



## Massachusetts Department of Public Health Annual Family Support Plan - Fiscal Year 2012

### **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 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 primarily housed 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 actively distribute outreach materials at conferences and regional and local meetings attended by families whose children have special health needs to gather input. These events included Interagency Coordinating Council meetings, skill building sessions for Spanish speaking families in Lawrence and Lowell, outreach meetings with families from Somalia, a family meeting for families whose children have hearing loss or are deaf and the annual Federation for Children with Special Needs conference where over 850 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. This information about unmet and under-met needs is included in planning activities for the DPH Family Support Plan. Outreach to families across the Commonwealth was conducted to ensure that information used to inform the Plan reflects geographic, linguistic, ethnic, cultural and socio-economic diversity.

In FY 11, the Chapter 171 survey was available in English, Spanish and Portuguese electronically and as a paper version. Over 150 families completed this information gathering tool including 38 Spanish speaking and 4 Portuguese speaking families.

Families were asked about unmet and under-met health needs, whether or not their children received care in a Medical Home, if they received information and support for health related transition, if they knew about community resources and parent-to-parent support opportunities and if they had made any preparations for emergency situations. Again this year, respondents had the chance to let DPH know their primary sources for health-related information.

Results of these surveys identified a number of areas of unmet needs. Among families for whom English is not their first language, it was noted that access to all needed medications, access to Personal Care Attendants, and adequate insurance coverage, were issues. These families also expressed a need for more family-to-family support and help in accessing community based recreational opportunities. As has been the case in past years, many of the issues raised by families go beyond the DPH purview. More than half of families responding to the survey in English, echoed the above concerns and raised the need for more and easier to access therapies, help in finding a medical home and assistance during periods of both physical and mental health crises. Many families receive services from multiple agencies and as a result continue to urge the Commonwealth to support better communication and cross-training among these agencies.

In FY12, DPH/DPECSHN will enhance existing partnerships and seek new opportunities for better coordinated and integrated linkages with agencies and organizations identified by families including but not limited to, Executive Office of Health & Human Services, Department of Elementary and Secondary Education, Department of Developmental Services, Department of Early Education and Care, the Mass Chapters of the American Academy of Pediatrics and Family Physicians, Massachusetts Developmental Disabilities Council and the LEND (Leadership Education in Neuro-developmental Disabilities) programs at the University Centers on Disabilities at U Mass.

### ***Focus Areas***

Results of substantial consultation activities for FY 12 continue to show that fewer than 50% of families felt their children's primary care was delivered in Medical Home. Less than half of respondents reported good communication between their primary care and specialty providers. Families from diverse populations broadly indicated concern about adequate health insurance, access to care and lack of partnership with primary care providers.

Many areas of need remain, including the need for reliable, easy to access, current information about resources, public programs and supports. Respite, nursing care and availability of services after age 22 continue to be concerns. Families again stressed the need for care coordination and support during critical life events, information and guidance about transition including development of self management skills, finding adult providers and information about changes in public benefits for young adults.

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

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

At DPH, family empowerment and family leadership activities are integrated 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 ways that families can impact and help define services systems. Through the Parent Leadership Project, DPH funds the Haussslein Leadership Awards which offer small grants to families enrolled in EI to design and implement inclusive projects that connect children and families to the 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, an affiliate of P2P USA, 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", DPECSHN programs bring 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.
- Contracts with Community Health Centers and community-based primary care practices to implement Medical Home activities. A requirement of each contract is 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 the Office of Family Initiatives, 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:*

- Explore and expand use of social networking sites to facilitate communication and information sharing with a broad and diverse group of families.
- Collaborate with Harvard School of Public Health to:
  - 1.) Develop a guide to safe and effective use of web based resources. Engage families to share their information needs, current methods of obtaining information and reactions to new materials.
  - 2.) Develop and pilot a Family Leadership Curriculum leading to a credential for family members to partner with health care organizations
- Broadly share information about family outcomes so that families can better assess their services and identify areas in need of improvement.
- Expand creation and use of digital stories as a training tool for providers and a catalyst for families to reflect on life experiences and use this knowledge to grow leadership skills.

### **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. Parent-to-Parent curriculum has been translated into Haitian Creole, Portuguese and Vietnamese. 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 11, the Line received over 1500 calls of which 792 were from families. An additional toll free line staffed by Family TIES responded to over 2000 calls from families.

### **Medical Home**

DPECSHN continues to promote the spread of Medical Home within community-based pediatric practices. DPH Care Coordinators are placed in 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. Family members are 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. The CYSHCN Program works collaboratively with EOHHS, Community Health Centers and Children's Hospital/UMass in a number of statewide medical home initiatives.

### **Emergency Preparedness**

The Director of Family Initiatives, a parent of a young adult with complex special health care needs, continues to serve as the family representative to the state Emergency Medical Services for Children Program. In FY 11, she facilitated training for EMS staff statewide around responding to young children with autism spectrum disorders.

### **Program Supports**

Family support initiatives within the Bureau are provided by six statewide Early Intervention Regional Consultation Programs (RCPs). Funding cuts to these programs have reduced the number of family support activities, but the programs continue to offer consultation to EI programs around children with complex medical needs. Support from the Department of Early Education and Care (EEC) allows RCP programs to work in the community at child care and public schools to facilitate inclusion for children aged 3-5 years.

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. An MOU allows DPH to connect families 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 11, 695 English and 218 Spanish Parent Information

Kits were distributed. The UNHS program brought families together to offer input about support needs and to network with others experiencing similar circumstances.

The Pediatric Palliative Care Program provides services to children with life limiting illnesses and their families. In FY11, 255 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 2011, approximately 500 families received over \$2,000,000 in funding from the Catastrophic Illness in Children Relief Fund (CICRF), Care Coordination Family Support funding and the Hearing Aid Program for Children. Over \$60,000 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:*

- Plan and implement coordinated family supports for families of older children with hearing loss
- Develop and disseminate resources for families about medical home, including, translation of fact sheets, identification and/or develop of materials, skill building to support medical/health related advocacy and a webinar, "Medical Home 101."
- Identify and offer a "train the trainers" program for multilingual families from underserved communities to offer Listen & Learn, our Parent-to-Parent mentor training program.

### **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, 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. The DPH Public Benefits Specialist provides training [to whom? Parents, other agency staff?] across the state and offers technical assistance through a toll free number and at in-person trainings. In FY11, 57 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 FY11, over 3000 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, 2000 Family TIES Resource Directories, 6000 project brochures in English, Spanish and Portuguese and four 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. CYSHCN Program brochures are widely disseminated and available in English, Portuguese and Spanish.

*New Initiatives:*

- Support ICC Parent representatives to hold regional meetings with families currently in or recently graduated from EI to learn about DPH resources
- Expand and deepen Family TIES work with organizations serving diverse communities to access services and grow leadership skills
- Utilize DPH social networking capability to extend outreach to more families

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

*Current and On-going Initiatives:*

Collaboration with the Office of Health Equity is on-going within the CYSHCN Program. 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 have 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 works with a number of community based organizations, including the Somali Development Centers in Holyoke and Boston and SCAN 360 serving the Hispanic population in Springfield. Staff share information about community resources and the availability of flexible family supports. Project training is available in Spanish, Portuguese and Chinese. Family TIES continues to 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 works with CBO staff and families.

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 are 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.

In FY 11, families from a number of CBOS were supported to attend the annual Federation for Children with Special Needs Conference.

*New Initiatives:*

- Family members trained to offer the Parent -to-Parent Curriculum in multiple languages (see bullet in Family Support Resources section)

- Expanded outreach to underserved communities to grow leadership skills and provide culturally competent supports to encourage participation in policy and program planning activities

### **Interagency Collaboration**

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

- Participation in EOHHS planning for a new agency to better coordinate services for children and families. Director of Family Initiatives serves as the DPH Family Representative in this activity
- Convening of a Steering Committee and Task Force to plan and apply for federal funding for expanded home visiting programs
- Early Intervention collaborates with the Department of Early Education and Care (EEC) and Department of Elementary and Secondary Education (DESE) to expand RCP services to children 3 -5, provide on-line training about transition from EI to public school and use of the Battelle Developmental Inventory as an eligibility tool across agencies.
- DPH early childhood programs collaborate with EOHHS around Project Launch/My Child, an initiative to support families whose children have serious emotional disorders.
- Collaborate with EEC, ACF/Head Start and community agencies to implement Special Quest inclusion supports and CSEFEL behavior management strategies to early education and care programs 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.
- 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:*

- Convening of a cross agency and community summit around best practices in implementing Medical Home approach
- Placement of DPH Care Coordinators in community based pediatric practices serving Mass Health eligible children through CHIPRA project
- Collaborate with EEC in submission of a Massachusetts Early Learning Challenge Funding proposal for federal Race to the Top funding