



Massachusetts Department of Public Health Annual Family Support Plan - Fiscal Year 2014

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 children & youth 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

Substantial consultation to inform the DPH, Family Support plan for FY 14, was gathered in a variety of ways based on meeting families where they were at. The questionnaire (attached) was distributed at the Universal Newborn Hearing Screening Program Family Forum, at the annual Federation for Children with Special Needs conference, the Massachusetts Early Intervention Consortium Conference and at regional and local meetings, support groups and outreach events by staff of Family Initiatives projects. In addition, based on input from our parent staff about "where are the families, and how do they access and give information," a decision was taken to send the information gathering tool to all families who had received Care Coordination services from January 2012 through April 2013. This came to over 600 families. Other DPECSHN program staff all include questions about services and supports in their regular contacts with families. The methodology outlined above ensures that consultation reflects the geographic, linguistic, ethnic, cultural and socio-economic diversity of the state.

For the FY 14 plan, 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 150 families completed this

information gathering tool. Additional information was obtained as families shared their thoughts and needs with Care Coordinators and staff on the Community Support Line and the Family TIES Program.

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 this substantial consultation identified a number of areas of unmet needs. Among families for whom English is not their first language, there continues to be gaps in access to culturally and linguistically competent therapists and other health care providers. As has been the case in past years, many of the issues raised by families go beyond the DPH purview. Well over 50% of respondents cited needs for respite care for older children & youth, assistance in working with educational systems, and access to behavioral health resources.

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

Substantial consultation activities for FY 14 indicate that many families are looking for assistance with emergency preparedness for their children with complex medical needs, information about public benefits and changes that occur at different points in their children's lives and access to information about medical home and how to share this knowledge with their children's primary care providers.

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. Through the EIPLP, DPH offers a variety of opportunities that assist families to take on roles across the early childhood and special health care needs systems of care. 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.

- 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.
- Care Coordinators, Community Support Line and Family TIES staff guide families through service systems and support them 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 training and support and 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 a variety of sources to share information about programs, policy and opportunities for family engagement. These include continuation of the Family Leadership Training Institute for emerging family leaders, and a CYSHCN Face book page.
- Utilize the DPH/CYSHCN website to disseminate resources for families around public benefits and medical home that can be shared with providers.
- Develop a plan, identify resources and provide supports to assist families with emergency preparedness.

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 forming local support groups and expansion of the statewide Parent-to-Parent program. This program trains volunteer parents to offer telephone support to families with similar life experiences. To date, in FY 13, 56 Parent-to-Parent matches have been made. There are over 295 trained support parents including Mandarin, Cantonese, Haitian Creole, Portuguese, Spanish and Vietnamese speakers.

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 13, the Line received 1246 calls of which 677 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 2500 calls from families in FY 13.

Medical Home

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

Mental Health

Project Launch - utilizes a team of professional and parent partners to embed understanding of early childhood mental health into medical homes. DPECSHN maintains a focus on social emotional wellbeing both internally as a performance measure, through the MECCS (Massachusetts Early Childhood Comprehensive Systems Project) and through cross agency work to build capacity at the community level within child care programs and at state and community agencies to raise awareness and to support children with behavioral health needs and their families.

Down syndrome

Chapter 126 of the Acts of 2012, named DPH to provide families receiving a pre or post natal diagnosis of Down syndrome, "up-to-date evidence-based, written

information." In response to this mandate DPH has created, in collaboration with the Mass Down Syndrome Congress, a website with resources for families and providers - www.mass.gov/dph/downsyndrome - containing information about medical, educational, developmental, clinical and support options.

Program Supports

Family support initiatives are provided by six statewide Early Intervention Regional Consultation Programs (RCPs). To date, respite has been offered to 293 families. RCP staff provides training and on-site consultation to center-based and family child care programs and to public preschools to support the inclusion of over 200 children, 0-5 with complex medical needs.

MASSTART (Massachusetts Technology Assistance Resource Team) - DPH contracts with agencies across the state to provide consultation to school personnel and families to support the inclusion of children assisted by medical technology in public schools.

MassCARE (Massachusetts Community AIDS Resource Enhancement) provides medical, care coordination and family & youth support and training to individuals living with or affected by HIV-Aids.

The Universal Newborn Hearing Screening Program (UNHS) provided support and information to over 2150 families whose children either did not pass or missed their initial hearing screening. Of 176 infants diagnosed with hearing loss, 138 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 89,000 brochures in multiple languages, as well as 198 English and 10 Spanish Parent Information Kits. The UNHS Program has a strong focus on family support activities. In FY13, the Program hosted four events across the state which were attended by over 60 families and their children. The UNHS Program works closely with Family TIES of Massachusetts to provide parent-to-parent support. In FY 13, 15 parents of children with hearing loss were trained to be Mentor Parents in the Parent-to-Parent Program.

The Pediatric Palliative Care Program provides services to children with life limiting illnesses and their families. In FY13, 225 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 FY13 approximately 800 children and families received over \$2,000,000 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. \$110,000 was allocated for family involvement activities across the Bureau including participation in focus groups, proposal reviews, as trainers, community-based projects, attendance at conferences and other skill building opportunities and as participants in the Family Leadership Training Institute.

New Initiatives:

- A guide to web-based health literacy, developed in collaboration with the Harvard School of Public Health will be available on the DPH/CYSHCN and HSPH/MCH websites.
- Continue to recruit, train and mentor families from diverse cultures to serve as Support Parents and trainers in the P-2-P Program.
- Provide training to DPH Family Advisors to participate in policy development and RFR reviews.

Accessing Services and Supports

Current and On-going Activities:

The Department utilizes a number of strategies 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. The Universal Newborn Hearing Screening Program (253 likes), CYSHCN Program (70 likes) and the EIPLP (175 likes) have active Face book pages which post articles, ideas and links to local, statewide and national sites with interesting and helpful resources for families whose children have special health needs. 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 FY13, 29 parents received personalized TA and training from this Specialist. Staff from Early Intervention, 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, 1100 Family TIES Resource Directories, 5500 project brochures in English, Spanish and Portuguese and eight editions - four hard copy and four electronic of the ***Parent Perspective***

have been distributed to families and professionals. These materials are available for down-load on Project websites. In FY 13, PLP staff developed and delivered training and support to families whose children are enrolled in EI to develop their leadership capacity as Parent Contacts at their EI programs. DPECSHN 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 DPECSHN 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:

- Participants in the Family Leadership Training Institute will identify and implement community based projects to share information with other families and improve systems of care.
- DPECSHN programs will grow their capacity to distribute resources, information and support via social networking.

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. As part of a major focus on outreach to underserved groups, 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, the Vietnamese Community Centers in Boston and Worcester and Haitian Community Center in Boston, sharing information about community resources and the availability of flexible family supports.

The EIPLP hosts families to attend the annual Massachusetts Early Intervention Consortium Conference. In FY 13, close to 1/3 of families attending the Conference were from diverse communities.

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.

New Initiatives:

- Engagement of families from culturally and linguistically diverse communities to serve as Advisors to DPECSHN.
- 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 - Awaiting funding for implementation.
- Completion of Interagency Memorandum of Understanding (MOU) Concerning Early Childhood Programs. The document replaces the 1994 Interagency Agreement on Transitions and reflects a cross-systems approach to strengthening collaborations for developing local and/or regional agreements (local MOUs) to enhance services for young children and their families.
- 6 state agencies serve on the Steering Committee of the Massachusetts Home Visiting Initiative led by DPH
- 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.
- Collaboration with DEEC to train and place mentors in child care settings to support physical activity and nutrition to combat childhood obesity.
- 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 with children diagnosed with hearing loss
- Participation in the Children's Vision Massachusetts Advisory
- Regular collaboration with the Coordinated Case Management Program

New Initiatives:

- Participation on a cross agency working group of Early Childhood leaders working to enhance the system of mental health care available to young children and their families.

- Development of a Toolkit for clinical sites to embed mental health knowledge and supports into the medical home.
- Leadership of a cross agency training partnership to increase resources to support social-emotional well being of young children and their families and to respond to complex behavioral needs of these children.
- MECCS will develop four part training for providers to support them in their care of young children exposed to trauma and those living with parents with substance abuse, mental health and cognitive and intellectual disabilities.
- Collaboration with the Office of Refuge and Immigrant Health to expand outreach to underserved, culturally and linguistically diverse populations.
- Continuing work with EOE and DESE to promote data sharing to track and evaluate educational and developmental outcomes for children in Early Intervention and the public schools. In FY14, a restoration of funding will allow this activity to continue.
- In collaboration with the Federation for Children with Special Needs work to ensure that families/children participating in activities to share data are supported to provide informed consent to all data sharing.

**Department of Public Health (DPH)
Chapter 171 Family Support Plan Information-Gathering Survey**

This survey asks about how your child's health care and health related needs are met

1. Right now, what is your child's/family's most important unmet or under-met **health** need?

2. Please check the DPH programs you have used in the past 2 years:

- | | |
|---|---|
| <input type="checkbox"/> Care Coordination Program | <input type="checkbox"/> Catastrophic Illness in Children Relief Fund |
| <input type="checkbox"/> Community Support Toll Free Line | <input type="checkbox"/> New Parents Initiative |
| <input type="checkbox"/> Early Intervention Project | <input type="checkbox"/> Early Intervention Parent Leadership Project |
| <input type="checkbox"/> Family Initiatives | <input type="checkbox"/> Early Intervention Partnerships Program |
| <input type="checkbox"/> Family TIES* | <input type="checkbox"/> Regional Consultation Program |
| <input type="checkbox"/> F.O.R. Families Program | <input type="checkbox"/> MASSTART |
| <input type="checkbox"/> Pediatric Palliative Care | <input type="checkbox"/> Universal Newborn Hearing Screening Program |
| <input type="checkbox"/> Medical Review Team | <input type="checkbox"/> Hearing Aid Program for Children |
| <input type="checkbox"/> MassCARE | <input type="checkbox"/> SSI & Public Benefits Training & Assistance |
| <input type="checkbox"/> Other _____ | <input type="checkbox"/> None |

**A DPH funded project of the Federation for Children with Special Needs*

3. Have the services and supports you received from the DPH been family-friendly and easy to access? Yes____ No____ I have not used any DPH services or supports____

4. Do you have suggestions about how DPH could make services more family-friendly and easy to access? Describe: _____

The Department of Public Health works to promote **Medical Home** (*an approach to providing high-quality health care and related services to children and families that is community-based, family-centered, accessible, available and culturally competent*). In a Medical Home, families and providers work together to identify and access the medical and non-medical services that help children and youth reach their full potential.

5. Does your child receive care that meets this definition? Yes____ No____ Not Sure____

6. Does your child's Primary Care Provider listen to you and make you feel like a partner in your child's care? Yes____
No____ Sometimes____
7. [If you answered Yes or Sometimes to Question 6]: Does partnering with your child's Primary Care Provider improve his/her health and quality of life? Yes____ No____ Not Sure____

-OVER-

The Department of Public Health works to support youth, families and providers around Health Transition. **Health Transition** includes moving from pediatric to adult health care providers and learning how and beginning to take greater responsibility for one's own health care.

**If your child is 14 or older, please answer questions 8, 9 and 10.
If your child is under 14, go to question 11.**

8. Has your child's primary care provider talked to you and your child about Health Transition? Yes____ No____ Not Sure____
9. Has your child begun to learn how to manage her/his health needs? Yes____ No____
10. Have you received information about changes in public benefits (e.g. SSI, MassHealth) or legal rights that will occur when your child turns 18? Yes____ No____

Emergency Planning can include developing a family emergency plan, preparing a disaster kit, or completing and filing a (911) Disability Indicator Form, among other things.

11. Have you done any Emergency Planning for your child and family? Yes____ No____
12. If yes, what types of planning have you done? If no, what support do you need to help you prepare for emergencies?

Anything else?

13. Is there anything else you would like to tell us about how DPH can improve health related services?

Optional:

Age/diagnosis of child(ren)_____

Check here if you would like to be an advisor to DPH

If you want more information or are interested in advising DPH about programs and services, please provide :

Name:_____

Phone:_____ Email:_____

Mailing Address:_____

Check below if you would like additional information about:

Emergency Planning Medical Home Health Transition

THANK YOU!