



NYS Office For People With Developmental Disabilities

Putting People First

Facts

**About Autism and Finding Autism
Spectrum Disorder Services**



(866) 946-9733 • TTY: (866) 933-4889 • www.opwdd.ny.gov

Andrew M. Cuomo
Governor



Courtney Burke
Commissioner





Autism and Autism Spectrum Disorders (ASDs) are among the fastest-growing diagnoses among developmental disabilities in the United States. As an agency serving those with ASDs and their families, the Office For People With Developmental Disabilities (OPWDD) must respond to this increase in ASDs by not only providing quality supports and services that meet the needs of those in our care, but by offering much needed information, as well. This booklet, “Facts About Autism and Finding Autism Spectrum Disorder Services,” is just another way OPWDD is helping individuals

with developmental disabilities live richer lives.

A handwritten signature in black ink that reads "Courtney Burke". The signature is written in a cursive, flowing style.

Courtney Burke, Commissioner

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FACTS About Autism and Finding Autism Spectrum Disorder Services

What Is Autism?

Autism is a lifelong, neurodevelopmental disorder characterized by difficulty with socialization and communication skills. It can result in mild to severe difficulties in thinking and learning and is frequently marked by unusual interests and repetitive behaviors such as twirling, rocking, and flapping one's hands. Autism can significantly impede an individual's ability to lead a fulfilling life and mature to independence. It is believed to be a dysfunction in the central nervous system (the brain and spinal cord). Although knowledge of the possible causes and effective treatment of autism is growing, to date, no cure exists. Symptoms typically occur by the time a child is three years old.

Autism is one specific condition within a larger group of conditions known as Autism Spectrum Disorders (ASD) or the Pervasive Developmental Disorders (PDD). You may find the words autism, ASD and PDD are used interchangeably. The word "spectrum" is important in understanding autism because it refers to the wide range of behavioral signs, symptoms, and degrees of severity that affect individuals. Individuals on the autism spectrum include those with Autistic Disorder, Pervasive Developmental Disorder NOS and Asperger Disorder. In addition, Rett Syndrome and Childhood Disintegrative Disorder – two very rare, but serious disorders – are also included under the Pervasive Developmental Disorders. Each individual on the autism spectrum is just that – an individual. Their unique characteristics and needs are specific to them alone.

Still, despite the range of symptoms, people with ASDs often have similarities. They tend to have difficulty communicating, be inclined toward unusual, repetitive behaviors and become over-focused on a very narrow interest. Many people with ASDs also have unusual ways of learning, paying attention, and reacting to different sensations and situations. Although knowledge of the possible causes and effective treatment of ASDs is growing, to date, no cure exists.

Pervasive Developmental Disorders include:

Autistic Disorder: Sometimes called “classical autism,” Autistic Disorder is the most common ASD. Onset occurs before the age of three and is characterized by significantly delayed or unusual verbal or nonverbal communication skills and social interactions, as well as unusual, repetitive behaviors, and/or severely limited activities and interests. Individuals with Autistic Disorder have difficulty making eye contact, reading other people’s faces, nonverbal cues and gestures, and interacting with others. They may engage in repetitive or unusual movements such as twirling, rocking, hand flapping or clapping, posturing, or self-abusive behavior such as head-banging, slapping or biting themselves. They tend to speak later in life, if at all, and may refer to themselves by name instead of using “I” or “me. Echolalia – the repeating of all or part of what is said to them by someone else – is another common speech pattern among individuals with Autistic Disorder.



Asperger Syndrome: Individuals with Asperger Syndrome generally do not have language or cognitive delays but do have impairments in social behavior and communication and display unusual behaviors and interests. They may have unique speech patterns, or speak in a monotone or rhythmic voice. They often have difficulty engaging in conversations, reading social cues, and developing social relationships. They may also find it difficult to express and classify their feelings or to connect with and understand others’ experiences. It is not uncommon for individuals with Asperger Syndrome to develop an obsessive interest in one narrow, specific subject and to become ‘experts’ on that subject. They can also be sensitive to different stimuli, such as sounds or noise level, the texture of certain materials, or certain foods or types of food, and they often follow strict schedules to feel in control.



Pervasive Developmental Disorder — Not Otherwise Specified (PDD-NOS): If a child has symptoms of autism, but does not meet the specific criteria for a diagnosis of Autistic Disorder or Asperger syndrome, a diagnosis of PDD-NOS is given. As with Autistic Disorder, this condition is recognized by marked difficulties in communication, social interaction with peers, and/or stereotyped behavior patterns or interests. Children with PDD-NOS display a range of traits. They may lack interest in interacting with other children and seek to avoid them altogether. They may enjoy some interaction, but still be unsure of how to behave with others, or they

may tend to become over stimulated easily. Some may experience unusual sensitivities to certain events or objects in their environment or have a strong need for sameness and routine and react poorly to change. Some children may engage in noticeable movement patterns such as hand-flapping or twisting, toe-walking, lunging, darting, pacing, jumping, body rocking, and head rolling or head-banging.

Rett Syndrome: Rett Syndrome, also known as Rett's Disorder, is a rare genetic disorder that almost always affects females. It occurs at a rate of about one in every 10,000-15,000 female births. It is included among the Pervasive Developmental Disorders because in its early stages it resembles autism. Like the other disorders, this condition ranges from mild to severe in its expression. Development is normal during the first 6 to 18 months of life. At some point during this time, however, parents may notice a change in their child's behavior and the loss of muscle tone and related abilities such as walking and hand use. Changes in the rate of head and brain growth, development of speech and reasoning, and the repetition of meaningless gestures, such as hand-wringing or hand-washing gestures, also occur. Approximately eight in 10 girls with Rett's Disorder are prone to seizures.

Childhood Disintegrative Disorder (CDD): Also called Heller's Syndrome, CDD affects boys more often than girls, and is diagnosed if the symptoms are preceded by at least two years of normal development before the age of 10. CDD is an extremely

rare disorder that resembles Autistic Disorder wherein a period of normal development is followed by a period in which the child loses already-developed skills. Skills loss occurs in language, self-care, toilet training, motor coordination, interest in the social environment, and social interactions. Over a period of two to four years, these children develop behaviors that appear autistic. Children who have CDD are also at greater risk for seizures.

Who does Autism affect?

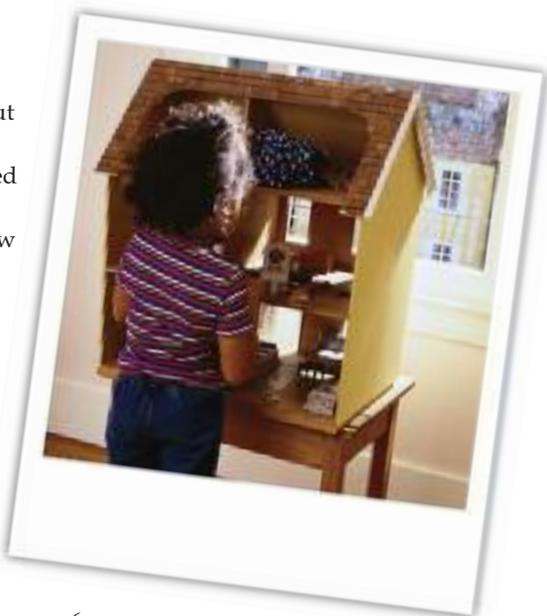
ASDs occur in all racial, ethnic, and socioeconomic groups, and except for Rett's Disorder, are four times more likely to occur in boys than in girls. Children who have a sibling or a parent with an ASD should be observed carefully, as recent studies suggest that some people may have a genetic predisposition to autism. In families that have one child with autism, scientists have found the risk of having a second child with the disorder is 1 in 20, or 5 percent.

How common is Autism?

ASDs are the fastest-growing diagnoses among the developmental disabilities in the United States. According to the Autism Society of America, the diagnosis of autism is increasing at a rate of 10 to 17 percent a year. Depending upon the methods used and the groups included, recent reports estimate ASD prevalence to range between one in every 150 children and one in every 91 children. At this rate, ASDs are more common than pediatric cancer, diabetes and AIDS combined.

Does my child have Autism? — getting an early diagnosis

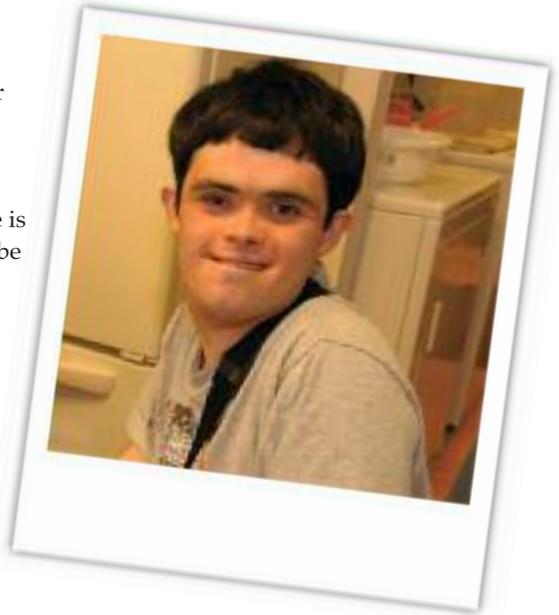
There is no genetic test for autism, but there are prenatal biological tests for other conditions sometimes associated with autism such as Fragile X syndrome. The fact that autism is now known to often have a genetic link offers hope that prenatal screening and diagnosis will be possible someday.



OPWDD: Putting People First

Research shows that when parents believe something is wrong with their child, they are often correct. Parents should gather information and seek guidance if they have concerns about their child's development. Experience is showing that the earlier children can be diagnosed and begin treatment, the more effective treatment can be.

All young children should be monitored to make sure they are reaching developmental milestones on time. The American Academy of Pediatrics (AAP) recently recommended that all children be screened for indications of ASDs at 18 and 24 months of age.



Some “red flags” for atypical development in children include:

- As early as infancy, a baby with autism may be unresponsive to people or focus on one item for long periods of time
- Lack of response to name
- Poor eye contact
- No smiles or warm expressions by 6 months or thereafter
- Lack of sharing interests or enjoyment
- No babbling by 12 months
- No words by 16 months
- Any loss of early speech or movement or social skills at any age
- Lack of “showing,” pointing, reaching or waving gestures by 12 months
- Impaired ability to relate to peers
- Impaired ability to begin or maintain a conversation with others
- Disinterest in play or in play with others
- Repetitive or unusual use of language
- Restricted patterns of interest that are atypical in intensity or focus

- Obsession with certain subjects or repetitive movements with objects
- Rigid insistence on specific routines or rituals

In New York State, only licensed physicians and psychologists are allowed to make a formal diagnosis. However, a complete evaluation, prior to diagnosis, can involve assessment by several professionals (psychologist, speech therapist, neurologist, psychiatrist and others) working together as a multidisciplinary team. Because hearing problems may cause behaviors that could be mistaken for autism, children with delayed speech development should also have their hearing tested. After a thorough evaluation, the team or the individual specialists usually meet with parents to explain the results and present a formal diagnosis.

Treatment Options

Helping someone with an ASD to reach their full potential typically involves finding ways to increase their communication and social skills and diminish any inappropriate behaviors. Both educational and behavioral intervention and medication may help achieve these goals.

- **Educational/Behavioral Interventions:** Specially trained and certified practitioners known as Applied Behavioral Specialists can evaluate an individual to determine what lies beneath their behaviors and develop a plan to encourage the development of positive behaviors. Speech and language therapists can identify a child's communication needs. Through intensive, skill-oriented training sessions developed for a particular child, therapists can then help a child build social and language skills. Family education and counseling for the parents and siblings of children with autism often helps families cope with the challenges of living with a child who has autism or another ASD.



- **Medications:** Doctors often recommend antidepressant medication to handle symptoms of anxiety, depression, or obsessive-compulsive disorder which can accompany an ASD. Antipsychotic medications are used to treat agitation and severe behavioral problems. Seizures can be treated with one or more of the anticonvulsant drugs. Stimulant drugs are sometimes used effectively to decrease impulsivity and hyperactivity.

After the Diagnosis—Mapping a Course

After a family receives a diagnosis of ASD for their child, it is critical that they pursue appropriate intervention services. Research indicates that early intervention in an appropriate educational setting for at least two years around the pre-kindergarten years can result in considerable improvements for many children. Intervention programs focus on reducing inappropriate or undesirable behaviors and developing social, communication, and cognitive skills.

Accessing the best services for a child and understanding the bureaucracies that provide services to people of different ages and disabilities can be a challenging task. In New York State, services for children with ASD derive primarily from the Department of Health (DOH), the State Education Department (SED), and the Office For People With Developmental Disabilities (OPWDD). Obtaining help in mapping a course through these systems is essential. The diagnosing physician is key to getting started. He or she should refer parents to the age-appropriate service systems (described below). Those systems will work with parents to help plan treatment, intervention and educational services appropriate and most effective for their child.



Services for Children

Early Intervention – Birth to Age 3

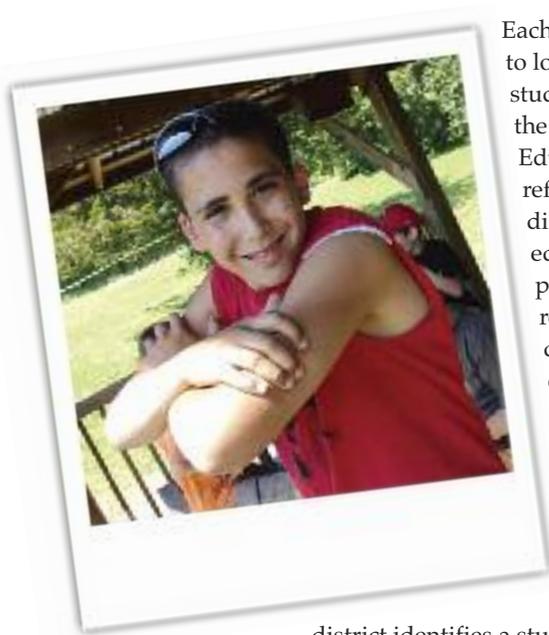
Children under the age of 3 years old can receive Early Intervention (EI) services provided by the New York State Department of Health through local public health offices. EI services provide screening and a case manager to create an Individualized Family Services Plan (IFSP) for the child and guide the family through the process of identifying and accessing the services needed. All EI services are individualized to the needs of the child and family. EI services include speech, physical, and occupational therapy, psychological and social work services, special instruction, family support groups and assistive technology. EI services are provided at home or at the child's daycare setting.



Special Education and OPWDD Services – Ages 3 to 21

If the child is three years of age or older, parents should contact their local public school district to arrange for special educational services. These services are free and include comprehensive assessment of a child's educational needs, as well as speech and language therapy, occupational therapy, physical therapy, curriculum modifications, one-on-one or shared aides, and other educational supports as necessary to meet those needs. Prior to age five, special education is typically provided in a pre-school setting. After age five, they occur in a public school setting or in specialized schools that serve individuals with more significant educational needs.

By law every child is entitled to a free and appropriate public education provided in the least restrictive environment. This means that placing students with disabilities in special classes, separate schools or somehow removing them from the regular educational environment occurs only when the disability is such that, even with the use of supplementary aids and services, education cannot be satisfactorily achieved.



Each school district has a responsibility to locate and plan for the needs of all students in their district. Part 200.4 of the Regulations of the Commissioner of Education outline the process for referring a child suspected of having a disability to the committee on special education in each district. This process includes standards and requirements for student evaluations, qualification for services, development of an individualized education program (IEP), educational accommodations, and an annual review. Part 200.5 lays out parents' legal due process rights (such as meetings, parental notifications and written consents) which must occur before the

district identifies a student as having a disability, evaluates a student's educational needs or provides special educational services. Part 200.6 identifies a continuum of services available to students with disabilities that can be expected from a local school district.

It is important for parents or guardians to be active and involved in the special education process, and there are several important rights provided to them to ensure opportunities to be involved and heard. Parents have the right to receive copies of the school district's evaluation of the child, to request that the school district pay for an independent educational evaluation (IEE) of the child by a qualified examiner who does not work for the school district, to request educational records be amended, and to request mediation and impartial hearings to resolve any disagreements between them and the school district.

It is important to understand, however, that special education services are provided by local school districts to support individuals in their education. A student with an ASD may also need services that are not educational in nature. These students may qualify for services from OPWDD that range from respite (caregiver time-outs) and family training to crisis intervention and behavioral supports and Medicaid Service Coordination (someone to help find, plan and coordinate additional supportive services). Parents should contact their local Developmental Disabilities Services Office (DDSO) to begin the process of determining their child's eligibility for OPWDD services.

From High School to Adulthood – Transition Services for Ages 15-21

As a child approaches adulthood and the end of their high school education, it is important for the student and parents to take part in a planning process that will prepare that child for his or her most successful future. This process, referred to as transition planning, is intended to enable youth with disabilities to live, work and continue to learn in the community as adults – with supports if necessary.

The transition process begins with the school district conducting a vocational assessment of the student as early as age 12. This assessment is based on a review of school records, comprehensive assessments, parent and student interviews, and it determines vocational skills, aptitudes and interests. The process, which begins in earnest, and by law, at age 15, is intended to look beyond the traditional educational focus of the IEP. Students and parents should be actively involved in this process. As transition planning continues up to the student's completion of school, it is important that the student's transition goals be prescribed in the student's IEP, with progress and updates noted annually.

Services for Adults – Age 22 and Above

By the time a student reaches adulthood, plans should be in place – based on their abilities and desires – for that individual to continue his or her education or training, to find work or to receive the kinds of supports and services needed to allow them to pursue their desires. School district personnel can and should assist a family to understand the array of services available after leaving school and what options might be most rewarding and successful for the young adult.

A vocational training program through New York State Education Department's Vocational Education Services for Individuals with Disabilities (VESID) is often an appropriate option. VESID Counselors guide individuals through service programs that will help them reach their employment goals. Services may include vocational assessment, vocational counseling, assistance with transition from school to the world of work, job training and placement, job follow-up, and other services to support an individual's employment goals. VESID ensures that both the individual and the employer are satisfied with the placement and will intervene if problems occur on the job. VESID works with the business community, as well as a vocational rehabilitation provider system, other agencies, labor organizations, and schools to provide these services.

Also, VESID administers 38 Independent Living Centers (ILCs) across New York State. Independent Living Centers are private, community-based nonresidential organizations that help people with developmental disabilities live more independently in their communities.

In addition, just as with school age students, an adult with autism may qualify for supports and services through OPWDD. These services can range from supervised residential services to in-home habilitation services, supported employment, caregiver respite, family support services, or clinical therapies. Parents or guardians of adults with an ASD should contact their local DDSO to begin the process of determining their adult child's eligibility for these services.

For Additional Service System Information:

Infants/Toddlers (Birth to Age 3) NYS DOH
Family and Community Health
Early Intervention Program
(518) 473-7016
www.health.state.ny.us/community/infants_children/early_intervention

Children Local Public School Districts

NYS Education Department
Office of Vocational & Educational
Services for Individuals with Disabilities
Special Education Policy Unit
(518) 473-2878
www.vesid.nysed.gov/specialed/autism/home.html

NYS OPWDD
VOICE: (866) 946-9733
TTY: (866) 933-4889
www.opwdd.ny.gov

Adults NYS OPWDD
VOICE: (866) 946-9733
TTY: (866) 933-4889
www.opwdd.ny.gov

NYS Education Department
Office of Vocational & Educational Services
for Individuas with Disabilities
518-474-1711 or 1-800-222-JOBS (5627)
www.vesid.nysed.gov

Resources:

Parent to Parent of New York State

Janice Fitzgerald, Executive Director
PO Box 1296
Tupper Lake, NY 12986
Tel: 518-359-3006 or 1-866-727-6970
Fax: 518-359-2151
<http://www.p2pnys@centralny.twcbc.com>

Autism Society of America

7910 Woodmont Ave, Suite 300
Bethesda, MD 20814-3067
Tel: 301-657-0881 or 1-800-3AUTISM (328-8476)
Fax: 301-657-0869
<http://www.autism-society.org>

Autism Speaks, Inc.

2 Park Avenue
11th Floor
New York, NY 10016
Tel: 212-252-8584
Fax: 212-252-8676
<http://www.autismspeaks.org>

National Institute of Child Health and Human Development (NICHD)

National Institutes of Health, DHHS
P.O. Box 3006, Rockville, MD 20847
Tel: 1-800-370-2943 or 1-888-320-6942
Fax: (703) 738-1473
<http://www.nichd.nih.gov>

National Institute of Mental Health (NIMH)

National Institutes of Health, DHHS

6001 Executive Blvd. Rm. 8184, MSC 9663

Bethesda, MD 20892-9663

Tel: 301-443-4513 or 866-615-NIMH (-6464)

or 301 443-8431

Fax: 301-443-4279

<http://www.nimh.nih.gov>

The American Academy of Pediatrics

141 Northwest Point Boulevard

Elk Grove Village, IL 60007-1098

Tel: 847-434-4000

Fax: 847-434-8000

<http://www.aap.org>

Centers for Disease Control and Prevention (CDC)

1600 Clifton Rd, Atlanta, GA 30333

Tel: 404-498-1515 or 1-800-311-3435

<http://www.cdc.gov/>

**To learn more about OPWDD services,
contact the Developmental Disabilities Services Office nearest you:**

Bernard Fineson DDSO

County: Queens
(718) 217-4242

Brooklyn DDSO

County: Kings
(718) 642-6000

Broome DDSO

*Counties: Broome, Chenango,
Delaware, Otsego, Tioga,
Tompkins*
(607) 770-0211

Capital District DDSO

*Counties: Albany, Fulton,
Montgomery, Rensselaer,
Saratoga, Schenectady,
Schoharie, Warren, Washington*
(518) 370-7331

Central New York DDSO

*Counties: Cayuga, Cortland,
Herkimer, Lewis, Madison,
Onondaga, Oneida, Oswego*
(315) 336-2300

Finger Lakes DDSO

*Counties: Chemung, Livingston,
Monroe, Ontario, Seneca,
Schuyler, Steuben, Wayne,
Wyoming, Yates*
(585) 461-8500

Hudson Valley DDSO

*Counties: Orange, Rockland,
Sullivan, Westchester*
(845) 947-6100

Long Island DDSO

Counties: Nassau, Suffolk
(631) 493-1700

Metro New York DDSO

Counties: Bronx, New York
(212) 229-3000

Staten Island DDSO

County: Richmond
(718) 983-5200

Sunmount DDSO

*Counties: Clinton, Essex, Franklin,
Hamilton, Jefferson, St.
Lawrence*
(518) 359-3311

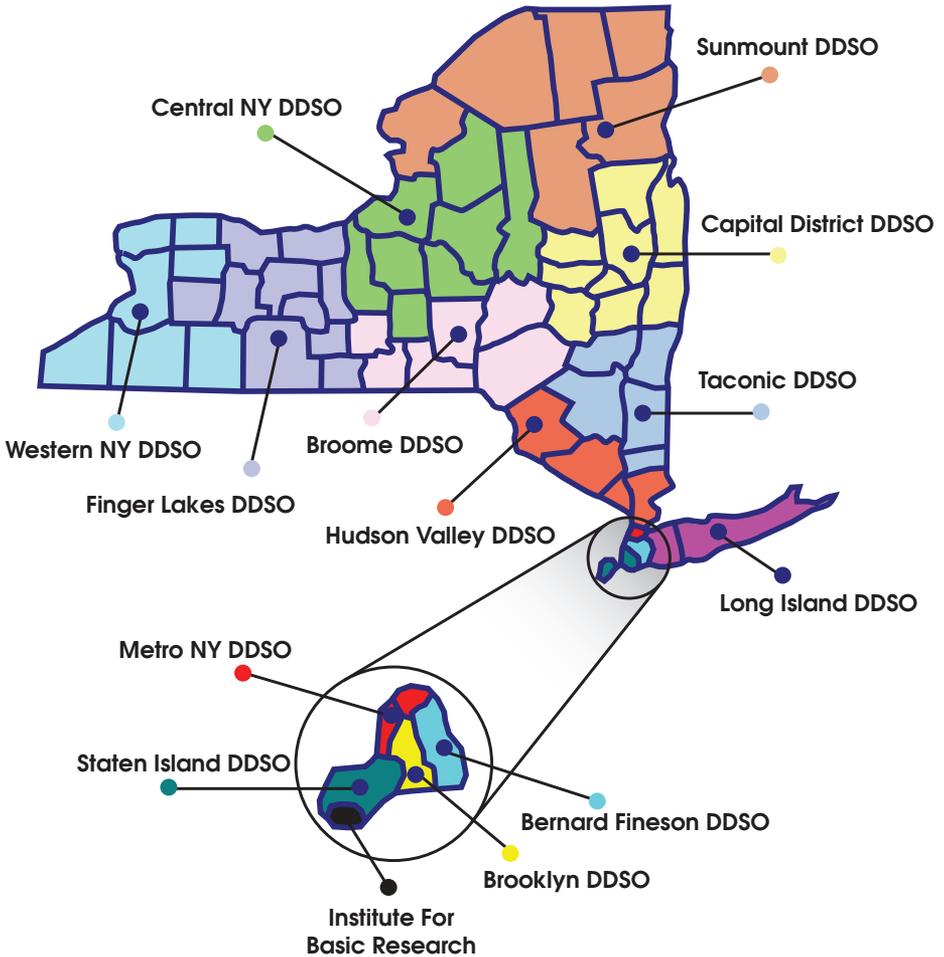
Taconic DDSO

*Counties: Columbia, Dutchess,
Greene, Putnam, Ulster*
(845) 877-6821

Western NY DDSO

*Counties: Allegany,
Cattaraugus, Chautauqua, Erie,
Genesee, Niagara, Orleans*
(716) 517-2000

OPWDD's Developmental Disabilities Services Offices Map



This brochure is a publication of the OPWDD Communications Office, 44 Holland Avenue, 3rd Floor, Albany, NY 12229.



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For further information, please check the OPWDD Website:

www.opwdd.ny.gov

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