



Massachusetts Department of Public Health Annual Family Support Plan - Fiscal Year 2013

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 BFHN employs a variety of mechanisms to gather information from families/consumers about their support needs. Staff from Office of Family Initiatives projects actively seek input at conferences and regional and local meetings attended by families whose children have special health needs to gather input. These events include Interagency Coordinating Council (ICC) meetings, events at CBOs (community based organizations), Universal Newborn Hearing Screening Program family meetings and the annual Federation for Children with Special Needs conference where over 900 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 is conducted to ensure that information used to inform the Plan reflects geographic, linguistic, ethnic, cultural and socio-economic diversity.

In FY12, the Family questionnaire used to gather input to inform the DPH Chapter 171 Plan was available in English, Spanish and Portuguese electronically and as a paper version. Over 250 families completed this

information gathering tool. 20 Spanish speaking and 6 Portuguese speaking families offered input using the questionnaire. Others shared their thoughts and needs with Care Coordinators and staff on the Community Support Line and the Family TIES toll free line.

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 adequate insurance coverage and a lack of culturally and linguistically competent therapists and other health care providers were issues. As has been the case in past years, many of the issues raised by families go beyond the DPH purview. Over 50% of families responding to the survey in English, not only cited the same concerns about access to adequate insurance and difficulty finding and paying for speech, occupational and physical therapies, but also indicated a need for assistance in coordinating the multiple health care and other services needed by their children. As has been seen in past substantial consultation efforts, families named the need for educational and behavioral health resources and supports as their greatest unmet needs.

In FY13, DPH/DPECSHN will continue to work collaboratively with sister state and community agencies to address these concerns, enhance existing partnerships and seek new opportunities for systems improvements.

Focus Areas

Results of substantial consultation activities for FY 13 call attention to the need for capacity building among adult health care providers to meet the needs of youth transitioning from the pediatric system. Support for community-based pediatricians to develop and implement consistent policies around transition and skill sets to communicate this information to families and youth.

In addition, families requested current, comprehensive information about mandates and resources broadly as well as DPH/CYSHCN programs specifically.

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 (EIPLP). 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 EIPLP, 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 give 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:

- Develop and disseminate a CYSHCN Program electronic newsletter sharing information about programs, policy, resources and opportunities for family involvement.
- Develop a Leadership Training Institute for ICC Parent Representatives and Emerging Family Leaders

- Develop and disseminate fact sheets around changes in public benefits for families and health care providers as youth turn 18
- Utilize new technologies such as digital stories, and You Tube to share information about family experience and offer accessible opportunities.

Family Support Resources and Funding

Current and On-Going Activities:

Direct Service Programs

Family support activities continue to focus on skill building and leadership development at the community level, production and dissemination of informational materials, assistance in development of local support groups and expanding the statewide Parent-to-Parent program. This program trains volunteer parents to offer telephone support to families with similar life experiences. To date, 47 Parent-to-Parent matches have been made. There are over 250 trained support parents including Mandarin, Cantonese, Haitian Creole, Portuguese, Spanish and Vietnamese speakers. The CYSHCN programs continue to collaborate 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.

BFHN maintains a toll free Community Support Line available to families of CYSHCN and their providers. In FY 12, the Line received 1459 calls of which 725 were from families. Social workers on the line offer information about state wide resources and public benefits and make referrals to Care Coordination for eligible families. An additional toll free line staffed by Family TIES Parent Coordinators provides information about local and community resources and responded to over 2000 calls from families in FY 12.

Medical Home

DPECSHN continues to promote the spread of Medical Home within community-based pediatric practices. CYSHCN Program has worked collaboratively with the CHIPRA project (Children's Health Insurance Program Reauthorization Act) to place DPH Care Coordinators in the 13 selected practices, whose primary patient population is ensured by Mass Health. 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.

Program Supports

Family support initiatives within the Bureau are provided by six statewide Early Intervention Regional Consultation Programs (RCPs). In FY 12 funding for respite and family support was restored to these programs who served over 300 families. RCP staff also facilitates referrals to health and behavioral consultants for community child care programs and provides training 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 2100 families whose children either did not pass or missed their initial hearing screening. Of 191 infants diagnosed with hearing loss, 147 of them were enrolled in Early Intervention.

An MOU (Memorandum of Understanding) 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 UNHS 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. The Program distributed 50,000 brochures in multiple languages, as well as 277 English and 62 Spanish Parent Information Kits. The UNHS Program again held a Family Forum to gather input about support needs and to assist families to network with others experiencing similar circumstances.

The Pediatric Palliative Care Program provides services to children with life limiting illnesses and their families. In FY12, 240 children and their families 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 2012, approximately 800 children and families received \$3,000,000, in funding from the Catastrophic Illness in Children Relief Fund (CICRF), Care Coordination Family Support funding, RCP respite and family support funding and the Hearing Aid Program for Children. \$100,000 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:

- Finalize and disseminate a guide to health web literacy developed in collaboration with the Harvard School of Public Health.
- Recruit families and produce additional digital stories.

- Provide small group and individual training sessions for families around public benefits, Listen and Learn P-2-P curriculum and community resources.

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 families and providers across the state and offers technical assistance through a toll free number and at in-person trainings. In FY12, 36 parents received personalized TA and training from this Specialist. The Universal Newborn Hearing Screening Program developed a Facebook page where information about hearing loss and deafness as well as links to local, statewide and national resources is shared. 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. Community Support Line, Family TIES and EIPLP all maintain toll free numbers. Family TIES and EIPLP 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. DPEC SHN program information, including the Family Support Plan is available on-line at www.mass.gov/dph. There is interactive capability on the DPH website and on DPEC SHN project sites for families to offer feedback and suggestions. CYSHCN Program brochures and magnets are widely disseminated and available in English, Portuguese and Spanish.

New Initiatives:

- Continue to grow the EI Parent Contact network to learn and share information with families currently enrolled or recently graduated from EI
- Develop social networking capability for the CYSHCN Program and Family TIES and grow the capacity of the EIPLP Facebook page

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, designed to build relationships and reduce health disparities take place 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, SCAN 360 serving the Hispanic population in Springfield and the Vietnamese Family Center in Worcester. 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. DPEC SHN programs continued to utilize the Office of Health Equity telephonic interpreter services line.

New Initiatives:

- Recruitment of and support for diverse family members to partner in medical home practices
- Support for diverse families recruited from CBOs to take part in Block Grant planning and review.

Interagency Collaboration

Current and On Going Activities:

- Participation in interagency efforts to build a cross agency integrated data system
- On-going representation on EOHHS coordination of services efforts
- 6 state agencies serve on the Steering Committee of the Massachusetts Home Visiting Initiative led by DPH
- On-going collaboration with DEEC and DESE to enhance the Early Childhood System of services.
- 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.
- Regular collaboration with the Coordinated Case Management Program

New Initiatives:

- Collaboration with DEEC to utilize Race to the Top funding to increase health consultation and support capacity at child care programs
- Work with DEEC and DESE on a pilot to enhance data sharing by assigning a state student identifier to children participating in Early Intervention programs with the goal of tracking and evaluating educational and developmental outcomes for those children, and determining cost savings associated with the early intervention program;
- Work with the above agencies and the Federation for Children with Special Needs to ensure that families/children participating in this pilot are supported to provide informed consent to all data sharing.