NEW YORK STATE OF OPPORTUNITY.

Office for People With Developmental Disabilities

Facts About Developmental Disabilities

(866) 946-9733 | www.opwdd.ny.gov

At OPWDD, our motto is “putting people first.” With that in mind, we are committed to providing a variety of residential supports and services for people with developmental disabilities. This brochure provides an overview of the different types of developmental disabilities impacting the individuals we support. Our goal at OPWDD is to provide high quality, individualized service, ensuring that all can live their lives with as much independence and choice as possible.

Kerry A. Delaney, Acting Commissioner

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What are Developmental Disabilities?

The definition of "Developmental Disability" in New York state is described in Subdivision 22 of section 1.03 of the Mental Hygiene Law, as amended by Chapter 269 of the Laws of 1990. The most recent amendment of this law was enacted on July 31, 2002. The law states:

"Developmental disability means a disability of a person which:

(a) (1) is attributable to mental retardation, cerebral palsy, epilepsy, neurological impairment, familial dysautonomia or autism;

(2) is attributable to any other condition of a person found to be closely related to mental retardation because such condition results in similar impairment of general intellectual functioning or adaptive behavior to that of mentally retarded persons or requires treatment and services similar to those required for such person; or

(3) is attributable to dyslexia resulting from a disability described in subparagraph (1) or (2) of this paragraph;

(b) originates before such person attains age twenty-two;

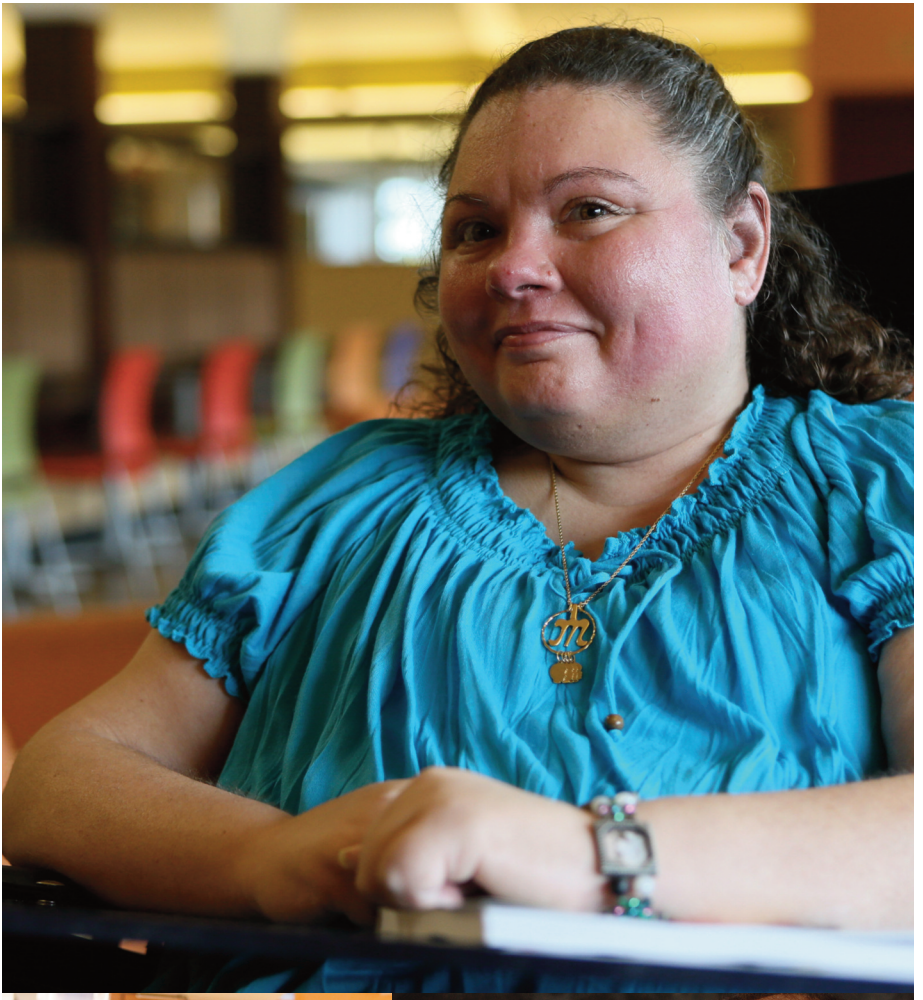
(c) has continued or can be expected to continue indefinitely; and

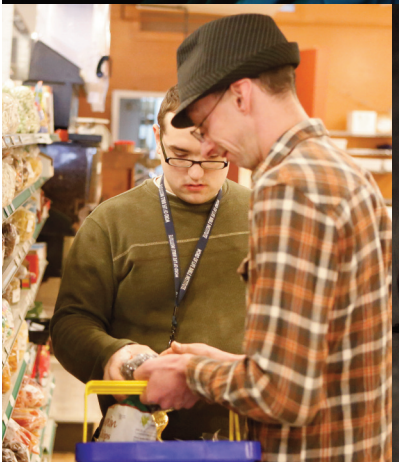
(d) constitutes a substantial handicap to such person's ability to function normally in society."

People with developmental disabilities may have trouble learning as quickly as others or expressing themselves clearly. They may have insufficient ability to take care of their physical needs or limited mobility. Many have more than one disability.

Developmental disabilities have a variety of causes, which can occur before, during or after birth. Those occurring before birth include genetic problems, poor prenatal care or exposure of the fetus to toxic elements, drugs or alcohol. Occurrences during birth, such as a cut off of oxygen to the baby, or accidents after birth, like car accidents causing traumatic brain injury, can also cause developmental disabilities.

It is difficult to define the limits of people with developmental disabilities, as we continue to discover extraordinary abilities within them. While those with developmental disabilities face a more challenging future than most, they can still enjoy a full and active life. What they need most is encouragement, understanding and the willingness of others to help them maximize their opportunities for becoming a part of the community they live in.





MENTAL RETARDATION

People with mental retardation show delays in learning, a slower pace of learning and difficulty in applying learning. More than 280,000 people in New York State are thought to have mental retardation.

Mental retardation can result from a variety of factors, among them premature birth, genetic abnormalities, malnutrition, exposure to toxic agents and social deprivation.

After diagnosis and support early in life, other assistance for people with mental retardation usually includes family counseling and training, education, job training and housing services. Most people with mental retardation can learn to take care of their basic needs, and virtually all can live in the community with appropriate supports. Today, supports focus on assisting a person to become an active member and contribute to his or her community. Person-centered planning is used to develop an individualized plan of formal and informal services and supports.

CEREBRAL PALSY

Cerebral palsy is a group of conditions that result in limited or abnormal functioning in the parts of the brain that control movement. Cerebral palsy is usually caused by a brain injury before or during birth. However, brain damage or injury at any time in life can have the same effect.

People with cerebral palsy primarily have difficulty with muscular coordination. They may have seizures or be unable to see, speak, hear, or learn as other people do. Severe speech problems are also common, sometimes leading others to make the mistake of thinking that people with cerebral palsy have mental retardation. This is often not the case.

Treatments for cerebral palsy include physical, occupational and speech/language therapy by skilled professionals. Adaptive equipment is individually designed to assist with communication and body movements. In-home and out-of-home residential services are also available. More than 24,000 New York residents have cerebral palsy.

EPILEPSY

Epilepsy is a general term that applies to numerous nervous system disorders that result in recurrent seizures due to abnormal electrical discharges of brain cells. Seizures may cause an involuntary change in body movement or function, sensation, awareness or behavior. There are more than 20 different types of seizures. Scientific advances have made it possible to control many forms of epilepsy. As a result, most people with the condition lead normal lives.

Estimates of the number of people with epilepsy in the United States range from 1.4 to 2.7 million people, depending on the diagnostic criteria and study method used to identify people. Only a small percentage of people with epilepsy also have mental retardation. New cases of epilepsy are most common among children and the elderly.

The term “epilepsy” can be used interchangeably with “seizure disorder.” Epilepsy is not contagious and poses no risk to others.*

AUTISM

Autism is one of a group of disorders known as Autism Spectrum Disorders (ASDs). ASDs are developmental disabilities that cause substantial impairments in social interaction and communication and the presence of unusual behaviors and interests. Many people with ASDs also have unusual ways of learning, paying attention and reacting to different sensations. The thinking and learning abilities of people with ASDs can vary — from gifted to severely challenged. An ASD begins before the age of three and lasts throughout a person’s life.

ASDs include autistic disorder, pervasive developmental disorder — not otherwise specified (PDD-NOS, including atypical autism), and Asperger syndrome. These conditions all have some of the same symptoms, but they differ in terms of when the symptoms start, how severe they are, and the exact nature of the symptoms. The three conditions, along with Rett syndrome and childhood disintegrative disorder, make up the broad diagnosis category of pervasive developmental disorders. ASDs occur in all racial, ethnic and socioeconomic groups and are four times more likely to occur in boys than in girls.

There is no known cause for ASD, and while the incidence of autism is still under debate, the Center for Disease Control's Autism and Developmental Disabilities Monitoring Network released data in 2007 that found about one in 100 eight-year-old children in multiple areas of the United States had an ASD. ASDs can often be detected as early as 18 months. While all children should be watched to make sure they are reaching developmental milestones on time, children in high-risk groups — such as children who have a parent or sibling with an ASD — should be watched extra closely. A child who has any of the ASD warning signs should be checked by a health care professional.*

FAMILIAL DYSAUTONOMIA

Familial Dysautonomia (FD) is a rare genetic disease which is present from birth. The genetic defect results in incomplete development of the nervous system causing a decreased number of nerve cells. The nerve cells that are affected are those destined to control certain sensations and autonomic functions. The sensory nerve cells control bodily functions such as sweating, swallowing, regulation of blood pressure and body temperature and the ability to cry with tears. Children with FD all have incomplete development of their nervous system, and may have secondary symptoms that include poor growth, spinal curvature and lung problems.

FD only affects Ashkenazi (Eastern European) individuals of Jewish descent. Because there is no cure for FD, treatment attempts only to control symptoms and avoid complications. Presently, there are 340 people with FD worldwide, and 33 percent of those affected live in the New York metropolitan area.

Some common symptoms of Familial Dysautonomia include: lack of tears while crying; decreased ability to feel pain or temperature sensations; uncommon changes in blood pressure and body temperature; difficulty feeding and swallowing; and developmental delays.

OTHER NEUROLOGICAL IMPAIRMENTS

Neurological impairments are a group of disabilities including disorders of the brain and central nervous system that considerably limit a person's development, understanding, memory, attention span, fine muscle control, use of language, or ability to adjust to new situations. Generally, these impairments begin during childhood or adolescence.

People with neurological impairments may experience a variety of learning difficulties or social behavior problems. They also may have special care needs because of problems in memory, conversation, organization and impulse control.

Approximately 34,000 people in New York State are thought to have some type of severe neurological impairment. Many of these people learn to compensate for their disabilities and lead fulfilling lives.

*Information from the Centers for Disease Control Web site

We Can Assist You in Finding the Help You Need

The New York State Office for People With Developmental Disabilities (OPWDD) is responsible for planning, administering and providing services for citizens with developmental disabilities and their families.

OPWDD is dedicated to helping these people and their families obtain the supports and services they want and need. OPWDD works closely with voluntary agencies and local governments to develop the supports that will help families care for children with developmental disabilities. OPWDD also helps people with developmental disabilities achieve their personal best, by providing individualized supports based on a person's interests, capacities and choices.

What Supports and Services are Available?

Service Coordination provides each person or family with an individually assigned service coordinator who helps to identify and obtain needed services and supports. Service coordinators develop and document the plan of care, advocate for people and their families and periodically assess services.

Day Programs/Day Habilitation includes daytime activities that provide a combination of diagnostic, active therapeutic treatment, habilitative and prevocational services to persons with a developmental disability. Such programs may vary in the services they offer based on the level of the individual's needs and his/her interests and preferences. A range of available day programs focus on providing the individual with developmental disabilities the necessary personal, social and vocational supports needed to live a typical life in the community.

Employment Services are supports to the individual, which may include vocational training, job coaching, travel training, technological aids, counseling, job placement and any other support needed to meet the person's unique circumstances.

Family Support Services help families care for a family member with a developmental disability in their home. This includes providing information

about developmental disabilities, referrals to service organizations, service coordination, parent counseling and training, prevention services and relief for families through respite services.

Residential Services include a range of community-living situations as well as in-home and out-of-home residential services to address individual needs at home or in a home-like setting.

For additional information about any of these programs, call the toll free OPWDD Information Line at (866) 946-9733 voice, or (866) 933-4889 TTY, or visit www.opwdd.ny.gov.

This brochure is published by the OPWDD Communications Office, located at 44 Holland Ave., Albany, N.Y. 12229.

Office for People With Developmental Disabilities

For further information, please check the OPWDD Website:

www.opwdd.ny.gov

A publication of NYS OPWDD Communications Office
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