

**Department of Mental Retardation  
Annual Plan for Family Support  
State Fiscal Year 2009 (July 2008-June 2009)**

**A. Background**

The Department of Mental Retardation (DMR) has been providing flexible family support services since 1995. These services are provided to children and adults living at home with their families who are eligible for services from DMR. In July 2002, Chapter 171 of the Acts of 2002, "An Act Providing Support to Individuals with Disabilities and Their Families," was signed into law. This legislation specifies that all named state agencies, with substantial consultation from individuals with disabilities and their families, need to prepare and submit on an annual basis an individual and family support plan that explains how the department intends to provide flexible supports to families and individuals. This is the Department of Mental Retardation's sixth Annual Family Support Plan.

DMR is organized into four regions with Regional Directors, and 23 Area Offices with Area Directors, all under the umbrella of Central Office. Each DMR region has a Director of Family Support, who works with the Assistant Commissioner for Policy, Planning and Children's Services, the Central Office Director of Family Supports, and the Project Managers for the DOE/DMR Project and the Autism Division. In each Area Office there is a Children's Coordinator 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. Individuals over the age of 22 who have met the adult eligibility criteria for DMR services are assigned a Service Coordinator and participate in an Individual Service Planning process.

**B. Overview of Family Support**

DMR provides a variety of Family Supports designed to enable children and adults to live with their immediate family and be welcomed, contributing members of their communities. The program offers a flexible array of supports and is based on the construct that families are experts regarding the strengths, competencies, capacities and needs of their family members and are in the best position to know what will help them support their family member with a disability. The overall goal of the program is to support families to keep their family member at home and to avoid residential out-of-home placement. Both children and adults are supported by these activities which are intended to supplement generic and natural supports.

DMR has defined the primary goals of family support as:

- Developing the family's 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.

DMR has a network of 72 Family Support Provider Agencies statewide with whom contracts have been established to deliver these services. The foundation and delivery of family support services is based on the Department's *Family Support Guidelines and Procedures*, last issued in July of 2002. This document describes the goals and principles of family support, the types of family support services available, and all of the operational requirements. In particular, these *Guidelines* define how families are able to use their flexible funding allocations, including the categories of allowable expenses, prohibited expenditures, and purchases that require prior approval. This document was first published in 1995, revised in July 2002, and is currently being revised once again. Input from a variety of sources, including DMR staff, the Statewide Family Support Council, MFOFC Board members, a representative group of Family Support Provider Agencies, has been solicited to help inform and offer feedback on proposed changes. All Family Support Provider Agencies are required to complete and are evaluated on **Performance Outcome Measures** designed around the key family support principles and core service elements.

### **C. Array of Family Support Services and Individuals and Families Receiving Services**

This summary describes the major types of family support programs and services offered by DMR which constitute the majority of the Appropriation Account in the budget, which totals about 53 million dollars. This account also includes an array of other types of services that are supportive to individuals and families living in the community such as Best Buddies, Special Olympics, Clinical Teams, Assistive Technology and Translation Services. In the upcoming fiscal year, there is a proposed increase in the family support appropriation account in the budget of almost 1 million dollars which will enable the Department to provide family support services to new individuals and their families and allow for expansion of some existing programs.

In our current family support system approximately **4,400 adults** and **8,850 children** are receiving services in the DMR funded family support programs for a total of about **13,250 individuals** across the state. It is important to note that many individuals receive more than one service within Family Support. For example, a family might receive General Family Support and also use Planned Facility Respite to meet their needs.

A review of Family Support Flexible Funding utilization based on a survey of Family Support Provider Agencies was completed in December 2007. Based on the information reported, the most frequent uses for flexible funding by families are for: 1) respite in the family home; 2) community integration and social activities; 3) adaptive equipment; and 4) individual skill building activities. Through this survey information was also collected on the cultural/ethnic diversity of the individuals and families receiving services. The results indicate that about 25% of the current families receiving services are non-Caucasian, with Latino/Hispanic families representing the largest group at 10.5%. This represents a dramatic shift over the course of the last 10 years due in large measure to the changing demographics in the state, the outreach by family support agencies and the influx of large number of families with children into our service system.

A brief summary of the types of programs and numbers of individuals and families who have accessed and benefited from these services is summarized below.

**General Family Support Services:**

This is the largest family support service offered to most families of children and adults. These services include two major components, the delivery of **Core Services** and administration of **Flexible Funding Allocations** for individual families. This past fiscal year approximately 4,400 adults and 5,400 children received these General Family Support Services.

**The elements of Core Services** include:

- responding to the specific ethnic, cultural and linguistic needs of the families in the geographic area they serve;
- offering specific timely and relevant information to families;
- offering support services and groups and training;
- providing family support coordination services including identification and coordination of other community resources (a type of case management);
- engaging families in a support planning process; and,
- developing partnerships and collaborations in the community

**Flexible Funding allocations**, which are a small individual budget provided to families, enables families to choose and purchase the services which will be of most benefit to their family from a menu of allowable service options. The most common uses of flexible funding are for: respite, usually in the family home, which provides short-term relief for caregivers; support for participation in integrated social and recreational activities in the community; and for purchase of adaptive equipment and materials not covered by other insurance programs. There are two options available to families to manage their flexible funding. The first is the stipend option, which provides families a specific allocation to directly purchase allowable goods and services. The second option, direct provider agency payments, allows the family to direct their allocation to the Family Support Provider agency to pay for goods and services on their behalf. This can include providing or arranging for agency-paid staff and support workers to provide for planned in-home and out-of home services, and assisting families to identify, and/or hire and train their own respite workers. Both options enable families to tailor their supports and purchases to best suit their needs within a set of guidelines established by the Department.

In addition, providers of General Family Support Services are responsible for offering Information and Referral about community resources and supports to all families who contact their programs for assistance. They also develop relationships with generic community providers to broaden the cadre of providers and resources available to assist families. There are approximately 3,100 families of children who are only receiving this Information and Referral assistance at this time

DMR again made available one- time funding to Family Support Provider Agencies to provide vacation programs during the school vacation weeks in February, April and for the last two weeks in June following the end of the school year. This decision was based

on the success and positive feedback received from families and provider agencies when this was first initiated in 2007. More than 1400 children and families were able to participate and benefit from these vacation programs. Not only did the children and teenagers who participated in these programs directly benefit from these opportunities for socialization and fun, but these programs were of great benefit to families by offering a safe, secure location for their child to spend some time away from home and thus, constituted a form of respite for the family caregiver.

**Enhanced Family Support Programs** are designed to provide more comprehensive and intensive services to meet the unique, complex and multiple challenges of individuals and their families. There are two components to this service.

Intensive Flexible Family Supports (IFFS): The primary goal of IFFS is to help families who are experiencing severe stress which could lead to the child being at-risk of an out-of-home placement. The service consists of an intensive case management service designed 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. The service is available to DMR eligible children between the ages of 3-18 who are living in their family home or with other primary caregivers such as grandparents. There are 22 programs statewide and last fiscal year about 475 children and their families received this service.

Medically Fragile Family Partnership Program: This program is a family-driven model of care which supports families who are caring for children with significant cognitive, physical, and complex health care needs who are living at home. The program offers support to families who are often isolated due to the demands of caring for their child and fosters connections with other families with similar challenges. It is a comprehensive wrap-around support which consists of an intensive medical wrap-around case management activity that helps families integrate the variety of resources and supports they are receiving and offers flexible funding to assist the family in the purchase of additional supports and goods not covered by health insurance. The service is available to families of children between the ages of 3-18. This program complements and is supplemental to other MassHealth, state plan and third party insurers. This program provides vital assistance to families who need help in coordinating all of the in-home care they receive, which helps to prevent pediatric nursing home placements. There are five programs geographically dispersed across the DMR regions. Last fiscal year about 225 children and families received these services.

**Specialty Family Support Projects:**

Autism Support Centers: The Autism Support Centers provide information and referral services to support families with a family member on the autism spectrum. The services are available to all DMR eligible families, although most of the users are families with children on the spectrum. They can also assist families while they are going through the eligibility determination process. The Centers also offer workshops, trainings, newsletters and sibling support groups to families. There is at least one Autism Support

Center in each DMR region, with two in the Central/West region, and three in the Metro region, for a total of seven statewide. In FY '08 approximately 7,000 families had some contact with and received information from these Autism Support Centers. It is important to note that these Centers also receive funding from the Autism Division to provide additional services.

Planned Facility Based Respite: Facility-based respite offers planned out-of-home respite service for either children or adults who have been determined eligible for DMR services. Referrals for the services are initiated at the individual's respective Area Office. The programs offer short-term temporary relief for families and include overnight, weekend, and/or vacation stays and provide individuals in the respite program with a variety of recreational, social, cultural and/or educational activities. There are two planned facility based respite centers for children in two locations across the state and eighteen centers for adults. On average about 450 adults and 200 children use these Planned Facility-Based Respite Services annually.

Camps: Camp programs offer integrated summer day camping experiences primarily to children. Most of the camps also serve non-disabled youth and adults in the community. Participants may attend the camp during school vacations or for a week or two or all summer based on available funding and capacity. Last fiscal year about 1900 children participated in a summer camp program.

Social/Recreational Programs: Social/Recreational programs promote an individual's social and emotional functioning while providing respite to families who care for their family member at home. These programs are for both children and adults. Social/recreational programs facilitate the development of interpersonal relationships, enhance daily living and interpersonal skills and provide greater community inclusion opportunities. On average about 300 adults and 225 children participate in these programs annually.

After School Programs: These programs focus on integrating children with disabilities into community programs and activities for non-disabled children. After school programs are limited to serving DMR eligible children between the ages of 3-22. Approximately 200 children participate in these programs annually.

Family Leadership Development: Family Leadership Development provides education, mentoring and support to families to enable them to care for their family member. A major focus is a comprehensive and intensive family leadership series which provides information and education about "best practices" for services for people with disabilities. A second goal is to help families gain knowledge about policy making at the local and state level to help them assume leadership roles in their local community and the disability community. Families who have either a child or adult DMR eligible family member of any age, may apply to attend. In FY '08 about 115 families participated in this comprehensive leadership series and more than 500 families participated in other types of family leadership activities.

**The Autism Division** at DMR was established in 2005. In fiscal year '08 the Division was funded at almost \$3.3 million dollars. Two million dollars of this amount was designated for implementation of an approved Medicaid Home and Community-Based Services Waiver program to provide intensive supports for up to 80 young children with autism who meet the established eligibility requirements. Sixty-six children were enrolled this past year and are receiving a comprehensive package of services to address their identified needs. Outreach and enrollment into the Autism Waiver Program continues. The remainder of this funding supports staff positions in the Autism Division and at the seven DMR funded Autism Support Centers. Other funds are designated for teacher training and other social/recreational autism programs. These social/recreational programs have reached over 1200 families. Community programming to train first responders, a very successful initiative, has reached 1500 individuals to date and will continue in the upcoming year. For the upcoming fiscal year an increase in the budget has been approved which includes additional funding for the Autism Waiver Program and will allow for service provision to at least 40 more children. This budgetary increase in the Autism Division will also provide additional programming and services for individuals and their families. There has been a steady increase in the budget since the inception of the Autism Division which reflects positively on the acknowledged need for services of this growing population of children with an Autism Spectrum diagnosis.

**The Department of Elementary and Secondary Education & Department of Mental Retardation Community Residential Education Project (previously known as the DOE/DMR Project and now the ESE/DMR Project)** continues to be a successful collaborative initiative. This Project provides an increased level of support services to families to assist them in supporting their child's return from a residential school placement, or to provide additional supports to children who have been deemed as "at risk" for escalated service needs and a more restrictive educational placement. The intent of the Project 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. This Project is currently funded at \$8 million dollars. During fiscal year 2008, 342 children participated in this project, including 11 new participants. In total, 17 of the participants in the Project were assisted to return from residential school placements to their home communities, and 325 students have utilized project resources to obtain a variety of supports as an alternative to an initial residential special education school placement. There continues to be a high demand for participation in the project. Feedback from participating families continues to be very positive and clearly illustrates the benefits of these resources and services to enable them to more effectively support their children at home and to be meaningfully included in their communities and schools. On a positive note, for FY '09 an additional 2 million dollars has been approved in the state budget which will enable the Project to provide new services to approximately 100-120 children and their families who are currently on the waiting list for the Project.

#### **D. Process for obtaining substantial input from families on current family support services:**

The Department has used and continues to develop different approaches to seek input from family members, in order to help assess the Department's current system of family support and to assist in revising and crafting this Annual Plan for Family Support. This past year input and feedback was obtained through a variety of approaches:

- Quarterly meetings of the Statewide Family Support Council (SFSC) with the Commissioner, the Assistant Commissioner for Policy, Planning and Children's Services, and the Statewide Director for Family Support. The SFSC has up to 15 members who are all parents or family members and represent different geographic regions of the state, different types of disabilities, and the cultural diversity of families. The Council has been actively involved in reviewing family support information and data collected by the Department, and have provided input and feedback on different ideas for re-designing and improving our array of family support services and how they are allocated.
- Five regional Town Meetings held by the Commissioner with self-advocates in the fall of 2007 with more than 300 individuals participating.
- Five regional Town Meetings held by the Commissioner with family members in the fall of 2007 with approximately 400 to 450 families who participated.
- The Commissioner met with the area and regional Citizen Advisory Boards in the four DMR regions in the fall of 2007.
- Meetings between the Commissioner and other Central Office leadership staff with family advocacy groups: MFOFC, Arc Massachusetts, and Autism advocates, and with the statewide self-advocacy group, MASS.
- Information-sharing, discussion and input from the DMR Statewide Advisory Council (SAC) and the regional and area Citizen Advisory Boards (CABs). Additionally, family members and self-advocates participate on DMR's Statewide Quality Council.
- Responses to a written *Family Support Survey* organized around the six major areas of focus in our Annual Plan for Family Support. This survey is posted on the DMR website and was also distributed through Family Support Provider Agencies.
- Family member review and input was solicited in the development of informational materials, family guides and manuals for the Autism Waiver Program, and in the design and piloting of quality assurance processes.
- A Task Force on Young Adults in Need of Intensive Community Based Medical Supports was convened in the fall of 2007 at the request of the Commissioner. This Task Force has strong family member involvement with one of the co-chairs who is a parent and nurse educator, and six parents who are active members.
- Continued work of a cross-stakeholder Statewide Employment Planning Team that meets bi-monthly and includes individuals with disabilities and family members. This is complemented by Regional Employment Solutions Teams that include parents and individuals with disabilities as well.
- Presentation by parent, SFSC member, and MFOFC Board member, Chris Peltier, to all the DMR management staff at a Commissioner's meeting in December 2007 on the topic of family support- "Imagining Better: Developing an Envable Life."

- Planning for the upcoming statewide Second Family Support Institute scheduled for October 2008.

Efforts and approaches will continue to evolve, through both organized and informal mechanisms, to gather ongoing feedback about DMR's family support services and the implementation and effectiveness of this Plan.

## **E. Focus Areas: Review of Activities & Accomplishments for FY '08 and Proposed Goals/Initiatives for FY '09**

**I. Family Empowerment:** Opportunities for families and individuals to be involved in the development of agency policies and procedures, program development, and evaluation of services.

### **Activities/Accomplishments:**

- Information-sharing and discussion with the Statewide Family Support Council on the re-design of DMR's system of family support services to develop approaches that create a more standardized, consistent and equitable system to make decisions about family support resource allocations. Input was also requested on priorities for use of any new family support funding that might be appropriated in the state budget. These policy and programmatic discussion will continue into next fiscal year.
- Piloting of new quality assurance processes and tools for participants in the Autism Waiver Program and for individuals and families who use participant-directed services. Review and ongoing development of these processes will continue.
- Preliminary work has been initiated in reviewing our performance outcome measure for family support contracts and exploring more effective ways to obtain information from families and individuals about their satisfaction with services. These activities will continue.

### **Proposed New Activities/Initiatives:**

- Continued involvement of the Statewide Family Support Council and other stakeholders in the re-design of family support services and development of a framework for how these services will be procured when they go out to bid in FY '10.
- Individual and family input will be sought on the new Home and Community Based Support Waivers that DMR is developing. Stakeholder forums will be held in the early fall of 2008.

## **II. Family Leadership**

### **Activities/Accomplishments:**

- Approximately 110 families participated in an intensive 3 week-end program of leadership development offered by Massachusetts Families Organizing for Change with funding provided by DMR for leadership training. These leadership development opportunities are very successful. One of the powerful aspects is the networking and connections that families make with other families, as families are each others best resource. Feedback from families reflect the informative, educational, uplifting, and inspirational aspects of the program, and the skills and

confidence they leave with to make changes both for their family and in the larger community.

- Many families and individuals participated in a variety of other leadership and training opportunities on a variety of topics and interest areas, related to transition, housing alternatives, first responder training, employment, etc.

**Proposed New Goals/Initiatives:**

- Continue to provide funding for Leadership Development series for families.
- DMR in collaboration with the Statewide Family Support Council is planning the *Second Family Support Institute: "The Changing Landscape of Family Support: Expanding Possibilities and Partnerships"* in October 2008 and will reach about 250 to 300 DMR and Family Support Provider Agency staff
- Explore options to offer advanced leadership training opportunities for interested family members with MFOFC, the Department of Public Health through their Family/Professional Partnership Institute, and other interested agencies and groups and expand other training opportunities
- Provide opportunities for individuals and families to be active participants in different planning initiatives undertaken by the Department, such as transition planning, re-design of employment and day services, etc.

**III. Family Support Resources and Funding**

**Activities/Accomplishments:**

- Approval and implementation of a new Home and Community Based Waiver Program for children with Autism under the age of 9. This program was funded at 2 million dollars to serve 80 children. To date 66 children have been enrolled and are receiving a comprehensive package of services. This Program was approved for 3 years and services will continue and more children enrolled until capacity is reached.
- Funding for social skills, recreational programs and vacation programs was provided to the seven DMR funded Autism Support Centers reaching approximately 1200 children and families.
- One- time funding (approximately \$350,000) was made available to Family Support Provider Agencies to offer vacation programs for children during the February and April school vacation weeks and during the last weeks in June after the end of the school year. These programs served approximately 1400 children and their families statewide.
- Pilot of a newly developed Family Support Allocation Tool for adults was completed in the fall of 2007 in all Area Offices.
- A survey was completed in December 2007 by all Family Support Providers who receive funding for General Family Support Programs, Medically Complex Projects, and Intensive Flexible Family Support Programs. Information and data was gathered on funding totals, numbers of children and adults receiving core and flexible funding, flexible funding ranges, uses of flexible funding, and the cultural diversity of families receiving services. This data was compiled and summarized and shared with DMR leadership staff and Family Support Council members to help inform policy discussions and development of proposals and ideas for the restructuring of family support services.
- A survey is underway with Family Support Provider Agencies who provide Core Services as part of their contract to obtain current information on caseloads for family

- support coordination and the array of other core services provided. This will be completed in August of 2008 and the information compiled, summarized and shared with DMR leadership staff and the Statewide Family Support Council to help inform planning efforts. This activity will continue.
- A resource manual on participant directed services and a guide about hiring your own staff has been developed for families participating in the Autism Waiver Program.

**Proposed New Goals/Initiatives:**

- Compilation of data gathered on Core Services provided by Family Support Provider Agencies. This information and the data collected on flexible funding will be used to guide planning for use of any new family support resources and the development of a blueprint for the re-design and re-procurement of these services.
- The resource manual on participant directed services and guide on hiring your own staff that has been developed for families participating in the Autism Waiver Program will be revised for use by individuals and families receiving services through DMRs Adult Home and Community Based Waiver Programs.

**IV. Accessing Services and Supports**

**Activities/Accomplishments:**

- DMR developed a ‘Guide on Transition to Adult Life’ that was customized for each Area Office. This guide was developed as an outgrowth of the Transition Forums held in the spring of 2007 and includes an introductory letter to families from the chairperson of MFOFC. In addition, each Area office hosted transition informational sessions for families and are broadly disseminating these Guides to families.
- A ‘Family Guide’ for families participating in the Autism Waiver Program has been completed.
- Family Support Resource Guides for each region have been completed and all will be available in the summer of 2008.
- DMR developed new brochures about DMR services and the Home and Community Based Waiver Programs for families and individuals. These brochures have been translated into Spanish and will be translated into other languages.
- Expanded use of the website to post and share information with families and individuals about services.

**Proposed New Goals/Initiatives:**

- Every Area Office will host *Transition Fairs* for families and young adults to provide information about the transition planning process and to find out about different service options and providers.
- In the spring of 2009 the Central/West region of DMR will be hosting a Family Support Festival- A Road Map for Success in Worcester based on the positive feedback to a similar event held in Springfield in 2007. Also a Recreation, Leisure and Wellness event is being planned and will be held at Springfield College.
- The DMR web-site will continue to evolve to include more information and resources that are helpful to individuals and families.

## **V. Culturally Competent Outreach and Support**

### **Activities/Accomplishments:**

- Annual Diversity Conference was held in October 2007 with approximately 250 participants. Numerous regional diversity council training activities and events have occurred and these activities will continue.
- DMR conducted effective multi-cultural outreach to solicit applications for participation in the Autism Waiver Program. All materials for families have been translated into Spanish, Portuguese, Khmer, Vietnamese, Mandarin Chinese, Haitian Creole and Russian. There were a total of 1,146 applications received during the initial outreach for participation in the Autism Waiver Program, and of the applications submitted, 214 families or 19%, indicated that English is not their primary language. Spanish speakers represented 60% of the applicants, and the other languages in descending order of frequency included: Cantonese, Creole, Vietnamese, Portuguese, Khmer, Russian, Turkish, Japanese, Arabic, and Amharic.
- DMR is successfully completing the fourth year of a five year grant in Springfield, MA focused on creating “one stop family services” for unserved and underserved families of diverse cultural, ethnic and linguistic backgrounds to help them navigate the service system. The space at the SC@N 360 Family Center has been expanded to develop a *Family Resource and Learning Center* which will provide opportunities to expand training and support services to families and to work collaboratively with other community organizations in the city.

### **Proposed New Goals/Initiatives:**

- Continue to expand and refine our system for translation of DMR information and materials.
- An annual Diversity Conference for DMR and provider staff will be sponsored in the fall of 2008 and DMR will continue to offer an array of training opportunities to improve understanding of the needs of families from culturally diverse backgrounds and enhance the delivery of culturally relevant family support services.

## **VI. Interagency Collaboration**

### **Activities/Accomplishments:**

- DMR collaborated with and worked in partnership with the Office of Medicaid, autism specialty providers, and advocacy groups in the implementation of the Children’s Autism Home and Community Based Waiver Program.
- DMR is actively participating with EOHHS staff and the other human service agencies in the re-design of the Chapter 688 Transition Planning process.
- DMR is working collaboratively with other human service agencies in the development and implementation of the Children’s Behavioral Health Initiative.
- DMR is participating with EOHHS and other agencies on the development of a *Comprehensive Integrated Employment Services Procurement*.
- Guidelines and a packet of ‘emergency preparedness’ information was shared with all Family Support Provider Agencies to distribute to families.

- The Department's Area and Regional Office staff participate in many different local inter-agency planning teams to promote more effective communication, coordination and collaboration around services.

**Proposed New Goals/Initiatives:**

- Continued collaboration and partnership with the Office of Medicaid, autism specialty providers, and advocacy groups in the implementation of the Children's Autism Home and Community Based Waiver Program.
- Continued collaboration and partnership with the Office of Medicaid in the development of new Home and Community Based Support Waiver Programs for Adults.
- The Department will work collaboratively with EOHHS and the other designated human service agencies named in the Chapter 171 legislation to coordinate activities and work on improving and expanding flexible support services for individuals and families.