



Office for People With
Developmental Disabilities

Family Support Services



Advisory Council



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Overview of Family Support Services (FSS)

The New York State Office for People With Developmental Disabilities (OPWDD) provides a wide menu of supports and services for individuals with developmental disabilities and their families. The Family Support Services (FSS) Program is designed specifically to help families who are caring for a relative with a developmental disability at home by aiding the caregiver and thereby enhancing family stability and preserving family unity. Through its commitment to FSS, OPWDD strongly recognizes the important work performed by families in fostering natural supports that help individuals living at home fully participate in their communities.

FSS programs are developed across the state in collaboration with individuals, family members, advocates, nonprofit providers, and government leaders. They are funded by NYS OPWDD and provided to families by non-profit service provider agencies that have contracts with OPWDD to provide these services. Examples of FSS that families receive include:

- Advocacy
- After-School Programs
- Behavioral Support
- Case Management
- Crisis Management
- Family Reimbursement
- Family Counseling and Training
- Home Care/Homemaker
- Information and Referral
- Parent and Sibling Support Groups
- Recreation
- Respite
- Social Skills Training
- Specialized Equipment and Home Modifications
- Transportation

Note: While FSS are available statewide, the specific types of FSS programs that are available in any given region vary. When a family seeks a specific type of support or service, it may be provided via FSS or through another type of OPWDD service such as a Home and Community-Based Services (HCBS) Waiver service (funded in part by federal Medicaid).

To receive FSS, or certain HCBS Waiver Services, an individual must be eligible for OPWDD services and live at home full-time with a family member. For more information about OPWDD eligibility visit: https://opwdd.ny.gov/opwdd_services_supports/eligibility. Information about the types of FSS programs that are available in any specific region of the state can be obtained by contacting the appropriate OPWDD Developmental Disabilities Regional Office (DDRO). DDRO contact information can be found on OPWDD's website at: https://opwdd.ny.gov/opwdd_contacts/ddro.

Nineteen local FSS Advisory Councils, made up of individuals with developmental disabilities and family members, assist the DDROs to plan, coordinate and monitor the delivery of FSS across the state. In addition, a Statewide FSS Committee, made up of one representative from each of the 19



local FSS Advisory Councils, advises OPWDD regarding families' support needs and the design, implementation and monitoring of FSS programs. The Statewide FSS Committee is a committee of the Developmental Disabilities Advisory Council (DDAC), a standing advisory body, established by New York State law, that has the ongoing responsibility to advise OPWDD in the development of its comprehensive state plan and on the ongoing improvement, policies, goals, budgets and operations of the developmental disabilities services system.

This guide explains how FSS programs are planned and delivered, as well as the roles of the Statewide FSS Committee, the local FSS Advisory Councils, OPWDD Regional Office FSS Coordinators and the Statewide FSS Coordinator.

NYS OPWDD & FSS: A Partnership for Families

Background on OPWDD

OPWDD is the state agency responsible for coordinating supports and services for more than 128,000 New Yorkers with developmental disabilities, including intellectual disabilities, cerebral palsy, Down syndrome, autism spectrum disorders, and other neurological impairments. It offers services both directly and through a network of approximately 700 nonprofit agencies. About 80 percent of these programs are provided by nonprofits while the remaining 20 percent are state-run programs.

OPWDD was created in 1978 as the Office of Mental Retardation and Developmental Disabilities (OMRDD), an independent cabinet-level state agency to implement the Willowbrook¹ consent decree and the resulting closure and downsizing of institutional services. In the decades that followed, it has become one of the state's largest human services agencies. Individuals supported by this agency and their family members forged a strong working partnership that shaped the way the system grew to support increasing numbers of individuals to live with greater independence in their communities. In 2010, the agency and its stakeholder partners marked an historic milestone for the people they support when New York State changed the agency's official name to the Office for People With Developmental Disabilities, eliminating the term "mental retardation" from its new title.

The underlying principles of the FSS program are firmly rooted in OPWDD's mission and vision:

Mission — OPWDD's mission is to help people with developmental disabilities live richer lives.

Vision — OPWDD's vision is that people with developmental disabilities: enjoy meaningful relationships with friends, family, and others in their lives; experience personal health and growth; live in the home of their choice; and fully participate in their communities.

OPWDD also has identified *five values* that agency employees uphold as they work with individuals with developmental disabilities, their family members, staff and community members to fulfill the agency mission and make its vision a reality: compassion; dignity; diversity; excellence; and honesty.

¹ *The Willowbrook Consent Decree was approved by the US District Court on May 5, 1975, requiring New York State to provide a range of individualized services to the plaintiff class, those parties who had resided in the Willowbrook State School. In 1993, the Willowbrook Permanent Injunction replaced the Consent Decree, requiring protection from harm and high quality, appropriate, community-based services.*

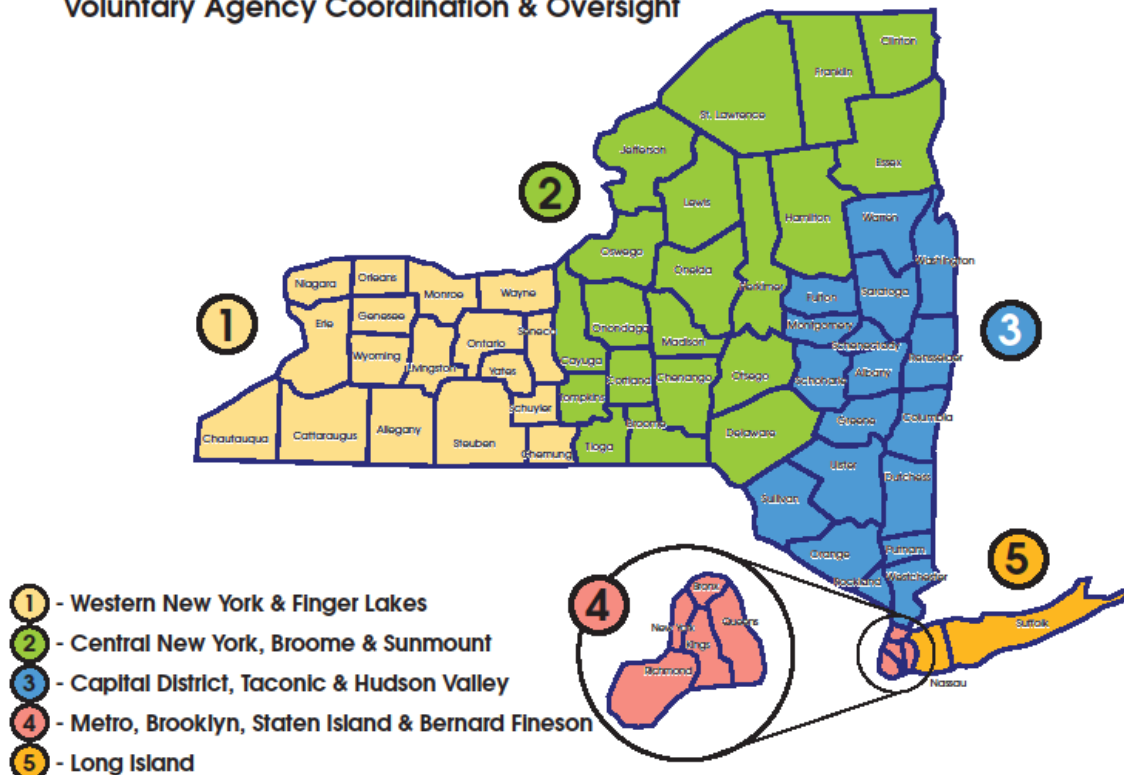
OPWDD's Organizational Structure

Families and individuals with developmental disabilities access OPWDD supports and services through five Developmental Disabilities Regional Offices (DDROs). For information on how the DDROs operate and how to access OPWDD supports and services, visit

https://opwdd.ny.gov/opwdd_contacts/ddro

5 Developmental Disabilities Regional Offices

Voluntary Agency Coordination & Oversight



History of Family Support Services

From its earliest years, OMRDD worked closely with individuals with developmental disabilities and their family members to develop and deliver the kinds of supports and services that would meet their needs. A demonstration project that began in 1984 provided supports to 200 families with loved ones living at home. It was supported by an advisory council of parents and guardians. In 1991, the Commissioner invited family members from across the state to offer their collective input on policy issues affecting individuals with developmental disabilities. This statewide committee shared their personal stories and offered insight and perspective on key supports and services necessary to keep their loved ones living at home. The concept was soon expanded across New York State, with local Advisory Councils created in each of OMRDD's Developmental Disabilities Services Offices (DDSOs). (These Advisory Councils were originally known as Consumer Councils.) The following year, legislation was enacted to formalize the role and responsibilities of the Statewide FSS Committee, and OMRDD charged these affiliated local advisory councils with establishing local priorities for new FSS. Today, working in partnership with the DDROs, local councils design and review FSS Requests for Proposals (RFPs), determining how funding will be dispersed. Throughout the year, local council members work with the DDROs' FSS Coordinators to assess FSS provider performance, service quality as well as family and individual satisfaction with FSS programs.



FSS Goals and Principles

As outlined in Section 41.43 of the NYS Mental Hygiene Law, the goals of the FSS program are:

- 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; and
- To maximize the potential of the family member with a developmental disability.

The program's guiding principles, which were based on the key recommendations made by families in shaping FSS policy, include:

- Individuals, regardless of the severity of their disabilities, need families and enduring relationships with adults in a nurturing home environment to have the best opportunity to develop to 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 a developmental disability should have the option, when in the best interest of the individual with a developmental disability and of the family receiving services and supports, to maintain the individual at home.
- Families caring for a family member with a developmental disability should be offered assistance to make informed choices and to access, purchase or otherwise obtain goods and services necessary to maintain that family member at home and strengthen families' caregiving capacity.
- The services which should be made generally available to families caring for a family member with a developmental disability at home should include information and referral to available community services, benefits and counseling, coordination of services, crisis and emergency services, and assistance in the securing of needed goods and services.
- FSS should be person-centered, family driven, designed to meet the needs of the particular family requesting assistance as well as the needs of the individual with a developmental disability, 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 FSS for individual families.
- FSS should be delivered in a manner which is culturally and linguistically appropriate to families.
- FSS 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.

A full text of Section 41.43 of the NYS Mental Hygiene Law, which authorizes FSS, can be found here:

https://opwdd.ny.gov/opwdd_services_supports/supports_for_independent_and_family_living/family_support_services/full-law



Delivery of FSS: Structure, Roles and Procedures

Statewide FSS Committee

Purpose: The Statewide FSS Committee is a standing committee of the Developmental Disabilities Advisory Council (DDAC), established by sections 13.05 and 41.43 of the New York State Mental Hygiene Law. Its purpose is to inform the commissioner of the OPWDD on the needs of families who are caring at home for a family member with a developmental disability. The Committee advises the commissioner and makes recommendations on the design, implementation and monitoring of FSS programs.

Membership: The Statewide FSS Committee may include persons with developmental disabilities, their family members and professionals working in the field of developmental disabilities.

There is one representative to the Statewide FSS Committee for each of the 19 local FSS Advisory Councils.

Representatives must have a family member living at home with them at the time of their initial appointment to the Statewide FSS Committee.

New Appointments: Committee members serve a three-year term. When a three-year term limit is met, the Statewide FSS Coordinator will advise the local FSS Coordinator.

When a FSS Committee member's term is complete or when he/she is unable to continue as a FSS Committee member, the member's local FSS Advisory Council must vote on a proposed replacement. The nomination is forwarded to the Statewide FSS Coordinator with a written biography on the candidate. The Statewide Coordinator will discuss the candidate with the DDRO Director and the DDRO FSS Coordinator and forward this recommendation to the OPWDD Commissioner for approval. The local Council may vote to allow the current member to be re-appointed for a subsequent three-year term.

Roles and Responsibilities: The primary function of the Statewide FSS Committee member is to act as the liaison between the OPWDD Commissioner and his/her local FSS Advisory Council. The Statewide FSS Committee members should communicate to the Commissioner the concerns of families who have a child or family member living at home with them. They should communicate concerns reflecting their local area's diverse needs related to culture, diagnoses, levels of needs, and ages of the family members with a developmental disability.

Committee members are expected to attend each Committee meeting either face-to-face in Albany or via telephone or video conference. Frequent absences may be addressed at the local level.



Substituting others to take the place of the appointed Statewide FSS Committee member is not permitted.

Committee members must notify the Statewide FSS Coordinator if they cannot attend a Committee meeting.

Committee members must share all information received at the Statewide FSS Committee meetings with their local FSS Advisory Council by attending their local FSS Advisory Council meetings.

Operations:

The Statewide FSS Committee meets four times a year, and the calendar is established in advance.

FSS Advisory Councils

Purpose:

The purpose of each FSS Advisory Council is to represent the needs of local individuals and families and to work in partnership with the DDRO to plan, develop and monitor FSS programs in that area.

Each FSS Advisory Council works with the DDRO to evaluate current FSS programs to determine whether they meet the needs of families and individuals. They also provide direct input regarding program viability and whether or not programs should be renewed based on merit and performance. The Council may also make recommendations about how to improve the quality and effectiveness of FSS programs.

The local FSS Advisory Councils also seek to increase community outreach and to promote awareness of FSS programs in their local areas.

Membership:

Membership on FSS Advisory Councils is open to anyone in that region who has a family member with a developmental disability living full time in their family home, as well as to individuals with developmental disabilities.

A family member may remain a member even if their family member with a developmental disability no longer lives in their home, or is deceased.

Family members who are also service providers (including executives, paid staff, board members and volunteers) are eligible to be members of a local FSS Advisory Council.

There is no maximum number of FSS Advisory Council members, but each Council shall have at least five members. The council shall be large enough to accommodate the interests of all families and individuals.

FSS Advisory Council membership should reflect the diverse characteristics and needs of local individuals and families.



Membership should include, but not be limited to, representation which reflects:

- The cultural diversity of the region;
- A wide range of developmental disabilities (including intellectual disability, autism, epilepsy, cerebral palsy, neurological impairment, traumatic brain injury, and other developmental disabilities);
- Varying levels of need (needs for complex health care, assistive technology, behavioral support, etc.);
- A range of ages (families with infants, preschool and school-age children and adults); and
- Geographic distribution within the region (urban, suburban, rural counties within the DDRO area).

New Members:

Anyone interested in serving on their local FSS Advisory Council should contact their local FSS Coordinator. For contact information, an email may be sent to FamilySupportServices@opwdd.ny.gov.

Roles and Responsibilities:

The primary responsibility of the FSS Advisory Council is to use the knowledge and experience of individuals with developmental disabilities and their families to:

- Identify priorities for needed family supports within the region, and as appropriate, on a county or multi-county basis;
- Work with Regional FSS coordinators to design FSS RFPs;
- Review proposals submitted in response to FSS RFPs and advise local FSS coordinators regarding the relevance of proposals to regional priorities and their ability to meet stated goals, according to the NYS Office of the Comptroller's scoring protocols;
- Establish appropriate mechanisms for obtaining input from individuals and family members regarding their family support needs;
- Advise the DDRO regarding operating policies to effectively meet the needs of families and individuals living at home;
- Select a representative from the local Advisory Council to serve on the Statewide FSS Committee;
- Evaluate the effectiveness of FSS programs, which may include, but not be limited to, conducting periodic site visits, reviewing reports and documentation submitted by providers, and participating in agency interviews;
- Provide input to new contract and contract renewal negotiations; and
- Inform families about OPOWDD policy/program changes that could affect them.



Operations:

FSS Advisory Councils are aligned regionally based on OPWDD's former DDSOs. There are 19 local councils across the state.

Each FSS Advisory Council shall:

- Establish its own policy for determining its voting membership, establishing consensus, selecting members for its governing structure, selecting a chair and any other leadership positions, and determining the length of office for the chair and any other leadership positions;
- Meet at least quarterly at an accessible location at times convenient to its members;
- Develop a mechanism for announcing in advance the date, time and location of each meeting, and identifying agenda items;
- Develop meeting agendas to reflect the needs of the families, individuals and the community;
- Develop a governing structure appropriate for the local FSS Advisory Council to carry out its responsibilities;
- Ensure each Council member signs and adheres to the provisions of the FSS Council Code of Conduct, including annual statement of conflict of interest disclosure and recusal as appropriate. (See Appendix A);
- Keep written minutes of its meetings and distribute them to Council members;
- Assure confidentiality of personal information discussed and distributed at Council meetings; and
- Have \$3,000 to use to reimburse members for costs incurred while participating in the Advisory Council business. This reimbursement can include, but not be limited to, covering costs for transportation and family member care.

The Role of OPWDD's Regional FSS Coordinators

The DDRO FSS Coordinator plays an important role in supporting the work of the local FSS Advisory Council and the FSS program. The Regional Coordinators' primary responsibilities are to:

- Ensure that each FSS Advisory Council has access to the DDRO Director as needed to carry out its responsibilities;
- Disseminate information to families and individuals including information regarding conferences, trainings, forums and meetings, etc.;
- Provide logistical support, information and technical assistance to the local FSS Advisory Council;
- Advise and train the FSS Advisory Council regarding issues of privacy, confidentiality, and limits to information sharing;
- Provide training to local FSS Advisory Council members in areas requested by the Council;



OPWDD: Family Support Services Advisory Councils

- Serve as liaison between the FSS Advisory Council, the DDRO Director and Central Office staff; and
- Coordinate the RFP process for securing local FSS contracts, Advisory Council site visits to program locations, and annual program reviews, inviting local Advisory Council members to participate.

Additional Resources

Statewide FSS Coordinator

Questions or comments about OPWDD's FSS Program may be sent to the Statewide FSS Coordinator at FamilySupportServices@opwdd.ny.gov.

OPWDD Website

Additional information about OPWDD's FSS Program can be found at the following link on OPWDD's Website:

https://opwdd.ny.gov/opwdd_services_supports/supports_for_independent_and_family_living/family_support_services



Appendix A – FSS Advisory Councils Code of Conduct

This Code of Conduct describes the ethical responsibilities of members of the Family Support Services Advisory Councils

This Code does not supersede or replace any other applicable laws, regulations, or requirements.

Section 1. Code of Ethics

1. Conflicts of Interest: Members shall avoid actual and potential conflicts of interest and shall not allow their personal interests, financial or otherwise, or those of a Relative, to interfere with, or appear to interfere with their independent advice as a Member.

2. Confidential Information: Members shall not disclose information obtained as a result of Council membership that is not otherwise public, and shall not use information to further their own interests or those of another Member or a Relative.

3. Unwarranted Privileges: Members shall not use or attempt to use their position on the Council to secure unwarranted privileges for themselves, any other person, or any entity.

Section 2. Disclosure and Recusals

1. Statement of Interest Form: Within 30 days of appointment to the Council, and every year thereafter, each Member shall submit to the Advisory Council Chair a written statement identifying any entity, enterprise or real property (excluding personal residences), in which he or she, a spouse or emancipated child, has an interest, whether as an owner, officer, director, employee, investor, or consultant.

2. Recusal: No Member shall participate in any Council discussion or vote, attempt to influence such discussion or vote, or review materials provided to the Council or distribute materials to the Council relating to any entity where such Member or Relative has an interest as a board member, owner, officer, consultant or employee in the entity or in a potential competitor, or where such Member or Relative has a financial interest in the matter. No Member shall attend such Council discussions or votes, unless such discussions or votes are taking place as part of a meeting or proceeding open to the public.

Section 3. Definitions

1. "Member" means any member of any of the Family Support Services Advisory Councils.

2. "Relative" includes any person living in the same household as the Member, or the spouse, parent, child, or sibling of a Member.

Section 4. Ethics Officer

The New York State Office for People With Developmental Disabilities' ("OPWDD") Ethics Officer shall serve as Ethics Officer for the Councils. Council Members are not subject to the New York State Joint Commission on Public Ethics' ("JCOPE") ethics rules and requirements, however, if a Member is unsure if he or she has an actual or potential conflict of interest, or has any other questions regarding the interpretation and application of this Code of Conduct, the Member should contact the Ethics Officer for guidance at ethicsofficer@opwdd.ny.gov. Members are encouraged to disclose known relationships and potential conflicts of interest to prevent even the appearance of impropriety.



Section 5. Acknowledgement

I have read the foregoing, and I agree to comply with and be bound by, the Family Support Services Advisory Council Code of Conduct.

Print Name

Signature

Date

Join the Conversation

Help OPWDD keep you in the know –
Join the Conversation today and be
empowered with accurate,
timely information.

Join the Conversation today at
opwdd.ny.gov/jointheconversation



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