

Department of Developmental Services
Annual Family Support Plan
FY '13 (July 2012 – June 2013)
Final

Human Service Agency Overview of Family Support

A. Background

The Department of Developmental Services (DDS) has been providing flexible family support services since 1995 to children and adults living at home with their families who are eligible for services from DDS. This is the tenth Annual Plan for Family Support submitted by the Department as required by Chapter 171 of the Acts of 2002, “An Act Providing Support to Individuals with Disabilities and Their Families.

The Department is organized into four regions and 23 Area Offices managed by Regional Directors and Area Directors, all under the umbrella of Central Office. Each DDS region has a Director of Family Support. Area Office Service Coordinators provide assistance and supports to individuals/families, with a Children’s Coordinator position who generally works with children under the age of 18 years and their families, and a Transition Coordinator who works with individuals generally between the ages of 18 and 22 who are in the process of transitioning from school to adult services. Individuals over the age of 22 who have met the adult eligibility criteria for DDS services are assigned a Service Coordinator and participate in an Individual Service Planning process.

B. Overview of Family Support

The primary goal of family support is to provide a variety of options to families of individuals with disabilities that enable them to stay together and to be welcomed, contributing members in their home communities. The Department’s Family Support system is based on the principle that individuals and families know their own needs. For this reason, and because of the individuality of each family, the range of services available under the program is broad. This approach allows families the flexibility to identify the resources that will be helpful to support their family member in her/his home, The Family Support Centers and other family support programs are designed to be responsive to the dynamic and changing needs of the individual with a disability and his/her respective stages in life within the family context.

The Department has established *Guiding Principles for Family Support* which serves as the foundation for the delivery of services through the Family Support Centers and all of the other family support program services funded by the Department.

Family support strives to achieve the goal of helping families stay together through:

- ❖ developing families’ natural capacity to meet the needs of family members;
- ❖ offering additional supports such as staff resources, goods and services, and financial assistance; and
- ❖ enhancing the capacity of communities to value and support people with disabilities and their families.

The Department has specific funding designated for the delivery of family support services through the Family Support Appropriation Account in the state budget. This funding has been vulnerable since 2009 as a result of the economic challenges facing the nation and state. In FY 2010, this account was funded at \$46.5 million, a reduction of almost 10 million dollars from the previous year. The budget appropriation for FY 2012 was approximately \$46.5 million dollars, and for the upcoming fiscal year, FY 13, the amount has increased by 3 million dollars bringing the total to \$49.5 million. Of this total appropriation, approximately \$38-39 million is for specific family support services and the remainder for other community support services. This increase is positive and will result in being able to provide individual flexible funding allocations to more families to address important unmet needs. The array of family support services provided with this funding is described in more detail in Section III, Family Support Resources and Funding.

C. Process for obtaining substantial input from families on current family support services:

The Department uses both formal and informal approaches to seek input from families and individuals with intellectual disabilities in order to help assess the Department's current system of family support services, and to get input on policy development and future directions.

This past year the Department conducted a comprehensive planning process to seek input and information from families and other stakeholders to help set the course for the future of Family Support Services. This was initiated due to the recognition that the Department is at an important juncture: there are more and more children and adults with intellectual and developmental disabilities living with their families resulting in a greater demand for family support services, while at the same time funding for this service has decreased in recent years.

In partnership with the Statewide Family Support Council, Citizen Advisory Boards, and other advocacy groups, DDS hosted **twenty-six forums** in the fall of 2011 across the state and input was obtained from more than **600 caregivers** about what they need to support their family member at home and in their community. Several separate forums were held with particular ethnic and cultural groups and each region also met with self-advocates who live with their families to gain their perspective. In addition, a written on-line survey was developed to gather input from families with the assistance of the Shriver Center/UMass Medical School and more than **700 caregivers** responded.

The major themes and important support needs identified by the more than 1300 families in the forums and through the survey are described in a report, ***"In Their Own Words: The Need for Family Support Services."*** This report, written in the voices of families, describes the need to make adequate family supports available to caregivers and the cost-benefit of these supports to the Commonwealth. This report, intended as a preface to develop a more comprehensive and strategic plan of action, includes a series of recommendations that encompass both the need for additional funding resources, as well as identifies other need areas that will create a more robust and responsive system of supportive services. The next phase in this dynamic planning process is the development of an agency wide strategic action plan for family support.

Copies of the full reports, *"In Their Own Words: The Need for Family Support Services"* and the *"Summary Report: DDS Family Supports Survey,"* are available on the DDS website at: www.mass.gov/dds.

Listed below are several of the ongoing and central ways the Department obtains feedback and input from families and other stakeholders.

The Department's **Statewide Family Support Council**, comprised of 15 parents from across the state who have children and adult family members with disabilities living at home with them, provides an important and ongoing vehicle to obtain input and consultation on family support services, practices, policies, and needs. The Council meets four times a year with the Commissioner with conference calls scheduled at other times to discuss emerging topics and issues. This past year the Council has been an integral part of the strategic planning process that has been initiated, and they will continue to have an active role in assisting the Department, along with other stakeholders, to identify specific recommendations and action steps that will result in a comprehensive action plan for family support.

There is regular information-sharing, discussion, and solicitation of input from the Department's **Statewide Advisory Council (SAC)** and the regional and area office **Citizen Advisory Boards (CABs)**. These advisory groups play an important role in helping to inform and educate the public and other decision-makers about the needs of individuals and families and the importance of and benefits of the flexible services and supports that are provided.

The Commissioner and other Central Office leadership staff meet regularly with other representatives of family and individual advocacy organizations to seek input and obtain feedback on services and future directions. This includes representation from the Arc of Massachusetts, Massachusetts Families Organizing for Change (MFOFC), Advocates for Autism in Massachusetts (AFAM), Massachusetts Advocates Standing Strong (MASS) the statewide self-advocacy organization, and the Developmental Disabilities Council. Monthly meetings are also held with the leadership of ADDP, the Association of Developmental Disability Providers.

D. Focus Areas: Review of Activities and Accomplishments in FY 2011 and Proposed Initiatives for FY 2012.

The following section provides brief highlights of ongoing efforts as well as new activities the Department has undertaken this past year, and includes where relevant, initiatives for development in the upcoming fiscal year.

I. Family Empowerment

What is the agency currently doing to promote or enhance family input or direction in the development of agency policies and procedures, program development, and evaluation of services?

As previously described, the Department seeks input from individuals and families about agency services and new directions both formally and informally through a variety of organized groups and mechanisms, including the Family Support Council, the Statewide Advisory Council, the regional and area Citizen Advisory Boards, Massachusetts Advocates Standing Strong, the Arc of Massachusetts, AFAM, and the Massachusetts Down Syndrome Congress.

As noted previously, family member input has been central to the comprehensive planning process the Department has initiated to develop a strategic plan for the future of family support services. The information obtained, and the themes and needs identified serve as the basis for the

development of a comprehensive **Strategic Plan for Family Support**. In the upcoming year, Family Support Council members and other interested parents and professionals, in partnership with DDS staff, will be engaged in a series of work groups to identify specific implementation steps and recommendations to respond to the major needs that have been identified. It is anticipated that this Plan will be completed by January 2013. These work groups will be focusing on the following identified need areas and recommendations:

- Expanding access to information, resources and supports for families and improving communication methods through the use of technology and multi-media approaches;
- Pursuing approaches to developing a sufficient cadre of qualified staff to support individuals and families, and mechanisms for identifying staff, like an on-line directory;
- Improving communication about the Chapter 688 process and transition planning for individuals leaving school and entering the adult system;
- Expanding social activities and connections in the community, including opportunities to form relationships that may lead to friendships;
- Developing an effective and comprehensive approach to community education and development, to explore partnerships and leverage other resources that benefit individuals and families;
- Improving interagency collaboration to facilitate access to the service system; and
- Distributing and creating resources for families regarding planning for their family member's future.

Family members are integral participants in a **Family Support Implementation Work Group** that provides input on the services, processes, and reporting mechanisms that support implementation of the Family Support Centers and other Family Support programs to help ensure services are family driven and responsive.

Family members and individuals with disabilities are members to the Department's **Statewide Quality Council** and regional Quality Councils to assist in reviewing evaluation data and information about the quality of services provided and to identify areas for development as part of a continuous quality improvement process.

How will agencies change how they are currently doing business to make their agency and services more family-friendly and provide opportunities for families and individuals to have greater input and influence?

All of the Department's family support services are based on the principles that individuals and their families are recognized as primary decision makers about their lives and supports, and options need to be flexible to be responsive to the unique needs, strengths and cultural values of families.

The Department's Home and Community Based Waiver Programs for adults provide enhanced opportunities for individual and family empowerment, through increased choice in service providers, choice of service delivery method, and portability of services. Information and education will continue to be provided to individuals and families so they are aware of the options available and support them to exercise their rights and choices.

The Waiver programs also expand opportunities for individuals and families to engage in self-direction of services through two different approaches, the *Agency With Choice* model or through use of the contracted *Fiscal Management Service*, Public Partnerships Limited (PPL). Increased self-determination and use of self-directed service options is a major goal for DDS and ongoing education and support will be provided to ensure individuals and families are aware of the opportunities available.

II. Family Leadership

What training opportunities does the agency currently offer to families/individuals that would enhance their repertoire of skills?

The Department provides funding for five regional Family Leadership programs designed to provide education, leadership training and mentoring for families with children and adults with disabilities living in the community. A key feature is that all of the training and mentoring is developed and provided by families who have a family member with a disability. One primary vehicle for family leadership development is the sponsorship of a **Family Leadership Series**, which occurs across 6-8 days over a several month period. This past year three regional Leadership Series were held providing leadership development to approximately 75 families. Graduates of the Series frequently move into new leadership roles in a variety of capacities.

Several self-determination forums were sponsored this past year in partnership with DDS, the Family Leadership projects, and providers, reaching more than 150 families and individuals. These forums exposed individuals with disabilities and their families to the concept of self-determination, shared examples of how individuals and families have utilized the process, and provided workbooks to help people in their journey. Two workshops focused on strategies to promote the development of friendships were offered with more than 100 families participating. These trainings were provided in response to the feedback and concerns raised at the family forums held in the fall related to the social isolation of their children, and the challenges individuals face in developing real and lasting friendships.

The Department's Family Support Centers and Autism Support Centers provide an array of educational events and trainings on relevant topics of interest to families of both children and adults, offering a minimum of six trainings per year. Leadership development is also promoted through the Centers by facilitating parent networking and mentoring, sponsoring parent support groups and one-to-one parent connections, and sibling support opportunities.

What new ideas or proposals would the agency initiate to give families/individuals more opportunities to develop and/or exercise their leadership skills?

Families have opportunities to further develop and/or exercise their leadership skills through the DDS funded Family Leadership Projects, as well as through the Family Support and Autism Support Centers which are expected to actively engage families and seek their consultation to identify interests and needs in developing activities and the array of service options they will offer.

Through the Home and Community-Based Waiver Programs there are two services, Peer Support and Family Training, which participants in the Waiver programs can purchase with their individual resource allocation. These service options can provide interested and qualified individuals and families the opportunity to provide training and mentoring to others as well as provide learning opportunities for self-advocates and families who want to enhance their own leadership skills.

III. Family Support Resources and Funding

What are the current resources/funding that the agency allocates to family support? What are ways that the agency provides flexible funding to families that allow them to customize their services?

DDS provides funding for **Family Support Centers** which are designed to establish a local community presence and act as a hub for offering a wide range of general family support services and activities to families of children and adults eligible for DDS services. Centers are expected to develop strong local affiliations and partnerships with other state and grassroots community agencies, to become experts in generic resources and services, and work to maximize natural supports. Services provided include: information and referral, support groups, family trainings, parent networking and mentoring, facilitation of social/recreational events, among other activities. Centers also provide Service Navigation that includes comprehensive and individualized information, guidance, and support to families to address their needs, connect them to potential resources, assist with problem-solving and help them navigate the service system. Centers also administer flexible funding/stipends to families who are prioritized to receive an individual allocation which can be used flexibly by families to purchase allowable services and goods as defined in the Department's updated Addendum to the Family Support Guidelines and Procedures. There are 33 Centers funded across the State with funding totaling approximately 6.8 million dollars.

Cultural/Linguistic-Specific Family Support Centers are designed to respond to the unique needs of specific cultural and linguistic family groups in specified areas or regions of the State. English is not the primary language for many of these families, and as a result face linguistic barriers in accessing services and require more individualized and specialized assistance to learn about and access the service system. These Centers offer a similar array of services as the Family Support Centers described above. There are ten funded Cultural/Linguistic-Specific Family Support Centers with funding totaling approximately 1.2 million dollars.

Autism Support Centers provide an array of information and referral services, resources, and supports to children and young adults with autism spectrum disorders. The array of services and supports includes information and referral, family clinics, support groups, access to the latest information on autism, family trainings, parent networking and mentoring, and social/recreational events, among other activities. There are five large and two small regional autism support centers funded at approximately 1 million dollars.

The Intensive Flexible Family Supports (IFFS) Programs are designed to help families who are experiencing severe stress which can lead to the child being at-risk of an out-of-home placement. Intensive case management services are provided to help families integrate the variety

of available resources to support their family member in crisis, and flexible funding to purchase additional supports or goods. Annually, about 550 children between the ages of 3-18 and their families receive services through these 22 programs statewide funded at approximately 2 million dollars.

The Medically Complex Programs support families who are caring for children/young adults up to the age of 25, with significant cognitive, physical, and complex health care needs who are living at home. It provides intensive medical wrap-around case management services that help families integrate the variety of resources and supports they are receiving and offers flexible funding/stipends to assist the family in the purchase of additional supports and goods not covered by health insurance. This program complements and is supplemental to other MassHealth, State plan and third party insurers. Annually, these programs provide services to about 275-325 individuals and their families. These five regionally based programs are funded at approximately \$600,000.

There are two **Planned Facility Based Respite Programs for Children** that offer planned, out-of-home respite services for children to provide short-term temporary relief for families, and includes overnight, weekend, and/or vacation stays. Individuals are provided with a variety of recreational, social, cultural and/or educational activities during their stay. One program is located in the Central/West region and the other in the Metro region. On average, 100 children and their families are able to utilize this service annually and the funding amount is approximately \$200,000.

Family Leadership Development Programs provide education, mentoring and support to families. A major focus is a comprehensive and intensive family leadership series which provides information and education about “best practices” and helps families gain knowledge about policy making at the local and state level to assist them in assuming leadership roles in their local community and the disability community. There are five regionally based Family Leadership Programs funded at approximately \$275,000.

The Autism Division at DDS received \$4.9 million dollars in FY ‘12 to provide services and supports to children with autism. The Medicaid Home and Community-Based Services Autism Waiver Program served close to 200 children under the age of 9 over the course of the past fiscal year. The Division engaged in an open enrollment process to allow families with newly diagnosed children the opportunity to apply for the Waiver Program. The Division received about 800 applications during this period and did broad outreach and made all information available in nine different languages.

The community-based programs offered by the Autism Support Centers reached at least 2000 families from across the Commonwealth during the past fiscal year. The Autism Division also helps fund a specialty community program designed to train first responders called the Autism and Law Enforcement Education Coalition (ALEC). The program remains a successful initiative and trained another 2000 EMC, Fire, Police and Hospital personnel in this past fiscal year.

The Department of Elementary and Secondary Education & Department of Developmental Services Community Residential Education Program (DESE/DDS) is a successful

collaborative initiative. This program is designed to provide supplemental supports to children/young adults determined to need services to prevent a more restrictive educational or out of home residential placement or to assist families whose children are coming out of a residential placement. The intent of the program is to increase family capacity to support their child in the home and community, as well as to provide an individualized plan of supports that promotes skill building, independence, and social integration across the spectrum of the child's home, school and community.

The stable funding level of \$6.5 million for FY '12 provided additional resources to allow approximately 100 participants to receive a full allocation of supports based on an assessment process, and another 130 participants to come off the waiting list, some after several years, and receive a pro-rated allocation that will annualize in FY '13. The remaining 30 individuals on the waiting list received one-time allocations of \$5,000. In total 455 children/young adults received supports this past fiscal year.

Other new initiatives implemented this past year include:

- Opening of a new **Medical Respite Home** in Southeastern, MA for adults with complex medical, physical and developmental needs who require 24 hour, specialized nursing care. To date about 17 individuals and their families have been able to use this resource for extended stays, providing important relief and respite for families and a new experience for these adults.
- The *Real Friends Project* has been funded to identify approaches, programs, and practices that can lead to strong and lasting friendships among people with and without disabilities.

In the upcoming year, the increased funding of \$3 million dollars in the family support account will be used primarily to offer individual flexible funding/stipends to families in need, and will also provide some support for expansion of social and recreational opportunities.

IV. Accessing Services and Supports

What are current examples of ways the agency is educating families on how to access services in a timely and effective manner? What are some illustrations of different services and resources which promote good access to information and referral?

In addition to the Department's Service Coordinators who provide information, resources and support to families of both children and adults, the Family Support Centers provide timely Information and Referral services to families of children and adults within their geographic area. This includes assisting families to identify resources and service options available in their local communities, to learn about other financial and/or state services for which families may be eligible, and to provide guidance on how to navigate the service system. They use a variety of approaches to disseminate information to families, including email, list-serves, on-line newsletters and training calendars, webinars, social media, etc. as well as create and maintain a "library" of resources.

A 'Statewide Family Support Directory' has been developed to help families find the Family Support Center and other family support programs in their area and promote easier access to this

information and referral resource. The Directory is widely disseminated through DDS, service providers, and is posted on the Department's website.

A statewide Family Support event held in May and attended by 200 family support and DDS staff was designed to share information on resources and best practices, and to promote networking. Outreach strategies, fostering community partnerships and providing culturally responsive services were topics, among others, addressed in panel presentations and roundtable discussion groups.

A training event was held in June with the Medically Complex Family Support Program staff and DDS Transition Coordinators and Area Office staff, focused on sharing information and strategies to improve access and address the challenges facing young adults with complex medical challenges and their families in the transition process.

DDS helps to broadly share information about the Massachusetts Autism Law (aka ARICA) through multiple strategies.

The Department has several publications and informational materials posted on the web-site to help families learn more about services and how to access them. Examples include a guide on transition from school to adult life, "The Road Forward," and "Living Well" semi-annual newsletters developed by the Office of Quality Management, and resources related to the Department's Home and Community Based Waiver programs.

What new initiative(s) will the agency undertake to promote good local access to information and resources?

- DDS will begin sending a 'welcome flier' with information about the services offered by the Family Support Centers when eligibility letters are sent to families after their child/adult completes the eligibility determination process.
- In the upcoming year, every Area Office will sponsor informational and training events for families on transition to adult services to help families better understand the process and learn about adult service options and service providers.
- DDS, in partnership with a number of other state agencies, is developing a pilot project in Lawrence to improve access, coordination and integration of services for families.
- The Department will continue to expand use of our website as a vehicle for sharing resource information with individuals and their families, and work to make it more user-friendly and easier to navigate.

V. Culturally Competent Outreach & Support

What are the current activities or services that the agency offers that ensure culturally appropriate access and supports to ethnically, culturally, and linguistically diverse families and individuals?

The Cultural/Linguistic-Specific Family Support Centers provide bi-lingual and bi-cultural assistance to identified groups of families for whom English is not their primary language. They also conduct broad outreach and are frequently called upon by other organizations to help provide interpretation and translation assistance to families. These Centers primarily provide services to families who speak Spanish, Chinese, Vietnamese, Khmer, Russian, Haitian Creole, Portuguese, and Cape Verdean Creole. In addition, all Family Support Centers and providers are expected to develop resources and capacity to do outreach and be responsive to the diverse cultural and linguistic communities in the geographic area in which they are providing services.

The Department makes available translated informational materials and letters for individuals and families in multiple languages based on the needs of families in local communities. Positive working relationships have been established with several entities that provide these interpretation and translation services and they have developed a good understanding of disability terminology and concepts that leads to providing more culturally relevant and responsive information.

Several workshops were sponsored for family support providers and DDS staff to hear both from families from diverse communities about their experiences and perspectives in raising a child with a disability, and from providers about the approaches they have developed and used to offer culturally respectful and responsive services. Department staff will work collaboratively with providers to share positive practices and support them as they further develop their capacity to provide culturally responsive services to increasingly diverse communities.

There is an active statewide Diversity Council, as well as one in each region and at central office that offer a variety of opportunities for education, training, and cultural experiences that promote increased understanding of different cultural and linguistic groups, and supports the delivery of culturally responsive services.

What new ideas/initiatives will the agency propose to outreach and meet the needs of culturally diverse families and individuals?

- Additional workshops and forums focused on the development of culturally responsive services will be provided for family support providers and DDS staff.
- Opportunities to bring together staff from the Cultural/Linguistic-Specific Family Support Centers across the state will be provided to foster information-sharing, networking and strengthening of efforts to provide more culturally competent services to families.

VI. Interagency Collaboration

Department staff participate in numerous inter-agency activities with other EOHHS agencies to promote more effective service delivery and maximization of resources. Regional and area office DDS staff participate in local inter-agency planning teams to promote more effective communication, and when there are individuals involved with multiple agencies, to work toward coordination and collaboration in service delivery. Representation on these teams typically includes staff from the Departments of Children and Families, Mental Health, Transitional Assistance and Public Health, and in some situations, representatives from local school systems.

DDS, in partnership with the Office of Elder Affairs and other human service agencies, are completing the second year of a three year *Lifespan Respite Grant* from the Administration on Aging. A unique aspect of this project is the cross-disability/special needs focus across the lifespan. A statewide lifespan respite coalition has been established, a database on varied respite options is under development, and training approaches and innovative models to expand the network of respite providers available to caregivers are being identified and implemented. A successful statewide caregiver event was held in November 2011 at the State House. A supplemental grant proposal was submitted for funding to support the delivery of respite services to unserved and underserved populations.

DDS leadership staff have been active members of the **Autism Commission** authorized by the Legislature to develop a plan and recommendations to address the growing needs of children and adults with an Autism Spectrum Disorder. Numerous family members, including staff from the DDS funded Autism Support Centers who are also parents of children with ASD, have actively participated on the Commission and sub-committees where their input has helped to shape the plans and recommendations being proposed.

The Department continues to work collaboratively with the Office of Medicaid, and the Departments of Mental Health and Children and Families, on the implementation of the **Children's Behavioral Health Initiative** (CBHI). DDS makes information available to the Department's children's service coordinators and family support providers so they are knowledgeable about the eligibility criteria and service options available in order to facilitate access to these services for children and families who may be eligible.

Department staff participate in **Unified Planning Team** meetings when requested for individuals who are eligible for DDS services and also continue to participate on the *One Child, One Plan* EOHHS initiative.

DDS leadership have participated on the Advisory Committee and selected work groups with EOHHS and other stakeholders in the planning and development of recommendations for **strengthening children, youth and family services** in Massachusetts, with a particular focus on the role and development of family access centers and networks.

DDS leadership staff have been working collaboratively with the **Readiness Cabinet** to promote improved school participation and educational outcomes for students in designated communities and school systems across the state.

What new activities or initiatives does the agency propose to demonstrate the above goals?

Department staff will continue to work closely with the Office of Elder Services and other human service and community organizations, family members and individuals to successfully implement the federal Lifespan Respite grant.

The Department will continue to work in partnership with the Office of Medicaid in the implementation of the Home and Community Based Waiver Programs for adults, and the Autism Waiver Program for Children. Additionally, Department staff will collaborate with MassHealth staff to identify the specific needs of individuals with intellectual and developmental disabilities, especially those with significant medical and health challenges, to promote access to necessary services to successfully live in the community with their families.