Understanding Family Support Services

A variety of services directed at parents, siblings, and other relatives to enhance a family's capacity to continue caring for a family member with a developmental disability living at home.
Family Support Services administered by:

NYS Office of Mental Retardation and Developmental Disabilities (OMRDD)

In New York State....

OMRDD is the State agency responsible for providing supports and services for individuals with mental retardation and developmental disabilities and their families.

OMRDD provides access to services for people with mental retardation and developmental disabilities. It does so through a regional system dividing the state into sections that are overseen by Developmental Disabilities Services Offices (DDSOs). Each New York State citizen lives in an area covered by one of the DDSOs. Contacting the DDSO is a person’s first step toward receiving the services they want and need. Funding options, availability of services, and coordination of services can all be discussed at the DDSO.

Services for persons who are eligible in New York State are provided through a network of public and private providers, all of whom work cooperatively to assure that high quality care that appropriately meets the needs of the individual is provided. Individualized Service Plans (ISPs) are developed for each person receiving services. They are developed through an interpersonal approach utilizing person-centered planning and should afford the individual choices that reflect the personal preferences of the individual being served while meeting his/her needs.

Government, private providers, and not-for-profit agencies provide services. The DDSO will assist in determining eligibility and applying for, identifying and receiving appropriate services.

New York State’s service system is based on providing opportunities for people with developmental disabilities and their families, offering choice, individualized planning and services that are appropriate to meeting individual needs. Programs and services are developed in collaboration with family members, providers, government leaders, advocates and the people served.
August 5, 1992

Mental Hygiene Law Article 41
Local and Unified Services
S 41.43 - Family support services

(a) The commissioner of the office of mental retardation and developmental disabilities, directly or through contract, and within amounts made available therefore, shall establish a family-directed, statewide system of comprehensive family support services. The purpose of family support services will be to enhance a family's ability to provide in-home care to their family members with a developmental disability.

(b) In administering family support services, the commissioner may, to the extent practicable, establish standards for outcome assessment and performance reviews of the goods and services obtained whether such goods and services are purchased pursuant to contract with the state, through reimbursement of families, through the issuance of vouchers to families for the purchase of goods and services, or through other means.

(c) For purposes of this section, family supports are goods, services, and subsidies, determined by the family and the commissioner of the office of mental retardation and developmental disabilities, which are provided to meet the goals of: (i) providing a quality of life comparable, to the extent practicable, to that of similarly situated families without a family member having a developmental disability; (ii) maintaining family unity; (iii) preventing premature or inappropriate out-of-home placement; (iv) reuniting families; (v) enhancing parenting skills; and (vi) maximizing the potential of the family member with a developmental disability.

(d) The mental retardation and developmental disabilities advisory council created by section 13.05 of this chapter shall establish a committee pursuant to the provisions of paragraph one of subdivision (c) of section 13.05 of this chapter, comprised of members selected by the commissioner, to be called the committee on family support services. The committee shall (i) provide information to the commissioner on the needs of families caring at home for a family member with a developmental disability; (ii) advise the commissioner on policies related to family supports and services; and (iii) offer advice to the commissioner on the design, implementation and monitoring of family support services. Members of the committee shall include persons with a developmental disability, family members of persons with a developmental disability, and professionals and others with an interest in the care of persons with developmental disabilities. A majority of the committee shall be family members of persons with developmental disabilities. Members shall only receive reimbursement for expenses incurred in connection with their duties on the committee.

(e) The commissioner, in consultation with the committee on family support services, shall submit by January first, nineteen hundred ninety-three, and annually thereafter for four years, reports to the governor and the legislature concerning family support services. Such reports shall include, but not be limited to, the following: an analysis of family support services provided by contract agencies and those provided by the state, the amounts and sources of funds expended annually for family support services by region and by type of service, the number of families receiving services, the number of families estimated to be in need of family support services, the results of consumer and family member assessments of family support services, and a description of any new initiatives and recommendations for future action.
Why Family Support Funding?

New York State endorses the important work that families do and it is helping make sure parents will not be forced to seek out of home placements for their family member. By fostering and strengthening natural community ties, family support is helping every member of a family to be a full participant in his or her community.

Family Support Services are designed to assist families in providing care for their family member with developmental disabilities who live full-time in their family home. Within each regional DDSO, there is one or more Family Support Consumer Council that is a partner with the DDSO in planning, developing and evaluating services on the local level.

The Family Support Law recognizes that families need assistance and support to care for their family members with disabilities. In a shift from earlier approaches to serving people with developmental disabilities, New York now makes resources available directly to families to help them with the job of raising and caring for their family member with developmental disabilities.

Description of Commonly Requested Family Support Services

Below is a listing and brief description of some of the more commonly requested Family Support Services offered in New York State. Since people receive individually designed plans to meet their needs that are developed locally, it is suggested that you contact your DDSO for specific information and to plan around your individual needs.

- **Respite**: Respite services provide the family with a temporary break from the constant care required for a family member with developmental disabilities who lives full time in their family home. Respite services may be provided during the day, after school or work, evening or overnight – in or out of the family home.

- **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.

- **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.

- **Advocacy**: Advocacy may include information and referral services, outreach, parent networking and service access 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 SSI.

- **Counseling, Training and Supports**: Counseling, training/educational activities and supports may be available for parents, siblings, and care givers, 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.
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

Guiding principles of Family Support Services

- Family Support Services is built upon the following guiding principles:
  - Individuals with disabilities, regardless of the severity of their disabilities, need families and enduring relationships with adults in a home environment to have the best opportunity to develop their fullest potential.
  - Individuals with developmental disabilities should have the freedom to remain at home with their families.
  - Families caring for a family member with developmental disabilities should have the option, when it is in the best interests of the child or adult with developmental disabilities and the family, of receiving services and supports necessary to maintain the individual at home.
  - Families caring for a family member with developmental disabilities should be offered assistance to make informed choices and to access, purchase or otherwise obtain the goods and services necessary to maintain that family member at home and strengthen the family’s care giving capacity.
  - The services which should be made generally available to families caring at home for a family member with developmental disabilities should include information and referral to available community services, benefits counseling, coordination of services, crisis and emergency services, assistance in securing needed goods and services.
  - Additional goods and services or assistance in the payment for such, whether by allowance, voucher, credit, reimbursement or other means, shall be offered to families to the extent allowable by existing state resources and legislative appropriations for such purposes.
  - Family Support Services should be family-driven, designed to meet the needs of the particular family requesting assistance as well as the needs of the individual with developmental disabilities, and flexible enough to meet the changing needs of such families and individuals.
  - The needs of the entire family should be considered in the development of Family Support Services for individual families.
  - Family Support Services should be delivered in a manner which is culturally and linguistically appropriate to families.
  - Family Support Services should promote the use of existing generic community resources, informal and natural sources of support, and the coordination of federal, state and local programs and services.
Eligibility for Family Support Services

To be eligible to receive Family Support Services, an individual with a developmental disability must reside at home with a biological or adoptive relative.

Eligibility must be determined by the local DDSO (Developmental Disabilities Services Office). There are usually emergency respite funds available until a notice of determination is received.

Eligibility is based on:

Section 1.03(22) of the New York State Mental Hygiene Law is the legal base for eligibility determination and defines Developmental Disability as:

A disability of a person that:

(a) (1) Is attributable to mental retardation, cerebral palsy, epilepsy, neurological impairment 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 persons; or

(3) Is attributable to dyslexia resulting from a disability described in (1) or (2);

(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.

Services offered through Family Support Services

- Family Reimbursement/Cash Subsidy
- Behavior Management
- Service Coordination
- Counseling
- Financial and Life Planning Assistance
- Home Care (Homemaker)
- Information/Referral/Outreach
- Recreation (Day/Evening)
- Recreation (Summer/Day Camp)
- Respite (Day/Evening/Weekend)
- Respite (Overnight)
- Training
- Transportation
- Vacation/Sleep Away Camp
- Other – not included in above list, e.g. parent/sibling support groups
Family Support Puts Families in Charge

_It is possible for families to get directly reimbursed for their expenses. This is the most flexible, direct and responsive way to meet families’ needs, because families figure out what they need and how they want to get it, rather than receiving services that may or may not meet their needs._

The Family Support Law puts families in charge of figuring out how the family support program should be set up. Through a state level Family Support Advisory Council, family members advise the Commissioner of the Office of Mental Retardation and Developmental Disabilities (OMRDD) about the program’s structure, funding priorities and evaluating the program’s effectiveness in meeting parents’ needs and fostering communities’ acceptance of people with disabilities, and their families. (Mental Hygiene Law Article 41Local and Unified Services S 41.43 Public Law references this committee as the Committee on Family Support Services).

The Commissioner of OMRDD has directed each DDSO to establish Local Family Support Advisory Councils, composed of a representative group of people who use family support services. At the state and regional level, advisory councils will set funding priorities, determine how services and programs should be structured, work with local families to identify and meet needs, develop innovative new approaches to the needs of families, and have a direct role in evaluation of the family support programs’ effectiveness.

Let Your Voice Be Heard

Family Support in New York is an opportunity for families to get the help and support they need to care for a family member with developmental disabilities who is living at home. In addition to being a cost effective and efficient way to provide services, it is a flexible response to very unique needs and a respectful approach to providing services and supports.

Interested parents can contact their local DDSO to find out how they can be involved, or Lori Lehmkuhl, Statewide Coordinator at (518) 473-7038

What is the role of the Consumer Council?

The Council's role is to provide a strong voice for individuals and families on the local level, working with and through the DDSO to plan, develop and monitor Family Support Services in that area.

What is the Consumer Council's goal?

It is the goal of the Consumer Council to evaluate current Family Support Services programs to determine whether they meet the needs of families and individuals who are receiving the services, and to provide direct input regarding program viability, assessing whether or not each one should be renewed based on its merits and performance record. To achieve this goal, the Consumer Council members review Requests for Proposals (RFPs) submitted by agencies for new funding, as well as Requests for Renewals Proposals (RFRPs) submitted by agencies seeking to renew previously funded programs. The Consumer Council seeks to increase community outreach and to promote awareness of Family Support Services programs in their local areas.
Who are the members of the Consumer Councils?

The membership is open to any volunteers who have a family member with a developmental disability. The Family Support Services Coordinator in your local area can give you information on how you may participate in your local Family Support Consumer Council. It is the goal of the Consumer Council to advocate on behalf of all families who have a family member with a developmental disability and to continually improve the quality of services for individuals and families throughout New York State. Local Councils welcome new members and strive for representation of all cultures, ages, levels of need and geographic distribution.

How do Consumer Councils evaluate community needs and Family Support Services programs?

Evaluation and review is accomplished in many ways; however, it is common practice for Councils to send surveys to families and conduct site visits to Family Support Services funded programs. The Council must review each program annually before renewal, and must meet with agencies regarding program review as appropriate.

Five Governing Principles of OMRDD

OMRDD's Proposed Governing Principles for Quality Assurance/Quality Improvement

OMRDD and the many other organizations in New York that provide services and supports to people with developmental disabilities are guided by five principles. These principles are to ensure that people with developmental disabilities receive supports and services to successfully live in their chosen environment. OMRDD and each provider organization shall embrace the spirit of these principles as they meet their obligations to each person with a developmental disability whom they serve. These guiding principles should be the policy and practice of each provider organization providing services and/or supports to people with developmental disabilities.

History has shown that we do not naturally extend to people with developmental disabilities the values and aspirations we have for people without disabilities. It is significant that these principles must be highlighted for people with developmental disabilities because clearly the concepts apply to all people. Those providing services are committed to fostering caring communities and to providing the safeguards, as needed, for people with disabilities.

Addressing each person's needs, preferences and requests should enable the provider organization to better achieve these principles and the related standards.

1. A person with a developmental disability shall relate to his or her family, friends and communities when and how he or she chooses.

It is important that people with developmental disabilities have the opportunity to develop and maintain relationships with their families, friends and communities. When these relationships are disrupted, providers should assist people in reestablishing them or establishing new relationships. The opportunity for these relationships, and the relationships themselves, should be similar to those of people without developmental disabilities. The potential isolation of a person with developmental disabilities due to only having relationships limited to members of a provider organization must be avoided. The provider organization should also be committed to fostering caring communities, to providing the safeguards, as needed, for people with disabilities, and to
ensuring that each person's decisions concerning relations with family, friends and community, and preferences concerning living circumstances, are respected and supported.

2. A person with a developmental disability shall be as independent as possible and determine the direction of his or her life.

Independence means that a person can pursue activities which he or she decides are important. They can be undertaken with various degrees of reliance on others. Every provider is expected to encourage and assist each person served and supported to be as independent in as many areas of life as possible. The ability to make decisions and take actions which improve one's self-esteem or self-image shall be encouraged by the provider.

3. A person with a developmental disability shall have the opportunity to make life choices that do not compromise health and safety, and such choices shall be respected and valued.

Every person with a developmental disability shall have the opportunity to make choices regarding his or her life. To respect and value this not only means that a provider will be responsive to such choices, but will enable, encourage, and teach individuals to make responsible and informed choices. The choices made should not compromise the individuals' immediate health and safety, nor the health and safety of their neighbors or communities. Providers are expected to ensure that this opportunity is afforded each person served and exercised regularly. Choices should be informed and/or aided as needed. The result should be an improved quality of life and greater self-satisfaction.

4. A person with a developmental disability should have the opportunity to communicate his or her fears and have them addressed, and not to be subjected to fear of harm or reprisal in connection with the provision of supports and services.

People with developmental disabilities should not suffer harm from their service providers. Further, an individual who is dependent upon others should not have to fear offending them and suffering reprisals, minor or major. Service providers have a basic and continuous responsibility to minimize the likelihood of harm, especially harm from within its own organization -- employees, volunteers, or other people with developmental disabilities. No provider shall tolerate the existence or exploitation of fear within any program of services or supports as a means of influencing or controlling persons served.

5. A person with a developmental disability should receive supports and services which are effective and meet his or her needs.

People with developmental disabilities can expect quality services that address their individual needs. Providers are expected to be diligent in ensuring high quality supports and services which are effective and adapted to meet specific needs and preferences. Effective supports and services -- from social activities to habilitation -- should be enabling for people with developmental disabilities. Supports and services should promote and achieve a better quality of life for each person, and the effectiveness of supports and services should be evaluated in terms of measurable and observable outcomes and the satisfaction of the person being served. Providers should keep themselves apprised of contemporary social values and technical information regarding the provision of supports and services.
### Family Support Services Coordinators

<table>
<thead>
<tr>
<th>Coordinator</th>
<th>Telephone Number</th>
<th>Fax Number</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>BERNARD M. FINESON DDSO</strong>&lt;br&gt;(Queens County)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sheila Green-Gholson</td>
<td>(718) 217-6117</td>
<td>(718) 217-4009</td>
</tr>
<tr>
<td><strong>BROOKLYN DDSO</strong>&lt;br&gt;(Kings County)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Peter DeRose</td>
<td>(718) 642-8659</td>
<td>(718) 642-8683</td>
</tr>
<tr>
<td><strong>BROOME DDSO</strong>&lt;br&gt;(includes Broome, Chenango, Delaware, Otsego, Tioga and Tompkins Counties)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Jeff Envid</td>
<td>(607) 771-7784 ext. 152</td>
<td>(607) 865-8169</td>
</tr>
<tr>
<td><strong>CAPITAL DISTRICT DDSO</strong>&lt;br&gt;(includes Albany, Fulton, Montgomery, Rensselaer, Saratoga, Schenectady, Schoharie, Warren and Washington Counties)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mary Beth Romanzo</td>
<td>(518) 486-1313</td>
<td>(518) 457-3016</td>
</tr>
<tr>
<td><strong>CENTRAL NY DDSO</strong>&lt;br&gt;(includes Cayuga, Cortland, Herkimer, Lewis, Madison, Oneida, Onondaga and Oswego Counties)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tom Nelson</td>
<td>(315) 425-5342 extension 342</td>
<td>(315) 336-0695</td>
</tr>
<tr>
<td>Sarah Nelson</td>
<td>(315) 336-2300 extension 306</td>
<td>(315) 336-0695</td>
</tr>
<tr>
<td>Anne Timmons</td>
<td>(315) 473-6978</td>
<td>(315) 473-5053</td>
</tr>
<tr>
<td><strong>FINGER LAKES DDSO</strong>&lt;br&gt;(includes Chemung, Livingston, Monroe, Ontario, Schuyler, Seneca, Steuben, Wayne, Wyoming and Yates Counties)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Judy Herlihy</td>
<td>(800) 452-4256 extension 203</td>
<td>(585) 241-5767</td>
</tr>
<tr>
<td><strong>HUDSON VALLEY DDSO</strong>&lt;br&gt;(includes Orange, Rockland, Sullivan and Westchester Counties)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Donna Debreuil</td>
<td>(845) 947-6025</td>
<td>(845) 947-6414</td>
</tr>
<tr>
<td>Claudia Mace</td>
<td>(914) 332-8958</td>
<td>(914) 332-8020</td>
</tr>
<tr>
<td><strong>LONG ISLAND DDSO</strong>&lt;br&gt;(includes Nassau and Suffolk Counties)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lindsey Ciaravella</td>
<td>(631) 434-6027</td>
<td>(631) 434-6040</td>
</tr>
<tr>
<td><strong>METRO NEW YORK DDSO</strong>&lt;br&gt;(includes Bronx and New York Counties)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Josie Astacio (Bronx)</td>
<td>(718) 430-0469</td>
<td>(718) 430-0842</td>
</tr>
<tr>
<td>Janet Davis (Manhattan)</td>
<td>(212) 229-3112</td>
<td>(212) 229-3234</td>
</tr>
<tr>
<td><strong>STATEN ISLAND DDSO</strong>&lt;br&gt;(Richmond County)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Leroy Smith</td>
<td>(718) 982-1903</td>
<td>(718) 892-1909</td>
</tr>
<tr>
<td>DDSO</td>
<td>Contact Information</td>
<td>Contact Information</td>
</tr>
<tr>
<td>-------------------------------------------</td>
<td>----------------------</td>
<td>----------------------</td>
</tr>
<tr>
<td><strong>SUNMOUNT DDSO</strong> (includes Clinton, Essex, Franklin, Hamilton, Jefferson and St. Lawrence Counties)**</td>
<td>Mary Chartier (518) 359-2962 (518) 359-7657</td>
<td>William Schaffer (518) 359-4103 (518) 359-8640</td>
</tr>
<tr>
<td><strong>TACONIC DDSO</strong> (includes Columbia, Dutchess, Greene, Putnam and Ulster Counties)**</td>
<td>Debi Kral (845) 473-5050 extension 2090</td>
<td>(716) 532-5549</td>
</tr>
<tr>
<td><strong>WESTERN NY DDSO</strong> (includes Allegany, Cattaraugus, Chautauqua, Erie, Genesee, Niagara and Orleans Counties)**</td>
<td>Christine Tremper (716) 532-5522 extension 2090</td>
<td>(716) 674-7488</td>
</tr>
<tr>
<td><strong>NYC REGIONAL OFFICE</strong></td>
<td>Mary Ellen Tarangelo (212) 229-3245</td>
<td>(212) 229-3234</td>
</tr>
<tr>
<td><strong>STATEWIDE COORDINATOR</strong></td>
<td>Lori Lehmkuhl (518) 473-7038</td>
<td>(518) 474-9921</td>
</tr>
</tbody>
</table>