

## Massachusetts Department of Public Health Annual Family Support Plan - Fiscal Year 2011

### **Background**

The Massachusetts Department of Public Health (DPH) provides programs and services that promote public health to the broad range of individuals living in the Commonwealth. DPH programs, services and educational initiatives are designed to prevent disease and disability and to reduce the impact on individuals and society of preventable health conditions and secondary effects.

The DPH Bureau of Family Health and Nutrition (BFHN), Division for Perinatal, Early Childhood and Special Health Needs (DPECSHN) the Massachusetts Title V Children & Youth with Special Health Care Needs program provides services and supports to individuals with disabilities and their families and was given the responsibility of developing the DPH Family Support Plan as mandated by **Chapter 171 of the Acts of 2002: An Act Providing Support to Individuals With Disabilities and Their Families**. In 2003, the Bureau began the process of examining existing programs to assess their level of meaningful family involvement soliciting family/consumer input to identify ideas about how programs and services could become more responsive and provide more flexible supports. This work was entirely consistent with the Title V philosophy of meaningful and sustained family involvement in all aspects of policy development and program planning.

### **Overview of Family Support**

The DPH has a long standing commitment to effective, collaborative partnerships with families and works to ensure that programming is responsive to family/consumer articulated needs. To achieve these goals, DPH employs a broad based definition and multi-faceted approach to Family Support, starting from a commitment to Family-Centered Care, a core component of maternal and child health which is defined by the Maternal and Child Bureau as:

*"Family-Centered Care assures the health and well-being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions and expertise that everyone brings to this relationship. Family-Centered Care is the standard of practice which results in high quality services." MCHB 2005*

In addition, DPH provides a variety of flexible family-identified supports, ranging from a small amount of funding that individual families can use as needed, to skill building opportunities that assist families to become confident, well-informed, active partners in their children's health. DPH programs provide opportunities for family to family support and networking, recreational activities and assistance with accessing community resources.

At DPH, Family Support activities are housed primarily within the Early Intervention (EI) and Children & Youth with Special Health Needs (CYSHCN) programs and are overseen by the Director, Office of Family Initiatives, which is a senior management position within BFHN. The Director's responsibilities include:

- Ensuring that all staff are aware of, receive information about and know how to work in partnership with families;

- Ensuring that all Bureau initiatives include families/consumers in planning and monitoring activities;
- Developing new and ongoing opportunities for family involvement;
- Providing training, mentoring, financial and other supports to families partnering in planning, policy making and program implementation;
- Identifying and sharing emerging issues for CYSHCN and their families
- Representing BFHN and its commitment to family-centered services in interagency initiatives;
- Representing BFHN and its commitment to family-centered services with other organizations on the state and national level; and
- Providing the “family voice”, both personally and via inclusion of other family members and family organizations, in Bureau and Department activities

***Process for obtaining "substantial consultation" from families regarding flexible support needs***

Every year, the DPH employs a variety of mechanisms to gather information from families/consumers about their support needs. Staff from Office of Family Initiatives projects have actively distributed outreach materials at conferences and regional and local meetings attended by families whose children have special health needs to gather input. These events included Special Education PAC meetings, ICC meetings, conferences for families whose children have hearing loss or are Deaf and the annual Federation for Children with Special Needs conference where over 800 hundred families had an opportunity to share information. Care Coordinators, Community Support Line and Family TIES staff and the DPH Statewide Public Benefits specialist all include questions about services and supports in their regular contacts with families. Outreach to families across the Commonwealth was conducted to ensure that information used to inform the Plan reflected geographic, linguistic, ethnic, cultural and socio-economic diversity.

In addition to these on-going strategies, 2010 is a Maternal and Child Health Needs Assessment year. Title V programs are mandated to carry out a comprehensive needs assessment every five years to build capacity and identify gaps and disparities, as well as effective strategies to address the needs of the maternal, infant, child, adolescent and CYSHCN population in Massachusetts. In 2010, the DPH utilized a variety of methods to gather this information including focus groups, key informant interviews and an electronic survey that was piloted by 30 families of children with special health needs and broadly disseminated to individual youth and families as well as a number of family organizations. The electronic survey was posted to the Family TIES and Early Intervention Parent Leadership Project websites and to the Mass Family Voices listserv. In all, 500 individuals provided substantial consultation to the needs assessment process and the development of the annual Family Support Plan. Surveys were available in and focus groups were conducted in English and Spanish. Individuals whose first language is Portuguese were able to respond to a bi-lingual staff person through the Family TIES toll free 800 line.

Families were asked about unmet and under-met health needs, access to a Medical Home and community resources, support for health related transition and degree of emergency preparedness. In addition, respondents were able to rank the importance of core public health concerns such as nutrition and healthy weight, physical activity and sexuality education.

Results of these needs assessment/substantial consultation activities indicated that fewer than 50% of families felt their children's primary care was delivered in Medical Home. Only 50% reported good communication between their primary care and specialty providers. Over 50% indicated that it was difficult to access community based services including recreation, afterschool care and support groups. 66% reported that they got information about resources and community support from other families or friends and that they would like it to come from agencies and health care providers. When responding to which health related needs were most significant for their children and youth, families ranked the following as most important:

- Mental Health
- Social Isolation
- Bullying
- Physical Activity
- Healthy Weight and Nutrition

As has been reported in the past, families indicated a need for reliable, easy to access, current information about resources, public programs and supports as essential. Respite, nursing care and availability of services after age 22 were key issues. Again, families asked for more collaboration and integration of services among human service agencies. They informed DPH that care coordination and support during critical life events, information about transition and education for health care providers about issues relevant to CYSHCN were top priorities. DPH will continue to partner with other human service agencies, academic, health care and family organizations to identify ways to address these systemic challenges.

### ***Focus Areas***

#### **Family Empowerment and Family Leadership Development Activities**

##### *Current and On-going Activities:*

Programs within the Department of Public Health seek input from practitioners, academics, consumers/families and other stakeholders via Advisory Boards. Boards generally meet at least quarterly and transmit information regarding community and individual needs directly to DPH. In FY10, Commissioner Auerbach conducted regional community dialogues around a number of public health issues and Ron Benham, Director of the Bureau of Family Health and Nutrition hosted six MCH Block Grant hearings as ways to promote family and community participation and empowerment.

At DPH, family empowerment and family leadership activities are entwined and are offered in the following ways:

- Participation in policy development, program planning, implementation and evaluation coupled with skill building opportunities that assist families/consumers to comfortably and effectively participate.
- Participation in the MCH Block Grant process, from needs assessment to priority setting, to implementation.
- The Early Intervention Parent Leadership Project. This parent designed and staffed project reaches families whose children are enrolled in EI offering skill building for leadership and lifelong advocacy skills development. Parents are encouraged and supported to partner with their own EI programs, at regional early childhood events; on the state level as advisors to the DPH; as members of the federally mandated Interagency Coordinating Council (ICC) and nationally to share information about Massachusetts and to learn and bring home information from other states about

opportunities for families to impact and help define services systems. Through the Parent Leadership Project, DPH funds the Hausslein Leadership Awards which offer small grants to families enrolled in EI to design and implement inclusive projects that connect children and families to their communities.

- Family TIES (Together in Enhancing Support) the statewide Information and Referral network for families of CYSHCN and their providers. Family TIES staff, who are all parents of children with special health needs, are located in each of the DPH regional offices which gives them familiarity with local resources. Family TIES also serves as the Massachusetts Parent-to-Parent program, connecting families with similar life circumstances and as the Early Intervention Central Directory. Families who access services from Family TIES are offered opportunities to become advisors to DPH and to take on roles within DPH programs and other public policy venues. Training, mentoring and financial support is available to these families.
- "Understanding Services", a collaboration between Family TIES and DPH Care Coordination program brings together families and service providers statewide to learn about and share information on public programs, eligibility requirements and "who to call."
- Collaboration with other family organizations such as the Federation for Children with Special Needs, Mass Families Organizing for Change and Mass Family to Family Health Information Center to share training and skill building opportunities.
- Positions for two family members as Advisors to the Catastrophic Illness in Children Relief Fund.
- Contracts with ten Community Health Centers and community-based primary care practices to implement Medical Home activities. A requirement of each contract was the establishment of Practice Improvement Teams that include family members who receive a stipend for their participation.
- Families are regularly surveyed about support needs, best uses of flexible funds and skill building needs through Office of Family Initiatives projects, Community Support, Care Coordination and Regional Consultation Programs. These programs also provide training and skill building opportunities for families to grow their leadership and advocacy skills.

#### *New Initiatives:*

- Work with EI Parent Contacts and Parent Liaisons at local EI programs to grow their leadership skills.
- Expand collaboration with Shriver Center and the Institute for Community Inclusion, University Centers of Excellence in Developmental Disabilities to identify joint priorities and projects.
- In collaboration with the DPH Early Intervention Training Center implement new skill building opportunities for families such as "Understanding Family Rights" and "You and Your IFSP."
- Work with families to create digital stories to capture their EI and other health care experiences as learning tools for providers.

### **Family Support Resources and Funding**

#### *Current and On-Going Activities:*

##### **Direct Service Programs**

Family support activities continue to focus on skill building at the community level, production and dissemination of materials, assistance in development of local support groups and expanding the statewide Parent-to-Parent program. The DPH produced 1500 copies of the Family TIES ***Directory of Resources for Families of***

***Children and Youth with Special Health Care Needs.*** This Directory, with resources in English, Spanish and Portuguese is in great demand among families, health care providers, insurers and community organizations. The CYSHCN programs collaborated with other human service agencies to share information and resources through regional ***Understanding Services*** workshops. CYSHCN direct service staff provides information about and referral to resources, public benefits and navigating the health care system. If families need information and support from other agencies, staff assists them to identify which agency would have primary responsibility for their presenting issue and facilitates connections with these agencies. CYSHCN programs work to support families whose children have complex special health needs experiencing critical life/health events.

DPH maintains a toll free Community Support Line available to families of CYSHCN and their providers. In FY 10, the Line received over 1600 calls of which 875 or 53% were from families. Resource Line Specialists have created an easy resource reference guide to facilitate their work.

### **Medical Home**

A continued focus is the promotion of the Medical Home within community-based pediatric practices. DPH Care Coordinators are currently placed in ten Community Health Centers and private practices across the state where they provide information and support to families and train staff in aspects of Medical Home. Twelve family members were recruited and mentored to work on practice improvement projects at each site. These family consultants receive a stipend for their time and share their work with other families. They also attend DPH sponsored regional and statewide meeting and conversations about best practices in Medical Home implementation.

### **Emergency Preparedness**

In response to the possible impact of H1N1 flu, the DPH prepared and disseminated a set of Frequently Asked Questions for Families whose Children have Complex Medical Needs. The Director of Family Initiatives, a parent of a young adult with complex special health care needs, serves as the family representative to the state Emergency Medical Services for Children Program. In this role, she helps to make connections between EMS and families that facilitate effective emergency response. She provides input to the program about the needs of families whose children have complex medical issues that would require individualized responses in the event of emergency or disaster.

### **Program Supports**

Family support initiatives within the Bureau are provided by Early Intervention Regional Consultation Programs (RCPs). Six programs statewide provide support to families of young children with complex medical needs that facilitate inclusion in community settings of family choice. RCPS also provide support groups, recreational activities and networking events to eligible families. In FY 10, DPH collaborated with the Department of Early Education and Care (EEC) to fund RCP programs to support child care and public school programs to include children aged 3-5 in community settings.

The Universal Newborn Hearing Screening Program (UNHS) provided support and information to over 1300 families whose children either did not pass or missed their initial hearing screening. Efforts are made to reach every family by phone, mail or through family-identified pediatrician. Families can access some on-going case management through DPH. With family permission an immediate referral is made to the Mass Commission for the Deaf and Hard of Hearing (MCDHH) which is able to provide additional supports. The program employs a parent of a young child with hearing loss as a parent consultant. This consultant makes personal contact with every family whose

child receives a diagnosis of hearing loss to offer family-to-family support and community and statewide resources. In FY 10, 800 English and 275 Spanish Parent Information Kits and 71,000 brochures in multiple languages were distributed to families. The UNHS program supported 40 parents to attend conferences where they gained current information about hearing loss and options for interventions. Families reported satisfaction with the opportunity to network with others experiencing similar circumstances.

The Pediatric Palliative Care Program provides services to children with life limiting illnesses and their families. In FY10, 230 children received palliative care services including, pain and symptom management, case management, respite, complementary therapies and bereavement care.

### **Flexible Funding**

In addition to these programs and services, the DPH is able to make some flexible funding available to families to address medical and other health-related needs not covered by other sources. Special funds help eligible families purchase (among other things) hearing aids, medications, assistive technology, respite services, home and vehicle modification and reimbursement for travel expenses incurred for the care of their children with special health needs. Funds are disseminated through DPH vendors and in some cases, from DPH directly to families. In Fiscal Year 2010, approximately 900 families received close to \$3,000,000 in funding from the Catastrophic Illness in Children Relief Fund (CICRF), Early Intervention Regional Consultation Program Family Support Care Coordination Family Support funding and the Hearing Aid Program for Children. Close to \$75,000 was allocated for family involvement activities across the Bureau including participation in focus groups, proposal reviews, as trainers, community-based projects and attendance at conferences and other skill building opportunities.

#### *New Initiatives:*

- Training for I & R staff about the Children's Behavioral Health Initiative (CBHI)
- Facilitation of training about CBHI for EMS providers
- CYSHCN participation in DPH obesity initiatives and healthy sexuality and abuse prevention programs
- Develop a Parent-to-Parent program for families whose children have hearing loss

### **Accessing Services and Supports**

#### *Current and On-going Activities:*

The Department supports a variety of efforts to educate families/consumers about availability of and access to services. Some of these include public service announcements, Early Intervention Child Find, development and dissemination of Medical Home fact sheets for families and providers, program specific newsletters such as EIPLP's **Parent Perspective** and the MassCare newsletter. CICRF, Community Support Line, Family TIES, Care Coordination and Pediatric Palliative Care staff outreach to hospitals, schools and community settings where individuals with disabilities and their families receive services. A new brochure designed for neonatal intensive care units was developed and distributed in FY 10. The DPH Public Benefits Specialist provides training across the state and offers technical assistance through a toll free number and at in-person trainings. 50 parents received personalized TA and training from this Specialist. Staff from Care Coordination, Community Support Unit and Family TIES continued their collaboration on a series of statewide public benefits and informational meetings for families and professionals to disseminate information about

available services and supports. Family TIES and EIPLP both maintain toll free numbers. In FY10, over 4000 families called these lines for information, referral, Parent-to-Parent matches, training and skill building opportunities. These projects also host web-sites and list servs. To date, 1500 Family TIES Resource Directories, 6000 project brochures in English, Spanish and Portuguese and five editions of the **Parent Perspective** have been distributed to families and professionals. These materials are also available electronically. DPECSHN program information, including the Family Support Plan is available on-line at [www.mass.gov/dph](http://www.mass.gov/dph). There is interactive capability on the DPH website and on DPECSHN project sites for families to offer feedback and suggestions.

*New Initiatives:*

- Distribution of CYSHCN brochure and magnets
- EI Parent Contacts and Family Advisors trained and supported to outreach and provide program and resource information to families
- Development of an electronic CYSHCN newsletter

### **Culturally Competent Outreach & Support**

*Current and On-going Initiatives:*

Collaboration with the Office of Health Equity is on-going within the CYSHCN Program. Staff participated in the piloting of the "Making CLAS Happen" tool kit and will share with colleagues and families. Materials about all programs for individuals with special health needs and their families are available in a variety of languages including but not limited to; Spanish, Portuguese, Haitian Creole, Russian, Cambodian and Vietnamese. All programs have staff with multiple language capability and/or access to interpreters. DPH hires and/or contracts with individuals who are bilingual, bicultural and familiar with the culture and customs of families who utilize our programs. Outreach initiatives take place collaboratively with community-based organizations where ethnically, linguistically and culturally diverse individuals and families receive services and are comfortable. These include community health centers, WIC offices and family organizations. The Family TIES Project contracts with native Spanish and Portuguese speakers to respond to requests for information and referral, and Parent-to-Parent matches. Family TIES staff has made connections with a number of community based organizations, included the Somali Development Centers in Holyoke and Boston and SCAN 360 serving the Hispanic population in Springfield. Staff shares information about community resources and the availability of flexible family supports. Project training is available in Spanish and Portuguese. Family TIES continues it focus on expanded outreach to linguistically and culturally diverse populations. Coordinators share materials and offer skill building sessions to families whose children have special health care needs. Bilingual/bicultural staff is available to support staff and families at the CBOs.

Specific training about organizing complex and multiple records, emergency preparedness and building community are available in Spanish, Portuguese, Chinese and Vietnamese. The EIPLP newsletter lead article and updates on the EI Family Survey is translated into Spanish in each edition. TTYs are in place in all DPH regional offices. DPECSHN programs continued to utilize the Office of Health Equity telephonic interpreter services line.

Care Coordinators in Western Mass have recruited five Spanish speaking Family Consultants to take part in Medical Home activities. In addition, they hosted a needs

assessment focus group attended by 20 family members whose first language is Spanish to ensure input from those individuals.  
Collaboration with the Office of Health Equity to provide training and resources about health disparities to all staff continues.

*New Initiatives:*

- Parent -to-Parent Curriculum will be available in Haitian Creole

**Interagency Collaboration**

*Current and On Going Activities:*

- Collaboration between DPH and Department of Early Education and Care (EEC) to expand RCP services to children 3 -5 and to provide on-line training about transition from EI to public school.
- Collaboration with DMH for Mass Launch, an initiative to support Community health Centers to offer a Medical Home to families with mental health and substance abuse issues.
- Collaboration between DPH, EEC, ACF/Head Start and community agencies to expand Special Quest activities at the community level.
- Participation in the Early Childhood State Advisory Council.
- Participation on the State Special Education Advisory Board to share information about children with special health needs in public schools.
- Interagency Coordinating Council, A federally mandated council that advises and assists the DPH as lead agency for the MA Early Intervention System in planning, implementation and evaluation of EI services. The ICC is made up of family members of children who receive or have received EI, representatives from state agencies, early intervention programs, higher education, and other interested organizations serving young children and their families.
- Participation in an EOHHS led working group of state agency liaisons responsible for development of Chapter 171 Family Support Plans. In FY 10, this group designed and delivered training at the Federation for Children with Special Needs annual conference to expand families' knowledge of each agency's methods of collecting substantial consultation and strategies for developing their Plans.
- Collaboration with the Mass Commission for the Deaf and Hard of Hearing to make early connections for families whose children are diagnosed with hearing loss
- Active participation in EOHHS Medical Home initiatives including the Qualis Project, and Medical Home Safety Net Project.
- Regular collaboration with the Coordinated Case Management Program

*New Initiatives:*

- Collaboration with EEC to fund purchase of kits and training for EI and public school programs to utilize the Battelle Developmental Inventory.
- Participation in an EOHHS initiative to enhance integration of case management services across multiple agencies
- Participation in EOHHS Medical Home procurement.
- Development of cross-agency training for information and referral staff