

Guide to Understanding Supports and Services

***Administered by the New York
State Office for People with
Developmental Disabilities
(OPWDD)***

***Compiled by
Parent to Parent of NYS***

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Welcome to the Guide to Understanding Supports and Services Administered through NYS Office for People with Developmental Disabilities (OPWDD). The Guide was developed to inform families about the wide range of supports and services available to qualified individuals and to assist them in accessing those services for their loved one with a developmental disability.

While the Guide includes a wide range of services, it is in no way inclusive of every service offered by OPWDD. New York State's "people first" philosophy allows qualified individuals with intellectual and developmental disabilities to build services around their specific goals, needs, and desires. When services and supports are created around people and not programs, the variety of ways to support individuals with developmental disabilities becomes limitless.

The staff of Parent to Parent of NYS are not experts in service delivery. We are family members of individuals with disabilities and special health care needs whose expertise lies in our desire and motivation to create a satisfying quality of life for all family members. We have learned that creating that life requires an understanding of the terms and acronyms associated with the provision of supports and services. We call it the language of service systems. While there is no one resource that can address every question, it is our objective that this Guide will provide direction and a general overview of the OPWDD service system.

Everyday, we receive calls from people trying to help their loved one with developmental disabilities. The questions are endless, but they always include a *heartfelt request for help*. The calls include requests for help with understanding how, in one way or another, to assist the person they support and care for. Often, the questions revolve around accessing services and understanding terms and acronyms.

Thank you is offered to the Office for People with Developmental Disabilities for their input and for reviewing and partnering in the creation of this Guide. We appreciate their recognition of the need to support the parents and caregivers who are such an integral part of the success of every child and adult with developmental disabilities.

The Guide is a valuable tool for people with disabilities, parents and caregivers. Copies of the Guide can be downloaded from the Health Care Information and Education section of the Parent to Parent of NYS website at www.parenttoparentnys.org.

Michele Juda
Executive Director

NYS Office for People with Developmental Disabilities has Opened the “Front Door”

Are you reaching out to NYS for assistance in caring for a child or adult with a disability?

The Front Door is the point of entry into accessing services for a person with intellectual and/or developmental disabilities.

The Front Door orientation provides an overview and historical perspective on services to persons with disabilities.

Front Door Information Sessions are held regularly for Individuals and Families

If you or your loved one is new to accessing services through OPWDD, attending an information session is required. The sessions offer participants an understanding of OPWDD’s mission and purpose; the process to become eligible for OPWDD supports and services; types of supports and services available; and where individuals and families can go to get assistance. To locate the Front Door contact for your region, follow this link:

http://www.opwdd.ny.gov/welcome-front-door/Front_Door_Contact_Numbers

From NYS OPWDD:

“Opening the door to a richer, fuller life—that’s the goal of OPWDD’s new Front Door—a person-centered approach for people with developmental disabilities that prioritizes individual choices, needs, and desires in making decisions.

Opening the Front Door to Possibilities

The Front Door strives to:

- Improve the way people learn about OPWDD and available service options
- Better connect individual needs to available services
- Give people as many opportunities as possible for self-direction

Front Door services rest on the philosophy of self-determination and the idea that people with developmental disabilities have the right to:

- Enjoy more meaningful relationships with family, friends, and others in their lives
- Experience personal growth
- Fully participate in their communities
- Live in the home of their choice

Ultimately, opening the Front Door means people with developmental disabilities will have the opportunity to pursue their dreams and live the lives of THEIR choosing.”

The following pages of this Guide provide an introduction to the eligibility process and terminology you will encounter as you apply for and access services.

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Services for People with Intellectual and Developmental Disabilities in NYS as Defined by OPWDD Guidelines

Are there services other than Special Education that my child with special needs may be eligible for?

Some children with exceptional needs may be eligible to receive services through the NYS Office for People with Developmental Disabilities (OPWDD).

What is OPWDD?

The New York State Office for People with Developmental Disabilities coordinates and provides services for people with developmental disabilities and their families and conducts research into the causes and prevention of developmental disabilities. (See appendix for OPWDD Mission, Visions, Values and Guiding Principles.)

OPWDD provides access to services for people with developmental disabilities through a regional system dividing the state into sections that are overseen by Developmental Disabilities Services Offices called DDSOs.

What is a DDSO?

There are 13 DDSOs across the State, thereby enabling people to connect with services that are locally provided and/or certified. Contacting the DDSO is a person's first step toward receiving the services he/she may want and need. Funding options, availability of services, and coordination of services can all be discussed at the DDSO.

(See appendix for a Directory of DDSOs.)

What kind of supports and services are available through OPWDD?

Some services provided through OPWDD include family support , case management, respite, housing, supported employment, recreation,

skills development, training, long term habilitative services, nursing and psychiatric services, respite (short-term caregiver relief).

Who provides these services?

Services for eligible persons in NYS are provided through a network of public and non-profit service providers, all of whom work collaboratively to assure that high quality care is provided.

Parent Tip: Contact your regional office of Parent to Parent of NYS or local DDSO (listed in Appendix) for assistance in locating service providers in your area.

How can I learn more about OPWDD?

For more information on OPWDD, visit their website at <http://www.opwdd.ny.gov/> or contact your local DDSO (see Appendix).

Accessing Services through OPWDD

How is eligibility for OPWDD services determined?

OPWDD uses Section 1.03(22) of the New York State Mental Hygiene Law as the legal basis for eligibility.

“Developmental Disability” means a disability of a person who is:

(A)

1. attributable to mental retardation, cerebral palsy, epilepsy, neurological impairment, familial dysautonomia, or autism; or
2. 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 persons; or
3. attributable to dyslexia resulting from a disability in (1) or (2).

And

(B)

Originates before the person attains the age of twenty-two;

And

(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.

Each of these requirements in section (A) is interchangeable; but, at least one of those three must occur in combination with the requirements of (B), (C), and (D).

What is mental retardation?

People with mental retardation show delays in learning, a slower pace of learning, and difficulty in applying learning. Over 250,000 people in New York 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, central nervous system trauma and social deprivation.

What is 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 usually is caused by brain injury before or during birth. However, brain damage or injury at any time in life can have the same effect. Often, people with cerebral palsy do not have mental retardation.

What is epilepsy?

Epilepsy applies to numerous nervous system disorders that result in abnormal electrical discharges of brain cells. This produces seizures that may cause convulsive movements, or partial or total loss of consciousness. Only a small percentage of people with epilepsy also have mental retardation.

What are 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.

What is familial dysautonomia?

Familial dysautonomia is a genetic disease present at birth in male and female Jewish babies, primarily causing dysfunction of the autonomic and sensory nervous systems. Dysfunction is a result of an incomplete development of the neurons (nerve fibers) of these systems.

What is autism?

Autism is a developmental disorder that limits learning and slows intellectual development. People with autism have great difficulty relating and responding to persons, events or objects. People who have mild autism may demonstrate some repetitive actions and a marked lack of sensitivity to other people. People who have more severe autism have difficulty listening to and communicating with others.

What is meant by a “Substantial Handicap to a Person’s Ability to Function Normally In Society?”

- A “substantial handicap to a person’s ability to function normally in society” exists when the person is prohibited from:
 - Engaging in substantial aspects of self-care or self-direction independently; and/or when the developments of self-care and self-direction skills are significantly below age level.

How is a Substantial Handicap determined?

- Typically, by using a nationally normed, validated, comprehensive, individualized measure of adaptive behavior, which is administered by a Qualified Practitioner.
- *A lower I.Q. does not automatically mean there is a substantial handicap.*

How is “substantial handicap” determined for children birth to seven years of age with developmental delay?

Consistent with Part 200.1(mm) (1) of the regulations of the NYS Department of Education, substantial handicap associated with delay can be documented by the results of an individual evaluation that indicates:

- A 12-month delay in one or more functional area(s); or
- A 33% delay in one functional area, or a 25% delay in each of two functional areas; **or**
- If appropriate standardized instruments are individually administered in the evaluation process, a score of 2.0 standard deviations below the mean in one functional area, or a score of 1.5 standard deviations below the mean in each of two functional areas.

For children ages birth to three years, clinicians may follow guidelines provided by the NYS Department of Health for the Early Intervention Program.

The Eligibility Determination

Process

How do I know if my child is eligible to receive services?

There is an Eligibility Determination Process that is used to determine if your child has a developmental disability and is eligible to receive OPWDD funded services.

NOTE: A DETERMINATION OF DEVELOPMENTAL DISABILITY DOES NOT MEAN YOUR CHILD IS ELIGIBLE FOR ALL SERVICES. SOME OPWDD SERVICES HAVE ADDITIONAL CRITERIA.

How do I get started with the process?

An Intake Coordinator at your local DDSO or one of many non-profit providers approved by New York State will assist you and your child with the Eligibility Determination Process.

What happens once I provide the Intake Coordinator with all of the necessary documentation?

OPWDD, through its local Developmental Disabilities Services Offices (DDSOs), uses a Three Step Eligibility Process to determine eligibility.

What happens during a 1st Step Review?

DDSO staff reviews your child's eligibility request for completeness. After this review, you will receive a letter informing you that:

- Your child is eligible.
- Additional documentation is required. The letter will describe the type of information needed.
- Information is being sent to clinicians who will conduct a 2nd Step Review.

What happens during a 2nd Step Review?

DDSO clinicians review submitted documentation to determine eligibility. If additional information or documentation not already

requested by 1st Step Review staff is required, you will be notified of the type of information needed and the date by which to contact the DDSO.

If your son or daughter is determined to have a developmental disability, a letter will be sent informing you of your child's eligibility for OPWDD services.

If the DDSO determines that, based upon the information provided, your child does not have a developmental disability and is not eligible for OPWDD services, you will receive a denial letter.

If my child is denied eligibility, can I appeal?

The denial letter following the 2nd Step Review will explain the following options:

- Meet with DDSO staff *
- Request a 3rd Step Review*
- Request a Medicaid Fair Hearing (if you are seeking Medicaid funded services)*

*** You may pursue one, two, or all three of these options.**

What is the purpose of the face-to-face meeting with DDSO staff?

Meeting with DDSO staff will allow you to:

- address questions concerning basis of denial;
- present additional documentation, if any;
- explain what additional documentation may be helpful;
- discuss any misunderstandings

What happens during a 3rd Step Review?

Eligibility Determination Committees located in the New York City Regional Office (for NYC residents) or at the Upstate Regional Office in Albany (for all other New York residents) will review all available documentation and forward recommendations on eligibility to the DDSO Eligibility Coordinator who will inform you, in writing, of any change in the DDSO's determination.

How long does the Eligibility Determination Process take?

As a guideline, except in unusual circumstances where additional information is needed, OPWDD makes eligibility determinations within 90 days.

What kind of documentation is required to demonstrate eligibility?

The following information is needed, in most cases, to determine whether someone is eligible for OPWDD services:

- A medical or specialty report (for example, a neurological report) including health status and diagnostic findings to support a qualifying diagnosis other than mental retardation. For persons qualifying with mental retardation only, a recent, general medical report.
- A psychological report which includes assessment of intellectual functioning with reporting of intelligence scores **(including subscale, part, and full scale scores)**, and, for people with IQs above 60, **standardized** assessment of adaptive behavior with reporting of scale and summary scores **(for people with IQ's below 60, assessment may be based on qualitative review via interview with care-providers, review of records, and direct observations)**.
- A social history, psychosocial report, or other background report that shows that the person became disabled before age 22 years (background information is still needed if the person is a child or adolescent).

Where can I go to get the necessary documentation?

Documentation is typically available from schools (especially School Psychological Evaluations and Individualized Education Plans), Health Care Providers, Clinics, etc.

These documents can sometimes be obtained by visiting your child's primary care physician and a licensed psychologist (usually a school psychologist).

If you feel your documentation is not sufficient, speak to the Intake Coordinator at your local DDSO for assistance.

Which measures of intellectual functioning are acceptable?

- Kaufman Assessment Battery for Children
- Leiter International Performance Scale
- The Stanford-Binet Scales
- The Wechsler series of Intelligence Scales

- Other intelligence tests are acceptable if they are comprehensive, structured, standardized, and have up-to-date general population norms.

Which measures of adaptive behavior are acceptable?

- AAMR Adaptive Behavior Scale, School version **only** (for use with children)
- Adaptive Behavior Assessment System
- Comprehensive Test of Adaptive Behavior
- Scales of Independent Behavior
- Vineland Adaptive Behavior Scales
- Other adaptive behavior measures are acceptable if they are comprehensive, structured, standardized, and have up-to-date general population norms.

What is Provisional Eligibility for Children from Birth – 7?

DDSOs may grant Provisional Eligibility, based on clinical judgment, when a young child presents with developmental delay and evidence of functional limitations, but without specification of a named or unnamed condition. Standard eligibility must be determined no later than your child's 8th birthday.

SUPPORT AND SERVICES

Administered by the NYS Office for People with Developmental Disabilities

***Note:** The Supports and Services identified are not an all inclusive list of services. The ones listed are the terms most families and people with disabilities will become acquainted with.*

Medicaid Service Coordination (MSC)

What is MSC?

Medicaid Service Coordination is a Medicaid State Plan service provided by OPWDD which assist persons with developmental disabilities in gaining access to necessary services and supports appropriate to the needs of the individual. MSC is provided by qualified service coordinators and uses a person centered planning process in developing, implementing and maintaining an Individualized Service Plan (ISP) with and for a person with developmental disabilities or mental retardation. MSC promotes choice, individualized services and supports, and consumer satisfaction.

Who is eligible to receive MSC?

In order to receive MSC, a person must:

- Have a documented diagnosis of a developmental disability;
 - Be enrolled in Medicaid;
 - Demonstrate a need for ongoing and comprehensive, rather than incidental, service coordination;
 - Choose to receive MSC or have consent given on their behalf by an authorized individual;
 - Live outside of an Intermediate Care Facility (ICF), Developmental Center (DC), Psychiatric Hospital, Small Residential Unit (SRU), Nursing Facility or Hospital, or any other Medicaid funded setting that provides service coordination, and,
 - Not be enrolled in any other comprehensive Medicaid long-term service coordination program.
-
- **Parent Tip:** Need help understanding Medicaid Service Coordination? Contact Parent to Parent of NYS coordinators in

New York City at 800-405-8818 or in Schenectady at 800-305-8817 and ask to speak to someone about understanding Medicaid Service Coordination and download the booklet Understanding Medicaid Service Coordination at <http://www.parenttoparentnys.org/Services/MSA/mscbooklet.htm>

Waiver Services

What are New York State Medicaid Waiver Services?

- Waiver Services provide services and supports to children and adults with long-term needs and their families to enable them to remain at home and in the community.
- Waiver services are designed for people who, without these services, would require the Level of Care provided in a long-term care facility.
- Waiver services allow Medicaid to pay for some services not provided through “regular” Medicaid, such as case management, respite and home adaptations.
- Under the HCBS Waivers, parental income and assets are not considered when determining the child’s eligibility for Medicaid. Only the child’s income and assets are counted.
- Although the Medicaid funding obtained only applies to the child, it can be used to defray the costs of caring for the child at home.
- Waiver services are funded by a mix of federal, state and county money.

What is the Care at Home Waiver for Children with Developmental Disabilities?

The goal of this program is to provide medical assistance to families with children living at home who have severe disabilities or medical conditions.

Who is eligible to receive the Care at Home Waiver?

To be eligible a child must be under 18 years of age; have a developmental disability; demonstrate complex health care needs; be eligible for the level of care provided by an intermediate care facility; not be hospitalized; and be eligible for Medicaid. Contact your local Developmental Disabilities Service Office (DDSO), Care at Home Waiver Coordinator. Website: www.opwdd.ny.gov

What is the Home and Community Based Services (HCBS) Waiver?

The goal of this program is to enable persons with developmental disabilities to obtain the supports and services needed to reach his or her goals in life. A person's independence and inclusion in the community are the primary concerns in designing this package of supports and services.

Who is eligible to receive the HCBS Waiver?

To be eligible a person must have a documented developmental disability; have needs comparable to a person residing in an Intermediate Care Facility; be enrolled in Medicaid*; and live with family, in a Family Care home, their own home, an Individual Residential Alternative (IRA) or a Community Residence.

*Children under the age of 18 who do not have Medicaid upon application for enrollment in the waiver will need to apply. The local Developmental Disabilities Service Office (DDSO) will provide guidance in how to apply. Website: www.opwdd.ny.gov

What services are available under the HCBS waiver?

Community Habilitation – A service designed to promote independence and community integration by offering skills training and other habilitative supports which take place in non-certified every day community settings.

Day Habilitation – A service that provides assistance to acquire, retain, or improve the skills needed to perform daily activities away from the home. These activities might include purchasing goods and services, communicating with fellow employees, traveling, community meetings or gatherings, or running errands.

Supported Employment – A service that provides competitive work in integrated settings for individuals for whom competitive employment has been interrupted or intermittent as a result of their disabilities, and need ongoing services to continue to work.

Prevocational Services – A service that prepares individuals for paid or unpaid employment. Services include teaching such concepts as attending, task completion, problem solving and safety. Activities included in this category are not primarily directed at teaching specific job skills, but are directed at

underlying habilitative goals, such as increased attention span and improved motor skills.

Respite – A service that provides short term “substitute services” on behalf of a primary caregiver who is either a family member, a legal guardian, an advocate, or a Family Care Provider or live-in/house parent staff. It is a means of providing services when the person normally providing care is absent or in need of relief.

Adaptive Devices – Devices, aids, controls, appliances, or supplies of either a communication or adaptive type, which are necessary to enable the person to increase his or her ability to live at home with independence and safety. Some examples are personal emergency response systems, communicators, speech amplifiers, standing boards/frames, and motorized wheelchairs.

Environmental Modifications – Changes or additions to the home environment necessary to ensure the health, welfare, and safety of the individual with developmental disabilities; or to enable the individual to function with great independence in the home. Some examples are ramps, lifts, hand-railings, roll-in showers, water faucet controls, and cabinetry.

Plan of Care Support Services – This service will only be provided to people who are participating in the HCBS Waiver and who have chosen to withdraw from Medicaid Service Coordination. The major responsibilities for staff providing this service will be maintaining the person’s Individual Service Plan, assuring that an annual level of care eligibility determination is completed, and assuring that necessary safeguards have been taken to protect the health and welfare of the consumer.

Family Education and Training – This service may be provided to the families of consumers enrolled in the HCBS Waiver who are under 18 years of age. The purpose of family education and training is to enhance the decision making capacity of the family unit, provide orientation regarding the nature and impact of developmental disabilities upon the consumer and his or her family, and inform them about service alternatives.

CSS – Self-Determination Using Consolidated Supports and Services – *Consolidated Supports and Services (CSS) enable an individual to design and direct their own services in accordance with a person centered plan and the principles of Self-*

Determination. CSS provides the mechanism for an individual to “purchase” the needed services and supports to live a fulfilling and safe life in the community. The individual, along with their support system (called a circle of support) have the responsibility and authority to manage a personalized budget with the assistance of a Fiscal Employer Agent.

Intensive Behavioral Services

Intensive Behavioral Services are designed for people who live in non-certified settings or Family Care Homes and who present substantial challenging behaviors that put someone at imminent risk of placement into a more restrictive living environment. Components of this service include a functional behavior assessment, behavior management plan, implementation and monitoring of behavioral interventions and training in the behavior management plan. The service is available for a 6 month period of time.

Residential Services

What is NYS-CARES ?

NYS-CARES is a multi-year plan to address the needs of people who are seeking out of home residential services. It operates in partnership with voluntary provider agencies to provide for the long-term needs of people who require out of home residential services. NYS-CARES enables OPWDD to provide needed supports and services when families say they need them.

- ***Parent Tip:*** *Ask your service coordinator if your child’s name has been identified with NYS CARES.*
- ***Parent Tip:*** *Need help understanding information on housing? Check out the Housing Resource website section at <http://www.parenttoparentnys.org/Services/Housing/housing.htm> or contact the Parent to Parent of NYS coordinator in Western NY at 800-305-8813.*

What kinds of residential services are available?

Residential settings are licensed by OPWDD to provide housing and related services, operated by either OPWDD or nonprofit agencies.

These settings include supervised group living (a home with 24-hour staffing and supervision), semi-independent (or "supported") group living (a home with less-than-24-hour staffing and supervision), and other residential options (typically, homes for 15 or more people with 24-hour staffing and supervision). See also Family Care, and Housing/Individual Support Services. Some examples of residential opportunities are:

- Individualized Residential Alternatives (IRA) - Are certified homes for 1 – 14 persons which provide room, board and individualized protective oversight in the form of (1) a supervised IRA with staff onsite or proximately available at all times or (2) a supportive IRA that provides practice in independent living under variable amounts of oversight with staff not typically onsite nor proximately available at all times.

- Community Residences (CR) – Provide semi-independent living. There are 2 types of CRs:
 - (1) Supervised; provide housing with staffing available 24hrs.
 - (2) Supportive; which are limited to 3 people, with staff support varying according to individual need.

- Intermediate Care Facilities (ICF) – Provide a residential treatment option in the community for persons with specified medical and/or behavioral needs. ICFs provide 24 hour on-site assistance and training, intensive clinical and direct care services, professionally developed and supervised activities, and a variety of therapies. ICFs are designed for individuals whose disability severely limits their ability to be independent.

- Family Care – Is a licensed residential program which provides a family living experience through a structured and stable home environment, including the support, guidance and companionship found within a family unit. Family Care providers are home owners who receive a monthly stipend to provide services within their homes.

- Non-Certified Housing Options – Includes services that assist persons with developmental disabilities to locate, lease or

buy, and access residential arrangements which are alternatives to traditional congregate living situations. Among these types of living arrangements are shared or matched home sharing, independent living, HUD rental subsidies and low income home ownership programs.

How do I go about choosing a Residential Service Provider?

Request a copy of the "Guide for Choosing a Residential Service Provider" from your Service Coordinator, visit the OPWDD Website, or contact your Regional Office of Parent to Parent of NYS. See Appendix for locations & phone numbers.

Family Support Services

What are Family Support Services?

The Family Support Services Program helps families who are caring for a relative with a developmental disability at home by aiding the caregivers and thereby, enhancing family stability and preserving family unity.

Family Support Services can be defined as a family-directed, statewide system of comprehensive family support services, designed and developed to enhance a family's ability to provide in-home care to their family members with a developmental disability.

What are the goals of Family Support Services?

- To provide a quality of life comparable, to the extent practicable, to that of similarly situated families without a family member having a developmental disability.
- To maintain family unity.
- To prevent premature or inappropriate out-of-home placement.
- To reunite families.
- To enhance parenting skills.
- To maximize the potential of the family member with a developmental disability.

What services are offered through Family Support Services?

- **Family Reimbursement:** Family reimbursement provides the possibility of purchasing services and goods that are not funded through any other sources as long as prior approval has been obtained and the goods and services have been deemed appropriate to meet the needs of the person being served. i.e. Respite (short-term caregiver relief)
- **Recreation:** Recreation is a planned program of social, recreational and leisure activities for people with developmental disabilities that include opportunities to interact with and participate as part of a community, such as such as day, evening, weekend, summer camp, recreation programs
- **Counseling, Training and Supports:** Counseling, training and educational activities and supports may be available for parents, siblings and caregivers, as well as for individuals with developmental disabilities through the local DDSO and/or other locally based programs. These services may be helpful for individuals and families who are looking to gain insight, resolve

- problems, develop alternate approaches to services and to address other issues of concern.
- **Advocacy:** Advocacy may include information and referral services, outreach, parent networking and service assistance for individuals and their families. It is possible to make connections with diagnostic, residential, habilitative, educational, vocational, medical and recreational services, and to other programs such as Medicaid and SSI.
 - ***Parent Tip:*** *Parent to Parent of NYS offers a program for parents and caregivers to speak to other parents about their child's disability or other topics that a parent so chooses (i.e. school district, neighborhood resources, etc.)*

Family Support Services Council

What is a Family Support Services Council?

Persons with developmental disabilities and their families can best determine the services they need and how these services should be provided. OPWDD stresses family and consumer empowerment, choice and flexibility in its Family Support Services Program. As a result, Councils were developed in every DDSO. The Guidelines for the Councils were developed by members of the local DDSO Councils.

What is the purpose of the Family Support Services Council?

The purpose is to recognize and use the knowledge and experience of families of persons with developmental disabilities, and consumers themselves, in developing New York State's family support policies, services and supports. The Council actively participates in the development of a DDSO family support plan for the region and monitors the supports provided pursuant to the plan. The Council represents the interests of families and consumers in all priority, planning and funding decisions that focus on supporting families and consumers. The Council works in partnership with the local DDSO.

Can I become involved in my local Family Support Services Council?

Membership is open to consumers or family members who have a relative with a developmental disability living at home or is deceased. The Family Support Services Coordinator in your area can give you information on how you can participate in your local Family Support Council. If you know someone on the Council, ask them about joining. If you are not sure if you want to join, you could request to be on their

mailing list to receive Minutes of the Meeting to help you decide. Each Council has established by-laws to work by.

- **Parent Tip:** *Being involved in your local FSS Regional Council is showing leadership in your community. Parent to Parent of NYS encourages families to offer to be part of their local Family Support Services Council. It is an excellent way to meet other people and to give back to the service system that is a help to you and your family member. Contact your local DDSO and ask to speak to the Family Support Services Coordinator to learn more about your local Council.*

RESOURCE LIST

For people who do not have access to the Internet, contact your local office of Parent to Parent of NYS. Copies of requested materials will be mailed to you.

Resources available to download from the website of Parent to Parent of NYS

www.parenttoparentnys.org

Understanding Medicaid Service Coordination:

<http://www.parenttoparentnys.org/Services/MSA/mscbooklet.htm>

Health Care Recordkeeping Notebook:

<http://www.parenttoparentnys.org/Family2Family/Record%20Keeping/recordkeeping.htm>

HCBS Waivers in NYS:

http://www.parenttoparentnys.org/Family2Family/Fact%20Sheets/hcb_swaiver.htm

Financial Aid Fact Sheet:

<http://www.parenttoparentnys.org/Family2Family/Fact%20Sheets/financialaid.html>

Recordkeeping Tips:

<http://www.parenttoparentnys.org/Family2Family/Tips%20Sheets/recordkeepingtips.html>

Regional News and Events Announcements

News & Events List – This list is for residents of New York State who would like to receive occasional electronic announcements from their local Parent to Parent office. Announcements contain pertinent news and events.

<http://www.parenttoparentnys.org/index.php/site/form-regional-list>

Families of Children who are Medically Fragile e-group

The purpose of this group is to disseminate and share information regarding children who have complex medical needs, are considered medically fragile and require skilled nursing care. This e-group is a place where parents can connect and support each other by

posting questions, sharing resources, comments and stories. It is interactive, and parents are able to receive feedback from other parents across New York State.

<http://www.parenttoparentnys.org/index.php/site/form-email-list-mffn>

Information available on the website of NYS OPWDD:

Catalogue of Training and Development Programs available to parents, professionals and people with disabilities:

<http://www.opwdd.ny.gov/wp/index.jsp>

Task Force on Special Dentistry:

http://www.opwdd.ny.gov/opwdd_services_supports/oral_health/subcommittees

Other:

“How can I get the Best Health Care for my Child” is viewable at this link: <http://www.health.state.ny.us/publications/3059/>

The Resource Directory for Children and Youth with Special Healthcare Needs is available in English, French, Chinese, Spanish, and Russian.

<http://www.health.state.ny.us/publications/0548/>

Medicaid http://www.health.state.ny.us/health_care/medicaid/

The Justice Center for the Protection of People with Special Needs

People with special needs shall be protected from abuse, neglect and mistreatment. <http://www.justicecenter.ny.gov/>

Self Advocacy Association of NYS – The Self-Advocacy Association of New York State, Inc. (SANYS) is a not-for profit, grassroots organization run by and for people with developmental disabilities.

www.sanys.org

Parent to Parent of New York State

MISSION STATEMENT

Parent to Parent of New York State builds a supportive network of families to reduce isolation and empower those who care for people with developmental disabilities or special healthcare needs to navigate and influence service systems and make informed decisions.

VISION STATEMENT

As a statewide network of parents who provide emotional support to families of individuals with special needs, we believe in the power of parents and family members helping each other. We believe that this connection among parents and family members reduces isolation, increases acceptance, and fosters the pursuit of dreams through the sharing of experience and information.

VALUES STATEMENT

- The world is a welcome, safe place for all.
- Family members are supported and encouraged to maintain their individual identities and lives, and to pursue their dreams.
- Families, service providers, schools and the medical community provide a collaborative foundation of positive support and encouragement.
- Families have the supports available to participate in community activities and are welcomed.
- Natural supports are a component of everyday life.
- Adequate funding for supports, education, therapies, services and medical care allows family members to lead fulfilling lives.
- Parents are a tremendous resource for other parents and families.

Parent to Parent of New York State Contact Information

1. WESTERN NEW YORK AND FINGER LAKES

WESTERN NY – Allegany, Cattaraugus, Chautauqua, Erie, Genesee, Niagara, Orleans & Wyoming counties

1200 East & West Road, Building 16, Room 1-173, West Seneca, NY 14224

1-800-305-8813 / 716-517-3448 / Fax: 716-517-2385

FINGER LAKES – Livingston, Monroe, Ontario, Wayne & Yates counties

c/o FL DDRO Office, 2165 Brighton-Henrietta Townline Road, Room #124, Rochester, NY 14623

Mail: 300 Hylan Drive, PMB 153, Rochester, NY 14623

585-424-7211 (phone & fax)

SOUTHERN TIER – Chemung, Schuyler, Steuben & Seneca

PO Box 205, 210-12th St. #210, Watkins Glen, NY 14891

1-800-971-1588 / 607-535-2802 (phone & fax)

2. CENTRAL AND NORTHERN NEW YORK

NORTH COUNTRY – Clinton, Essex, Franklin, Hamilton, Jefferson & St. Lawrence counties

PO Box 1296, Tupper Lake, NY 12986

1-866-727-6970 / 518-359-3006 / Fax: 518-359-2151

SOUTH CENTRAL NY – Broome, Chenango, Delaware, Otsego, Tioga, & Tompkins counties

213 Tracy Creek Road, Vestal, NY 13850

607-770-0211, ext. 787 or 891 / Fax: 607-786-6483 (include a fax cover sheet)

NORTH CENTRAL NY – Cayuga, Cortland, Herkimer, Lewis, Madison, Oneida, Onondaga & Oswego counties

c/o Exceptional Family Resources, 1820 Lemoyne Ave., Syracuse, NY 13208

1-800-305-8815 / 315-478-1462, ext. 322 / Fax 315-478-1467 (include a fax cover sheet)

3. CAPITAL REGION AND HUDSON VALLEY

CAPITAL REGION & TACONIC – Albany, Columbia, Dutchess, Fulton, Greene, Montgomery, Putnam, Rensselaer, Saratoga, Schenectady, Schoharie, Ulster, Warren & Washington counties

500 Balltown Road, Schenectady, NY 12304

1-800-305-8817 / 518-381-4350 / Fax: 518-393-9607

HUDSON VALLEY – Orange, Rockland, Sullivan & Westchester counties

c/o WIHD, Cedarwood Hall, Valhalla, NY 10595

1-800-305-8816 / 914-493-2635 / Fax: 914-493-8118 (include a fax cover sheet)

4. NEW YORK CITY

METRO NEW YORK – Bronx, Kings, Manhattan & Queens counties

25 Beaver Street, 4th Floor, New York, NY 10004

1-800-405-8818 / Fax: 212-741-5545

646-766-3459/3460/3461/3462

STATEN ISLAND – Richmond County

c/o IBR, 1050 Forest Hill Road, #108, Staten Island, NY 10314

1-800-866-1068 / 718-494-3462 / Fax: 718-494-0319

5. LONG ISLAND – Nassau & Suffolk counties

415-A Oser Avenue, Hauppauge, NY 11788

1-800-559-1729 / 631-434-6196 / Fax: 631-434-6151

BUSINESS OFFICE

PO Box 1296

Tupper Lake, NY 12986

518-359-3006

Fax: 518-359-2151

TECH SUPPORT

4 Commerce Lane

Canton, NY 13617

315-379-1538 (phone & fax)



www.ptopnys.org



info@ptopnys.org



facebook.com/parenttoparentnys



[@PtoPofnys](https://twitter.com/PtoPofnys)

NYS OPWDD – Office for People with Developmental Disabilities

The Mission Statement

We help people with developmental disabilities live richer lives.

The Vision Statement

People with developmental disabilities enjoy meaningful relationships with friends, family and others in their lives, experience personal health and growth and live in the home of their choice and fully participate in their communities.

Values

Describe how we as employees of OPWDD interact with the individuals we serve, families, staff, the community and each other:

Compassion – The capacity to appreciate what others think and feel.

Dignity – The recognition of the worth of each person and the treatment of individual rights and preferences with respect, honor and fairness.

Diversity – The celebration, respect and embracing of the differences among us because these differences strengthen and define us.

Excellence – The continual emphasis on innovation, increasing knowledge, and delivering the highest quality supports and services.

Honesty – The foundation on which trust is built and truth is communicated.

Guiding Principles that frame how OPWDD conducts its business:

Put the person first – People with developmental disabilities are at the heart of everything we do, and this person-first ethic is embodied in the way we express ourselves, and in the way we conduct our business.

Guiding Principles that frame how OPWDD conducts its business (continued):

Maximize opportunities – OPWDD's vision of productive and fulfilling lives for people with developmental disabilities is achieved by creating opportunities and supporting people in ways that allow for as many as possible to access the supports and services they want and need.

Promote and reward excellence – Quality and excellence are highly valued aspects of our services. Competency is a baseline. We find ways to encourage quality, and create ways to recognize and incentivize excellence to improve outcomes throughout our system.

Provide equity of access – Access to supports and services is fair and equitable; a range of options is available in local communities to ensure this access, regardless of where in NYS one resides.

Nurture partnerships and collaborations – Meaningful participation by people with developmental disabilities strengthens us. OPWDD staff and stakeholders create mechanisms to foster this participation. The diverse needs of people with developmental disabilities are best met in collaboration with the many local and statewide entities who are partners in planning for and meeting these needs, such as people who have developmental disabilities, families, not for profit providers, communities, local government and social, health and educational systems.

Require accountability and responsibility – There is a shared accountability and responsibility among and by all stakeholders, including individuals with disabilities, their families, and the public and private sector. OPWDD and all its staff and providers are held to a high degree of accountability in how they carry out their responsibilities. We strive to earn and keep the individual trust of people with developmental disabilities and their families, as well as the public trust. Creating a system of supports that honors the individual's right to be responsible for their own life and accountable for their own decisions is of paramount importance.

Developmental Disabilities Service Offices Directory

Bernard M. Fineson DDSO	Phone (718) 217-4242
Counties served:	Fax (718) 217-4724
Queens	

Brooklyn DDSO	Phone (718) 642-6000
Counties served:	Fax (718) 642-6282
Kings	

Broome DDSO	Phone (607) 770-0211
Counties served:	Fax (607) 770-8037
Broome, Chenango, Delaware, Otsego, Tioga, & Tompkins	

Capital District DDSO	Phone (518) 370-7370
Counties served:	Fax (518) 370-7401
Albany, Fulton, Montgomery, Rensselaer, Saratoga, Schenectady, Schoharie, Warren & Washington	

Central New York DDSO	Phone (315) 336-2300
Counties served:	Fax: (315) 339-5456
Cayuga, Cortland, Herkimer, Lewis, Madison, Onondaga, Oneida & Oswego	

Finger Lakes DDSO	Phone (585) 461-8500
Counties served:	Fax (585) 461-0618
Chemung, Livingston, Monroe, Ontario, Schuyler, Seneca, Steuben, Wayne, Wyoming & Yates	

Hudson Valley DDSO	Phone (845) 947-6000
Counties served:	Fax (845) 947-6004
Westchester, Orange, Rockland & Sullivan	

Long Island DDSO	Phone (631) 493-1700
Counties served:	Fax (631) 493-1803
Nassau & Suffolk	

Metro NY DDSO	Phone (212) 229-3000
Counties served:	Fax (212) 924-0580
Bronx & Manhattan	

Staten Island DDSO	Phone (718) 983-5200
Counties served:	Fax (718) 983-9768
Richmond	

Sunmount DDSO	Phone (518) 359-3311
Counties served:	Fax (518) 359-2276
Clinton, Essex, Franklin, Hamilton, Jefferson & St. Lawrence	

Taconic DDSO	Phone (845) 877-6821
Counties served:	Fax (845) 877-9177
Columbia, Dutchess, Greene, Putnam & Ulster	

Western NY DDSO	Phone (716) 517-2249
Counties served:	Fax (716) 674-7488
Allegany, Cattaraugus, Chautauqua, Erie, Genesee, Niagara & Orleans	

