

**Department of Mental Retardation  
Annual Plan for Family Support  
State Fiscal Year 2008 (July 2007-2008)**

**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 fifth 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.

**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.

### **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.

A review of Family Support Services utilization completed in March 2007 estimated that **4,600 adults** and **8,647 children** were receiving services in the DMR funded family support programs for a total of **13,247 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 brief summary of the types of programs and numbers of individuals and families who were able to access and benefit 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 4,600 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 an approximately 3,100 families of children who are only receiving this Information and Referral assistance at this time

A new initiative offered by DMR this past year was the availability of one- time funding to Family Support Provider Agencies to provide vacation programs during the school vacation week in April and for the last two weeks in June after school ended. More than 800 children and families were able to participate and benefit from these vacation programs, offered by twenty-eight provider agencies who organized a total of 53 weeks of vacation programs. These vacation programs were not only fun for the children but were of great benefit to families by offering a safe, secure location for their child to spend some time away from home and thus, constitute 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 500 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 with 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 an Autism Support Center in each DMR region, with seven centers across the state. In FY '07 approximately 6,500 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 2 planned facility based respite centers for children in two locations across the state and 18 centers for adults. Many families prefer to use their flexible funding to purchase respite relief within their home and with familiar caregivers rather than use a facility-based respite site. Last fiscal year about 455 adults and 210 children used these Planned Facility-Based Respite Services.

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 1850 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. Last fiscal year about 300 adults and 215 children participated in these programs.

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. Last fiscal year about 200 children participated in these programs.

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 '07 about 110 families participated in this comprehensive leadership series and another 550 families participated in other types of family leadership activities.

**The Autism Division** at DMR was established in 2005. The Division has been funded at almost \$3.3 million dollars for this fiscal year. Two million dollars of this amount is designated for implementation of an approved Medicaid Home and Community-Based Services Waiver program to provide intensive supports for young children with autism who meet the established eligibility requirements. The remainder of this funding is allocated to support 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. Community programming for training first responders, a very successful initiative which has reached 1100 individuals to date, will continue as well.

**The Department of Education & Department of Mental Retardation Community Residential Education Project (DOE/DMR)** continues to be a successful collaborative initiative. It is currently level-funded at \$8 million dollars. During fiscal year 2007, 366 children participated in this project, including 66 new participants, which is an increase in the overall total number of participants. Thirteen of the participants in the Project

were assisted to return from residential school placements to their home communities, and 353 students utilized project resources to obtain a diversity 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 families clearly indicates the benefits of these resources and supports to keep their children at home and assist them to be meaningfully included in their communities and schools.

***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 with the Statewide Family Support Council (SFSC)
- Meetings that involve the Commissioner, the Assistant Commissioners for Operations and Policy, Planning & Children's Services, Statewide and Regional Directors of Family Support, the Regional Office Directors and the Board members of Massachusetts Families Organizing For Change (MFOFC).
- Information-sharing, discussion and input from the DMR Statewide Advisory Council (SAC).
- Involvement in the "National Core Indicators Project" a multi-state collaborative effort to improve performance in state services for people with mental retardation and developmental disabilities. Activities include dissemination of mail surveys to: 1) families who have an adult family member living at home who is receiving some funded DMR services; 2) families of children who are DMR eligible; and 3) personal interviews of adult individuals receiving DMR services.
- A *Family Support Survey* was developed and distributed to families in the spring of 2006. This survey was organized around the six major areas of focus in our Annual Plan for Family Support.

In addition, during this past year DMR provided and participated in multiple forums with families and individuals to seek their input and hear their ideas about services and supports.

- In July- August, 2006, five regional Stakeholder Forums were held to discuss information on the Department's Home and Community Based Services Waiver Programs and to seek input in preparation for the new applications the agency would be developing. There were more than 800 participants who attended these forums that were facilitated by Assistant Commissioner Janet George. A summary from these forums was developed and is available on the DMR web-site.
- During the Fall of 2006, five regional family focus groups were held to discuss quality in family support services to inform the development of the Department's quality management and improvement system for family support & self-directed services; Approximately 75 family members participated in these forums which were facilitated by Assistant Commissioner Gail Grossman and the Statewide Director of Family Support, Margaret Van Gelder. A summary of information

- learned from these forums was provided to DMR staff, all the family members who participated and to members of the Statewide Family Support Council.
- During April and May, 2007 five regional forums were held to get input from families about the transition process from school to adult services. Approximately 250-300 individuals participated in these sessions which were facilitated by Larry Tummino, Assistant Commissioner for Operations, Victor Hernandez, Turning 22 Statewide Coordinator at DMR, the DMR Regional Training Directors in collaboration with the Governor's Commission on Mental Retardation and the Arc. A summary report with recommendations has been developed and is available.
  - In May, 2007 a meeting was held with staff and family members from the five DMR funded Medically Fragile Family Support Projects to discuss the unique needs in transition planning for individuals with complex medical challenges and other significant disabilities. Approximately 15 participants met with Assistant Commissioners Janet George, Larry Tummino, and the Statewide and Regional Family Support Directors to begin identifying some of the specific needs, gaps in services, and good practices to help inform planning activities.

Some related activities include:

- Individuals and family members have been active participants in a statewide strategic planning process to help redesign DMR's day and employment services. This has been facilitated by Bertha Young and Margaret Van Gelder at Central Office with consultation from the Institute for Community Inclusion.
- DMR was an active participant in the planning and implementation of two statewide forums for individuals and families held with the Governor's Commission on Mental Retardation and the Governor's Commission on Employment of People with Disabilities to hear good practices and to get input on ways to improve employment opportunities for individuals with disabilities.

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.

### **Focus Areas**

#### **Review of Activities & Accomplishments & Proposed Goals/Initiatives for FY '08**

**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:**

- Input obtained from stakeholders was used to help shape the design of new Home and Community Based Waiver applications. There will be increased opportunities for individuals and families to utilize 'participant-direction' in service design and delivery, including use of non-traditional providers.
- Regular meetings have been held with the Statewide Family Support Council and the Council will have an ongoing role in providing input and guidance on service and policy development

- Involvement of the Statewide Family Support Council in providing input to help develop approaches for creating a more standardized, consistent and equitable system for making decisions about family support resource allocations. The Council has provided and will continue to offer input on ways to re-design our system of family support services.

**Proposed New Activities/Initiatives:**

- Based on input from individuals and families, new quality assurance approaches are being developed for family support and participant-directed services. The Human Services Research Institute (HSRI), a nationally known organization is providing consultation to DMR in these activities. This will include re-design of the performance outcome measures for Family Support Provider Agencies
- DMR will seek to better utilize the information that Family Support Provider Agencies obtain through the required annual satisfaction surveys they conduct with families to whom they provide services. This will provide another avenue for reaching many more families to obtain feedback which will assist in informing areas that need to be addressed and/or new initiatives to pursue.

**II. Family Leadership**

**Activities/Accomplishments:**

- Approximately 100 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.
- Many families and individuals were able to participate in a variety of other leadership and training opportunities on a variety of topics and interest areas, related to transition, housing alternatives, etc.

**Proposed New Goals/Initiatives:**

- 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 activities, re-design of employment and day services, etc.

**III. Family Support Resources and Funding**

**Activities/Accomplishments:**

- A Home and Community-Based Services Waiver application to provide supports to young children with Autism Spectrum disorders was submitted for review to the Centers for Medicaid and Medicare in December 2006 and received approval in September 2007.

- Funding for social skills, recreational programs and vacation programs was provided to the seven DMR funded Autism Support Centers reaching approximately 2100 children and families.
- Funding for vacation and camp programs was made available to all Family Support Provider Agencies across the state, resulting in an array of interesting and exciting opportunities. Twenty-eight agencies provided 53 weeks of vacation programming in April and June serving about 800 children statewide.
- Changes were made to the Family Support Planning process to promote a more comprehensive and family centered approach to planning, and five regional training sessions were held in the spring of 2007 for all Family Support Provider Agency staff and DMR area office staff. The goals of these trainings were to: impart information on changes; help strengthen the quality of the family support planning process; and to facilitate a common understanding and interpretation of the Guidelines and support consistency in implementation.

**Proposed New Goals/Initiatives:**

- Dissemination of an Addendum to the Family Support Guidelines and Procedures that focuses on the family support planning process flexible funding options and a description of the allowable and disallowable expenses.
- To support increased understanding and utilization of ‘participant-direction’ in services, a guide for families and individuals is under development.
- A resource manual for families and individuals about hiring your own staff is under development and will be completed and made available.
- The Department will create and implement new data collection systems in order to better document the specific types and scope of services utilized by families with their flexible funding allocations in order to provide a more comprehensive report on the impact and benefit of these services. In addition, a systematic approach will be implemented to collect information from families about their specific identified needs for family support at the time of application and eligibility determination for DMR services.

**IV. Accessing Services and Supports**

**Activities/Accomplishments:**

- DMR areas and regions have offered an array of different events to share information about resources and providers to assist families and individuals in expanding their knowledge about service options and to support their choices in planning and service provision. Examples include the Family Support Festival in Springfield, transition resource fairs and panels held in the northeast region, etc..
- The Autism Division has developed regular newsletters to provide information and share updates which are broadly distributed and posted on the DMR web-site.
- The DMR web-site continues to evolve and be updated to include more information about DMR services as well as posting of other relevant information that might be helpful to families and individuals receiving services.

- Use of the Virtual Gateway- a “single-point of entry” tool developed by EOHHS which enables family support agency staff to assist families in applying for public benefits they may be eligible for as well as complete applications for other disability agency services.

**Proposed New Goals/Initiatives:**

- DMR is developing new brochures about DMR services and the Home and Community Based Waiver Programs. These brochures will be translated into multiple languages.
- The DMR Family Support Resource Guide that has been under development will be completed and distributed in the fall of 2007.
- Completion and distribution of an Autism Resource Guide.
- A Task Force will be convened in the fall of 2007 to explore the specific support needs of young adults with complex medical challenges and significant disabilities in the transition process from school to adult services. There will be strong family involvement in this Task Force as well as representation of other EOHHS agencies who also play a role in providing supportive services to this group of individuals. The goal is to identify recommendations for DMR and other relevant agencies to assist in developing a more responsive array of adult service options that can address the medical, health and support needs of this population.

**V. Culturally Competent Outreach and Support**

**Activities/Accomplishments:**

- A Diversity Conference was held in October 2006 for DMR staff which had about 300 participants.
- A five-part cultural diversity series was held in central Massachusetts for family support agency and DMR staff. Additional cultural diversity presentations and activities occur at the central, regional and area offices.
- Informational and training materials on a variety of subjects have been translated into multiple languages and made available to families and individuals. This has included information on autism, Asperger’s Disorder, the 688/transition process, and intake and eligibility forms, family support plans, etc. .
- Ongoing and successful implementation of a federal grant in Springfield designed to create a “one stop family center” for economically disadvantaged, culturally diverse families with a member with a disability to help them navigate the service system.
- DMR has been funding a demonstration project in Lynn, MA- the Lynn Time Bank- as alternative approach to community development and expanding access to resources in a community with large numbers of individuals who are culturally and ethnically diverse.
- DMR Central Office staff have participated in the development of a new statewide procurement for foreign language translation and interpretation services.

**Proposed New Goals/Initiatives:**

- Continue work on developing a more comprehensive and streamlined system for the translation of DMR information and materials, expanding the range of information provided, timeliness, and access to materials.
- An annual Diversity Conference for DMR staff will be sponsored in the fall of 2007 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:**

- Collaborated with the Department of Public Health and staff from the Family TIES program to provide training and resource information to DMR funded Family Support Provider Agencies on emergency preparedness. Presentations were also made at area and regional board meetings and at different training events for families.
- Guidelines and a packet of ‘emergency preparedness’ information was shared with all Family Support Provider Agencies to distribute to families.
- Participation on the six regional Planning and Review Teams, an EOHHS inter-agency initiative. This initiative is designed to develop a coordinated effort to better serve youth and children who require services from multiple EOHHS agencies.

**Proposed New Goals/Initiatives:**

- DMR continues to participate in multiple EOHHS inter-agency committees and initiatives including the PRT- Planning and Review Team, Adolescent Health Initiative, Employment Task Force, among many others.
- Work jointly with Department of Public Health in community forums to discuss local emergency planning activities and strategies for responsiveness and specialized supports to individuals with disabilities and their families.
- The Department will maintain an ongoing coordinating role with the other designated human service agencies named in the Chapter 171 legislation to discuss and monitor progress on family support initiatives, and to work collaboratively on improving and expanding flexible support services for individuals and families.
- DMR will continue to collaborate and work in partnership with the Office of Medicaid, autism specialty providers, and advocacy groups in the implementation of the Children’s Autism Spectrum Disorders Home and Community-Based Services Waiver Program.