

About Autism Spectrum Disorders (ASDs)

Children and adults with autism exhibit atypical, repetitive behaviors and deficits in social and communication skills. Autism is usually diagnosed during the first three years of life and is four to five times more prevalent in boys than in girls. It knows no racial, ethnic or social boundaries.

Autism, Asperger's Disorder and Pervasive Developmental Disorders Not Otherwise Specified (PDD-NOS) are commonly referred to as Autism Spectrum Disorders or ASDs. This label conveys the continuum of ability levels, but is not itself an official diagnosis. Autism Spectrum Disorders affect approximately 1 in 150 individuals.¹

Major Characteristics

Difficulty with social interactions

Many individuals with ASDs do not spontaneously reach out to others to share information or feelings. They often do not know how to engage in simple social interactions, such as sharing an experience with another person. For example, a three-year-old child with autism may not point to an animal so that his sister will notice it, too. Social skill deficits can make the development of intimate relationships quite difficult. However, with effective treatment, many people with autism eventually learn to initiate interactions and respond more successfully to others.

Difficulty with communication

One of the hallmarks of autism is a delay in or a lack of development of spoken language. Many individuals with autism do develop speech. Their vocabulary may consist of a few or many words; sentences may be simple (one or two words) or complex. Common speech abnormalities include echolalia (immediate or delayed repeating of information), unconventional word use, and unusual tone, pitch, and inflection. Even when more complex speech is acquired, individuals with autism typically have poor conversational skills. They also may have difficulty understanding common, nonverbal cues such as body language, facial expressions, and eye contact.

Unfortunately, not all individuals with autism develop functional speech. However, many individuals with autism do learn to communicate through picture boards, computers, sign language, and other augmentative devices.

Unusual Behaviors

Individuals with autism have a restricted range of interests. For example, a six-year-old child with autism may only play with his or her toy train to the exclusion of all other toys. Additionally, people with autism may engage in peculiar, sustained play activities such as spinning the wheels on a toy car rather than pretending to drive it, or finding a shoestring and dangling it in front of his or her eyes for long periods of time.

Individuals with autism also can be very resistant to changes in routine. Even a minor change could be a great upset to a child or adult with autism.

Centers for Disease Control and Prevention. (2007). Prevalence of autism spectrum disorders- Autism and developmental disabilities monitoring network, 14 sites, United States, 2002. *Morbidity and Mortality Weekly Report*, 56, SS-1. <http://www.cdc.gov/mmwr/pdf/ss/ss5601.pdf>

Associated Features of Autism Spectrum Disorders

No single individual with autism will display all of its possible characteristics. Instead, each person will demonstrate a unique combination of symptoms.

- Little or no eye contact
- Acts as though deaf
- Uneven development of skills
- Resistance to changes in routine
- Marked physical hyperactivity and/or extreme passivity
- Lack of demonstration of typical signs of affection
- Little or no apparent fear of real dangers
- Unusual responses to sensations, including a high tolerance for pain
- Inappropriate laughing or crying
- Inappropriate attachments to objects
- Eating, sleeping, and toileting difficulties
- Aggressive or self-injurious behavior
- Savant abilities (present in less than 2% of individuals diagnosed with autism)

About Adult Services in New Jersey*

Local school districts are responsible for providing services to students with disabilities through age 21; other state funding sources assume the responsibility for services after individuals graduate from school. Services for people with disabilities over age 21 are referred to as 'adult services' and, just as the autism spectrum covers a wide range of functional abilities, so do the services and supports for adults with disabilities. Many times we look to designated state agencies to assist in planning our future needs. We also rely on them to tell us what adults with autism are eligible for and entitled to receive. You must learn the adult service system in order to effectively plan for the future in a realistic and satisfactory way. Begin the next step!

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Understanding New Jersey's Human Services System

Division of Developmental Disabilities (DDD)

The primary source of services for adults with ASDs is the New Jersey Division of Developmental Disabilities (DDD).

Eligibility for DDD Services

Eligibility for DDD is governed by state statute. Essentially, a person must have a mental or physical impairment that occurred before age 22, and which substantially impairs at least 3 of 6 major areas of life activity (self-care; learning, mobility; receptive and expressive language; self-direction; capacity for independent living; and economic self-sufficiency).

ASDs are specifically listed in the statute. Eligibility is to be determined without regard to I.Q.

Application Process

To apply for DDD services, families should contact DDD to request an application. Once an application has been submitted, DDD must send a response letter indicating its determination of eligibility. If specific services such as residential services are requested, families may receive a letter advising them of the status of the request.

Service Rights

The nature of a person's right to DDD services is more complicated than in the special education system. In special education, a student with a disability is entitled to immediately receive services specified in the Individual Education Plan (IEP) regardless of cost. Unlike a local school, DDD is allowed to establish waiting lists for services. Therefore, even when an individual is eligible for services, DDD can require that a person waits for services. There are exceptions. For instance, DDD must provide immediate residential services when an emergency exists. There also are entitlements to DDD services under certain conditions: Once DDD agrees to provide services (such as when an individual reaches the top of the waiting list), it must provide services that meet stringent legal standards. Under the New Jersey Developmental Disabilities Rights Act (N.J.S.A. 30:6D-1, et seq.), services must maximize developmental potential and be delivered in a manner and setting that are least restrictive of personal liberty. These standards apply to both day and residential services. A 1994 decision by the New Jersey Supreme Court illustrates how the law works.

B.F. was a 21-year-old man with autism. School funding for his residential placement in New England was ending. DDD agreed to serve him, but for reasons of cost, proposed placement in a state institution. The record demonstrated that B.F. would regress in an institution, and that it did not meet the requirements of his transition IEP, which DDD helped to develop. The Supreme Court concluded that cost could not be a factor if the client would regress without proper services and ordered DDD to fund the out-of-state placement.

You should know..

If families disagree with DDD's findings on eligibility, they may appeal through a formal appeal process.

Service Planning

The purpose of the IHP is to establish goals and objectives that will enable the person with a disability to maximize his or her developmental potential in the least restrictive environment. The Individual Habilitation Plan (IHP) - State law requires that guardians, family members, DDD staff, service providers (e.g., day program or group home staff), and, to the extent possible, the person being served by DDD, work together to develop an annual IHP, regardless of whether the individual is currently receiving specialized services from DDD.

Federal law recognizes that families are the "primary decision makers regarding services." The IHP can be used as a long-range planning tool to guide the individual to a specific program. The IHP also can be used to obtain other types of services such as respite care, family support cash stipends, summer camp stipends for adults, and financial assistance for securing guardianship through a private attorney.

The Essential Lifestyle Plan (ELP) is the plan of care document that is used in place of the IHP when an individual chooses self-directed service options. This planning document was created to be more person-centered and strength-based than the traditional IHP document. Just as in the IHP process, training is presented as an introduction to the philosophy of person-centered planning in order to assist in effectively participating in the writing and implementation of the ELP.

You should know..

Often, the IHP is viewed as a formality and many are written so as to contain nothing of importance. However, the IHP is a very important document for planning and legal purposes.

Although the law governing DDD operates differently than the law governing special education, eligible adults with developmental disabilities do have service rights that impose mandatory responsibilities upon DDD. It is misleading to say there is no entitlement to services from DDD.

DDD Specific Services

Case Management assists in the individualized planning of services to meet the person's needs and abilities. DDD assigns a case manager to each eligible person to help identify, access, and coordinate services.

Family Support is a coordinated system of services, resources, and other assistance for families caring for individuals with developmental disabilities who live at home. The Family Support Act of 1993 expanded the list of services to include any service defined by the family. Funding is typically modest and subject to waiting lists.

Contracted Professional and Support Services can help meet acute and regular health care needs including medical specialties and dentistry. Certain legal services, integrated therapies, and case management also may be available through the Division of Developmental Disabilities.

Professional Supports include a DDD staff of psychologists, nurses, behavior management specialists and other professionals who can assist in meeting the social, medical, vocational and training needs of individuals. This can include referrals, the development of behavior management plans, and additional training to providers, families and staff.

Guardianship Services are available, if needed, to protect the rights of an adult with a developmental disability and ensure that care and treatment are appropriate. DDD can refer to the Bureau of Guardianship Services for a state-appointed guardian, or provide a process for the appointment of a family member to serve as guardian.

DDD Day and Vocational Services

Adult Day and Vocational Services are designed to provide an opportunity for individuals with ASDs and other developmental disabilities to earn wages or become part of their community through work, volunteerism, and social participation. Services include:

- Supported Employment Services are designed to assist persons in obtaining and maintaining competitive employment in the community. The individual receives on-the-job training from a job coach until proficiency is achieved. Follow-up or support services are provided as long as necessary.
- Adult Training Services train individuals in personal, vocational, social, and community-living skills.
- Crew Labor Programs train individuals to work on supervised, mobile work crews that are available for hire, specializing in service areas such as maintenance and landscaping.
- Extended Employment (Sheltered Employment) provides long-term employment within a private facility. Programs specialize in contract work such as packaging products, stuffing envelopes and collating literature, and secured through local businesses, paying per piece or below minimum wage. DDD selectively provides funding for individuals in need of extended employment, and who do not meet Division of Vocational Rehabilitation Services' criteria for continued workshop employment.

You should know...

- Adult training services are typically center-based.
- Some extended employment programs include some time in community settings.
- Sheltered workshops provide job-related evaluation, training and counseling.

DDD Residential Services and Supports

DDD funds most residential programs for adults with ASDs in New Jersey. There are a variety of community-based residential programs and residential supports for those in emergent need of housing, or incapable of living with family. Services include:

Skill Development Homes provide care and training for an individual who lives in the home of a trained provider, and who implements a formal training program developed with and supervised by the DDD case manager.

Family Care Homes are similar to skill development homes, but are available for individuals who are more independent than those who reside in skill development homes. The provider offers room, board and supervision.

Group Homes are households typically shared by six or fewer individuals. Supervision and training are provided by a house manager and trained staff. Supervision is generally provided around-the-clock.

Supervised Apartments are occupied by one or two individuals and monitored by a trained staff person who regularly visits and may live in the same complex. In some unique situations, a supervised apartment may have live-in staff.

Supportive Living refers to arrangements for individuals who receive support services such as training and tutoring, and need access to on-call assistance 24 hours a day.

Independent Living Arrangements, while not licensed and funded by the Division of Developmental Disabilities, can be planned to permit the least restrictive housing. Individuals can receive regular visits from their case manager, agency staff, or others, and receive emergency assistance.

Private Homes can be used. An individual can use his/her own resources to live alone or with family and/or pool funds with other residents to purchase or rent a house. Support services are funded by DDD.

Developmental Centers are large, state-operated institutions. Hundreds of people live together in a self-contained, campus-like facility.

You should know...

- The law requires that DDD services be designed to maximize developmental potential and delivered in the least restrictive manner (N.J.S.A. 30:6D-9).
- Usually, group homes are for individuals who are functioning at lower levels of independence and self-sufficiency.
- Usually, supervised apartments are for individuals able to live independently, with support from 24- hour staff living separately, but nearby.

- Most group homes and supervised apartments are operated by a community-based nonprofit organization under a contract from DDD.

Self-Directed Services is an umbrella term that describes services that are guided by the individual with a disability and his or her family.

Real Life Choices (RLC) is one such self-directed service in New Jersey. Individuals become eligible for RLC when they reach the top of DDD's priority waiting list for residential services. At that time, the individual is assessed and assigned to one of four levels of monetary support (ranging from \$14,000 to \$63,000 annually) based upon need. The individual and family may then use these funds to purchase their own services based on their individual budget and Essential Lifestyle Plan. DDD uses support coordinators as the case manager in self-directed services. Support coordinators are trained in Essential Lifestyle Planning in order to assist families in planning and implementing services.

You should know...

- Many individuals in private homes use self-directed services to pay for the supports they need.
- Nationwide, use of developmental centers is being phased out.
- DDD uses other Self-Directed Services for special education students aging out of the school system to offer them day and vocational services.

DDD's Waiting Lists

Residential Services

DDD's regulations stipulate that DDD can assign people to waiting lists when services are not immediately available. Currently, several thousand people are on the various waiting lists for residential services. There are three categories.

"Priority" is the top category for people who meet any ONE of the following criteria:

- both parents are 55 years or older;
- the person is living with someone other than the parent who is no longer willing to provide care;
- there is a risk of abuse, neglect, or exploitation;
- one parent has a chronic condition, which significantly limits the ability to care for the person; or
- the person's health or safety is at risk because of behavior or physical needs.

The **"Priority" category** is the only waiting list that actually provides residential placement.

"Priority-deferred" is for people who want residential services but do not meet criteria for "Priority." "General" is essentially a "registry" for people who do not want residential services in the near future.

Financial Contributions

DDD currently requires individuals who receive DDD residential services or supports to contribute approximately 75% of their Social Security benefits and other unearned income, as well as 30% of their wages. DDD allows individuals to retain more than 25% of unearned income to pay for guardianship and "extraordinary needs" such as excess shelter

costs, “unavoidable” medical costs, replacement costs of personal items, an irrevocable funeral trust, and costs of moving into an independent living arrangement. DDD also will seek reimbursement for residential services from an individual’s assets. Parental income by law is not subject to collection unless the individual is under age 18 and in a residential program funded by DDD, and the parents are under age 55.

You should know...

DDD will provide people with residential services in an emergency situation. These are people who are seriously at risk or are homeless. They must be immediately served.

- Anyone who applies for DDD eligibility also must apply for all other benefits for which they may be eligible, primarily Medicaid and Supplemental Security Income (SSI).
- Parents under age 55 can have their child’s name placed in the “Priority” category when circumstances warrant such as when the physical or emotional needs of their child are too great, there are health and safety risks to their child, the ability of the parents to care for their child is compromised, or there is only one parent to care for their child.

Eligibility for Division of Vocational Rehabilitation Services

To be eligible, an individual must have a physical or mental impairment that is a substantial impediment to employment. DVRS’ services are limited to employment and employment-related training and are geared toward successful employment. DVRS services are not of lifelong duration.

Application Process

Individuals interested in vocational rehabilitation services must complete an application available through one of 18 DVRS local offices throughout the state. A DVRS counselor will arrange an intake appointment no later than 14 days after the application is submitted. Eligibility for DVRS is determined within 60 days of the intake interview.

Service Planning

DVRS offers vocational evaluation services to determine strengths, interests, and support needs of the individual. The assessment considers the assistive technology needs of the individual to be successfully employed, and must be completed prior to the development of a service plan. DVRS uses an Individualized Plan for Employment (IPE), which outlines the necessary services and supports for the individual.

DVRS Services

Vocational Rehabilitation Counselors can assist an individual and his or her family members to understand available services and develop and implement the Individualized Plan for Employment (IPE) that should outline the necessary services and supports for the individual.

Individual Counseling & Guidance can help the individual and his or her family to understand the local job market and required competencies for successful employment.

Job-seeking Skills Training & Selective Job Placement can be done with the DVRS counselor or through a DVRS-approved Community Rehabilitation Program (CRP).

Follow-up Support Services are provided once an individual is successfully employed in a competitive job in the community to maintain that employment.

Physical Restoration Services can include corrective surgery or therapeutic treatments, prosthetic and orthotic devices, diagnosis and treatment for mental and emotional disorders, eye glasses and visual services, interpreter services, transportation (after all options have been explored), telecommunications, sensory and other technological aids and devices, and other areas that, if not corrected, could be an impediment to employment.

Job Coaching, Vocational, and On-the-job training is provided by a DVRS-approved community rehabilitation provider to support the individual in developing a competitive job based on his or her preferences, strengths, and support needs.

Funding for higher education (post-secondary education and training) can be considered after extensive efforts were made to secure grant assistance or other funding.

You should know...

- DVRS is required to consider all individuals seeking employment regardless of the severity of their disability.
- An effective, comprehensive assessment increases the chance of identifying the right kind of job for the individual.
- DVRS and DDD have collaborated on interagency agreements to ensure that communication and resources are used between Divisions in the most effective manner.
- People with ASDs have been and continue to be successfully employed in the community through supported employment services using DDD and DVRS funding.

DVRS' Waiting Lists

In the event of the need for a waiting list, DVRS must invoke an order of selection that prioritizes individuals with the most severe disabilities to be served first.

Financial Contribution for Services

Individuals are required to fill out a Financial Need Assessment form prior to the Individual Plan for Employment (IPE) conference to determine the financial contributions, if any, for which the individual is responsible. The Division may waive the financial participation if the individual has extraordinary medical and disability-related expenses or other unusual circumstances, which significantly affect the quality of family life and would preclude his or her participation in the cost of services. Services not based on economic need include:

1. Assessments
2. Counseling
3. Placement
4. On-the-job training
5. Supported employment
6. Work-adjustment training
7. Job coaching



You should know...

- Post-employment services can be provided if an individual no longer requires services and some support need arises. DVRS can provide that support on a short-term basis without reopening the individual's case.
- Long-term follow-along services provide communication among employers, the community, the person with a disability and a job coach, to help ensure that appropriate supports are in place.
- Both DDD and DVRS contract with provider organizations.

Medicaid Services & Supplemental Security Income

Medicaid Services

Medicaid is a federal funding system which is administered in New Jersey by the Division of Medical Assistance & Health Services (DMAHS). Medicaid pays for a wide array of services for people with disabilities and their families and provides government-funded health insurance, including prescription coverage and personal care services, for children and adults with disabilities who have limited financial resources. Medicaid also provides government funding for long-term services and supports, including institutional care, and, increasingly, community-based services such as group homes and self-directed services. These community-based services are funded through a "waiver" known as the Community Care Waiver (CCW).

In New Jersey, the CCW is the primary funding source for adult services through DDD. The CCW allows the State to use federal and state funding for flexible services that are more person-centered. The CCW is for individuals with developmental disabilities who would otherwise require an institutional level of care, but who can be served at home. The CCW funds case management, respite care, habilitation (including pre-vocational, educational, and supported

employment services), home and vehicle accessibility adaptations, personal emergency response systems, therapies, and other individual supports.

Even if a person has private health insurance, Medicaid may pay for services that most private insurance plans do not cover such as private duty nursing, medical supplies, or even residential placement. In order to maximize federal funding, DDD requires all participants to maintain Medicaid eligibility.

Eligibility

Eligibility for Medicaid is based on assessment of both disability and financial resources. Most adults who are DDD-eligible will meet the Medicaid definition of disability. Medicaid has stringent asset and earnings guidelines. Generally, Medicaid eligibility depends upon a person's satisfying the requirements for the federal Supplemental Security Income (SSI) program. Medicaid "waivers" permitting higher monthly earnings may apply in some circumstances. With the exception of these waiver programs, the income and resources of parents of children under age 18 are considered.

Service Rights

Once eligible for Medicaid, a person must receive services and cannot be on a waiting list. Under Medicaid regulations, a state cannot limit access to covered medical services simply because the cost of service exceeds the state budget. In New Jersey, certain "waiver" programs limit the number of participants.

Waiting Lists

Once eligible for Medicaid services, no waiting lists for services are allowed.

Financial Contributions for Services

If an individual acquires assets or resources, such as in the case of inheritance or earnings, they may become ineligible and be required to reimburse Medicaid.

Supplemental Security Income

Supplemental Security Income

Supplemental Security Income (SSI) is a program of monthly cash benefits that is available to many people with significant disabilities who have limited income. The SSI benefit usually ranges between \$400 and \$600 per month. A person who qualifies for SSI also will qualify for Medicaid.

Eligibility

In most cases, to qualify for SSI a person with a disability can have no more than approximately \$700 to \$800 in monthly income and no more than \$2,000 in countable resources. Countable resources are the person's property (other than certain exempt resources, such as the house one lives in and one car). The person also must have a disability that prevents gainful employment.

When the person is under age 18 and living at home, family income and resources will be counted. However, once the applicant turns 18, family resources will not be counted even if the applicant continues living at home. What then matters is only the income and resources of the person. For this reason, most people with disabilities qualify for the first time at age 18. There are several additional ways to qualify for Medicaid, even if the applicant cannot meet the SSI income and resource tests. For example, an applicant who loses SSI simply because he or she is collecting regular Social Security (SSA) as a dependent of a parent who dies or retires will continue to receive Medicaid benefits. Also, applicants whose income places them slightly over the Medicaid limit may still be eligible under alternative eligibility criteria.



You should know...

Many parents and well-intentioned relatives will open a bank account or purchase savings bonds in the name of a minor with a disability, only to realize that when the child turns 18, he or she is not eligible for SSI because savings are in excess of \$2,000. As harsh as this may sound, a child with a significant disability should not have assets put in his or her name. A special needs trust should be considered.

A bank account or other assets held in the name of the person with autism, which causes SSI disqualification, also will cause Medicaid disqualification.

There are waivers and work incentive programs that allow an individual to continue to receive SSI and Medicaid and still have earnings in excess of the minimum monthly allowable requirements. Families should inquire directly with SSI and Medicaid about these programs. For information on Social Security Work Incentive Programs, contact NJWINS. (866) 946-7465 (Toll Free) Website www.njwins.org