioral interventions and therapies mentioned above. You will also find information about a wide array of alternative treatments. As you try to decide whether to use an alternative treatment, make sure you research its potential benefits compared to side effects. **MyGoalAutism** offers free parent support groups for families interested in different treatments. www.mygoalautism.org

There are various alternative treatments that may be used for autism. These are referred to as "biomedical intervention." Biomedical intervention is a way of treating the individual with autism spectrum disorder through dietary changes, promoting a healthy gut (stomach), promoting a healthy body through natural and prescription medicines, removing toxins and chemicals from the body thereby reducing inflammation and preventing and treating infections (bad germs)/allergies. Diets such as gluten free/casein free (GF/CF) are based on experience and reports of individuals with autism not able to fully break down foods containing wheat, barley,

oats (called gluten), and/or dairy or milk (casein). Other dietary treatments remove different food groups. There are no medical tests that can conclusively tell whether your child will respond to dietary changes, but preliminary blood work should look for medical causes, nutritional deficiencies and immune problems. Generally a child has to be off offending foods for at least three to six months to see the full effects. Information on implementing a GF/CF diet can be found at www.gfcf.com or www.TACAnow.com

Promoting a healthy body includes supplements, vitamins, exercise and necessary foods. Not all children and adult vitamins are useful for the autistic individual, as these individuals require specially made vitamins and minerals in a form that the body can easily process. There are several companies that sell these vitamins, including but not limited to Kirkman Laboratories, Hopewell Pharmacy and Nordic Naturals.

How do I start a biomedical intervention?

Find out more information by joining a parent support group. Generally most children are followed by medical practitioners trained in alternative and complementary treatments. The Autism Research Institute provides information on such practitioners in your area.

Does my child need to see medical subspecialists?

Children who have a diagnosis of an autism spectrum disorder should be evaluated by a physician with expertise in the evaluation and management of autism spectrum disorders. Most developmental and behavioral pediatricians are skilled in the diagnosis of autism in very young children, as well as follow-up care. They can also evaluate your child for co-occurring medical problems and refer to appropriate specialists if needed. It is not rare for a child with ASD to also have medical problems such as a gastrointestinal disturbances (constipation, reflux, and diarrhea), sleep difficulties, feeding issues, or sometimes seizures. Treating conditions that go along with ASD may increase your child's comfort, improve learning and increase progress. Contact <http://www.aap.org/healthtopics/autism.cfm> for more information.

Does my child need medication?

There is no medicine that will cure autism, but there are medicines that can treat some of the symptoms. For example, some children benefit from medication for sleep problems, anxiety, hyperactivity, self-injurious behavior, and mood swings. If you consider medication, talk with your physician about the benefits and possible side effects, and whether the medicine is appropriate for young children. For more information, see the American Academy of Pediatrics website at www.aap.org

Should I tell other people my child has an ASD?

This is a very personal decision. In order to receive the early intervention or school services your child needs, you will need to share the diagnostic reports that mention autism or PDD-NOS. It will also be very helpful for your primary care professional and other therapists to have this information, since it will help them in planning what to do. It is up to you whether you want to share the diagnosis with relatives and friends. If they have spent a lot of time with your child, it is likely that they may have noticed something. However, they may have misinterpreted autism-related behaviors as your child being shy or spoiled. Sharing the diagnosis may help them better understand why your child is having difficulties interacting and communicating with others. It may also increase their availability as a support to you in the future.

Are my younger (or future) children at risk for autism?

We know that having one child with autism does increase the risk for later-born children. Studies have shown that families who have one child with autism have about a 5 - 10% chance of having a second child with autism. This risk is higher if there are two or more children in the family who have the diagnosis. A specific recurrence risk can be provided if your child is diagnosed with a genetic syndrome that is associated with autism. You will want to work with your primary care professional to be sure that your younger children get regular developmental and autism-specific screenings during well-child visits. Some developmental-behavioral pediatricians will provide screening evaluations for siblings of children with autism.

What else should I do?

Develop your own support system team. Parenting is often very challenging, and we usually don't receive adequate preparation even for typical development. When you are faced with a developmental disability like an ASD, parenting becomes even more complicated. Assembling a group of people you can trust and rely upon is very important. You will be better able to meet your child's needs if you take care of yourself. Find parent support groups. Spend enjoyable time with your other children or family members. Seek respite care. Ask for assistance from your faith community. If you are feeling so sad or overwhelmed that you feel hopeless or paralyzed, seek out the help of a counselor or therapist. Talking with other parents who have children with an ASD can be invaluable.

What can I expect for the future?

Even though you have just recently received a diagnosis of an ASD, you may already be worrying about what the future will hold for your child. Will he or she be able to go to college, hold a job, or have a family? For any child it is difficult to predict the future, and with young children, small positive changes can have a great impact on long term development. Work with your team (intervention providers and medical team) to monitor your child's progress and develop effective treatment plans.

New Jersey Resources:

The Autism Clinics at The Children’s Hospital at Saint Peter’s University Hospital

The clinics are a resource for early diagnosis and follow up for children with “Autism Spectrum Disorders”. The Clinicians provide assessment, treatment planning, and follow-up. The Autism Clinic coordinates specialty and subspecialty care and works with numerous state organizations.

The Center partners with local advocacy *MyGoal Autism.org* to provide monthly support groups, lecture series, and family counseling and stress management activities at Saint Peter’s; and collaborates with Rutgers Biomedical and Health Sciences, Rutgers University, The New Jersey Institute of Disabilities (NJID) and other schools on autism research and student externships. To make an appointment for an evaluation call

732-339-7045. The Children’s Hospital at Saint Peter’s has a number of specialty centers that care for children with Autism including genetics, neurology, adolescent medicine, endocrinology, speech and language and radiology. <http://www.saintpetershcs.com/spchildrenshospital/> or 732-745-8600.



MyGOALAutism.org is a non-profit organization with a vision to restore lives and families affected by autism through education and empowerment. MyGOALAutism believes that a solid family is the foundation for recovery of children with autism. It is based on the principle that the family unit is able to sustain as one when the support and resources are available to them. MyGOALAutism will support and promote family focused education, counseling, grants and advocacy. MyGOALAutism offers free parent education and support groups on treatments for children with autism. For further information phone: **877-88-MYGOAL (69462)**; Website: www.MyGOALAutism.org

SPAN: Statewide Parent Advocacy Network: A parent-advocacy network providing assistance and support for parents of disabled children. The program is run by parents, and is free of charge. SPAN offers parent support groups, parent training and resources for families with children with disabilities including autism. **973-642- 8100** or toll free: **800-654-SPAN (7726)**. www.spannj.org

MOM2MOM: www.mom2mom.us.com A toll-free 24/7 helpline for mothers of children with special needs who reside in Morris, Essex, and Union counties. Developed and directed by the University of Medicine and Dentistry of New Jersey-University Behavioral Healthcare, the helpline is staffed by mothers of children with special needs who have been trained in peer counseling and crisis support. A behavioral health clinician is also on staff 24/7. Mom2Mom Espanola was recently launched to assist with Spanish-language callers. **(877) 914-MOM2** or **(877-914-6662)**

Autism New Jersey: Autism New Jersey is a nonprofit agency providing information and advocacy, services, family and professional education, and consultation. The main number for the Autism New Jersey office is **609-588-8200**. To reach the toll-free Information and Referral Line, please call **1-800-4-AUTISM**. <http://www.autismnj.org>

Autism Speaks: Autism Speaks provides a directory of local resources in New Jersey and other states as well as a host of publications on education rights, advocacy, insurance needs and medical concerns. <http://www.autismspeaks.org>

NJ Department of Human Services Office on Autism (OAAA): (<http://www.state.nj.us/humanservices/ddd/home/ooa.html>) The OOA provides a centralized place to address issues associated with Autism Spectrum Disorder (ASD) within the Division of Developmental Disabilities. The OAA put out the manual: **Navigating the Maze** <http://www.state.nj.us/humanservices/ddd/home/ooaguide.html>

Parental Rights in Special Education New Jersey Department of Education. This document will describe the state and federal laws affecting the provision of special education. www.state.nj.us/education/specialed/form/prise/prise.pdf

Office of Special Education. The office monitors the delivery of special education programs operated under state authority, provides mediation services to parents and school districts, processes hearings with the Office of Administrative Law, and conducts complaint investigations requested by the public. In addition, the office funds four learning resource centers (LRCs) that provide schools and parents with information. <http://www.state.nj.us/education/specialed/>

Autism Program Quality Indicators NJ. A self-review and quality improvement guide for programs servicing young students with autism spectrum disorders. <http://www.special-ed-law.com/docs/autism%20program%20indicators.pdf>

Department of Health and Senior Services (DHSS). DHSS provides early intervention services and special needs assistance to children with ASD and other special health needs. <http://www.state.nj.us/health/>

Department of Human Services (DHS) serves individuals and families with low incomes; people with mental illnesses, developmental disabilities, or late-onset disabilities; people who are blind or visually impaired, deaf or hard of hearing, or deaf-blind; parents needing child care services, child support and/or healthcare for their children; and families facing catastrophic medical expenses for their children.) <http://www.state.nj.us/humanservices/>

Department of Human Services (DHS) Division of Disability Services (DDS). The Division serves as a single point of entry for people with disabilities who need information and/or services within the human services system. The New Jersey Division of Developmental Disabilities (DDD) has been providing and funding services for state residents with developmental disabilities since 1959. www.nj.gov/nj/community/disability/ or contact 888-285-3036.





www.mygoalautism.org



The Children's Hospital

AT SAINT PETER'S UNIVERSITY HOSPITAL

A MEMBER OF SAINT PETER'S HEALTHCARE SYSTEM

Treating you better...for life.

**254 Easton Avenue
New Brunswick, NJ 08901**

**732.745.8600
saintpetershcs.com**