



Massachusetts Department of Public Health Annual Family Support Plan - Fiscal Year 2015

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), is comprised of many programs serving children and youth and their families including the Massachusetts Maternal & Child Health (MCH) Title V Division for Children & Youth with Special Health Needs (DCYSHN). The DCYSHN 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 needs identified by families/consumers. To ensure that this commitment is realized, 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 information and referral to resources to assist families in the care of their children with special health needs as well as 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 Divisions of Early Intervention (EI) and Children & Youth with Special Health Needs (CYSHN) 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 CYSHN 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 15, was gathered in a variety of ways. We go to families, meeting them where they comfortable and most likely to spend time. We begin dissemination of the information gathering questionnaire (attached) at the annual Federation for Children with Special Needs conference, attended by several hundred parents. Family Initiatives staff meets families at regional and local meetings, support groups and outreach events asking for their input. As parents of CYSHN themselves Family Initiatives staff keep the Program informed about "where are the families, and how do they access and give information," which dictates distribution strategies. For FY 15, the information gathering tool was available on-line, mailed to over 400 families who had received Care Coordination services from April 2013 through March 2014 and administered over the phone to families calling our toll free lines Other DCYSHN program staff all include questions about services and supports in their regular contacts with families and in their individual program evaluation efforts. The methodology outlined above ensures that consultation reflects the geographic, linguistic, ethnic, cultural and socio-economic diversity of the state.

For the FY 15 plan, the 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 165 families completed this information gathering tool. Additional information was obtained as families shared their thoughts and needs with Care Coordinators and staff of the Community Support Line and the Family TIES Program.

Families were provided with a list of all DCYSHN programs and asked about their knowledge of these programs, their health care and health related needs and whether services and supports are delivered in a family-centered, family-friendly way. We asked 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 or wanted help in preparing for emergency situations.

Results of this substantial consultation identified a number of areas of unmet need. Most strongly, over 60% of families indicated the necessity for current and timely information about resources and supports and the need to “get the word out,” using a multi-media approach – telephone, emails, websites and social media. As several families put it, “the old ways of getting out information, aren’t enough, it’s time to update.”

38% of families said they had no knowledge of Medical Home, while 20% of respondents said they were not sure enough about whether the care their children received met this definition to offer an opinion. A synthesis of family comments gave us the following;

- “Why don’t I know about this concept? I haven’t heard about it from my child’s pediatrician or from DPH.”

Over 66% of respondents indicated that they had done no emergency planning for their families and children with complex medical needs and 82% said they wanted more information and support to be able to do so.

An on-going theme that emerges from the substantial consultation activities is that children and families may need or receive services across multiple agencies. Trying to parse out their health-related needs from many others can be difficult and leads families to request better communication and coordination among service providers as well as the understanding that we need to look at the whole child and family when planning services and supports.

As one agency DPH cannot respond to all the needs that come from substantial consultation. DPH/DCYHSN 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

Two key areas of emphasis consistent with Public Health priorities have emerged from information obtained through Substantial Consultation activities around which we will focus the activities of the for FY 15 Chapter 171 Family Support Plan. The first is to identify and implement a variety of strategies to share

information about Maternal & Child Health broadly and about services and supports for CYSHN in particular. Secondly, we will expand and enhance the provision of information about and continue to promote the importance of the medical home approach to care. In addition, we will continue efforts that were started last year to support the many families looking for assistance with emergency preparedness for their children with complex medical needs.

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), a program of the Federation for Children with Special Needs, funded by and in collaboration with DPH is 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.
- Family Leadership Training Institute – a pilot program offered to 19 emerging family leaders to grow their skills to participate in systems change activities.
- 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 and training needs and best uses of flexible funds 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:

- Build on past and existing initiatives to promote the medical home approach to care – a coordinated, comprehensive, accessible system of care that meets the health care and related needs of children and families. Share information, resources and training opportunities with families, community based organizations and health care providers.
- Work with the DPH Communications Office, guided by input from families to develop a variety of ways to effectively disseminate information about the Title V CYSHN program, the supports and resources available and how to access them
- Utilize multi-media approaches to information sharing. We will develop videos that support families' emergency preparedness efforts
- Share findings from the Family Leadership Training Institute and look for funding to continue to implement the training.

Family Support Resources and Funding

Current and On-Going Activities:

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. This year, 80 Parent-to-Parent matches have been made. **“Listen and Learn”** the training program for mentor parents is available in Chinese, Vietnamese, Haitian Creole, Portuguese and Spanish. Currently there are 300 trained support parents. DCYSHN direct service staff provides information about and referral to resources, public benefits and navigating the health care system. When families need information and support from other agencies, staff assist them to identify which agency would have primary responsibility for their presenting issue and facilitates connections with these agencies. DCYSHN 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 CYSHN and their providers. In FY 14, the Line received 1308 calls of which 705 were from families. Social workers on the line offer information about state wide resources, public benefits, and other DPH programs 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 14.

Medical Home

DCYSHN continues to promote the spread of Medical Home at the community level. With the conclusion of the CHIPRA project (Children's Health Insurance Program Reauthorization Act) DPH Care Coordinators who had been placed in the 13 CHIPRA practices have returned to the DPH regional offices. They work with eligible families in their communities, schools and health care settings. The DPH Medical Home Facilitator offers training and support to pediatric practices and their family partners striving to increase their ability to provide a medical home. Currently 17 family members serve as Family Partners.

Mental Health

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

Down syndrome

In accordance with Chapter 126 of the Acts of 2012, which named DPH to provide families receiving a pre or post natal diagnosis of Down syndrome, "up-to-date evidence-based, information for providers and families.," DCYSHN continues to work in collaboration the Mass Down Syndrome Congress to monitor and update the website of resources - www.mass.gov/dph/downsyndrome

Early Intervention

Family support initiatives are provided by six statewide Early Intervention Regional Consultation Programs (RCPs). To date, 582 requests for respite have been approved. 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 children, 0-5 with complex medical needs. The Early Intervention Parent Leadership Project collaborates with the RCPs to provide socialization and networking opportunities for families whose children have complex medical needs.

Other DCYSHN Programs

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 supports and training to individuals living with or affected by HIV-Aids.

The Universal Newborn Hearing Screening Program (UNHS) provided support and information to 2900 families whose children either did not pass or missed their initial hearing screening. Of 200 infants diagnosed with hearing loss, 143 or 71.5% 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 78,060 brochures in multiple languages, as well as 339 English and 47 Spanish Parent Information Kits to families and providers.

The UNHS Program has a strong focus on family support activities. In FY14, the Program hosted three in person events across the state which were attended by 50 families and their children, offered two conference calls and provided financial support for 12 families to attend conferences. The UNHS Program works closely with the Office of Family Initiatives and its Family TIES Program to provide parent-to-parent support. There are currently 15 parents of children with hearing loss trained to be Mentor Parents in the Parent-to-Parent Program.

The Pediatric Palliative Care Program (PPCN) provides services to children with life limiting illnesses and their families. In FY14, 364 children and their families – an increase of 46% over FY 13 - received palliative care services including, pain and symptom management, case management, respite, complementary therapies and bereavement care. Working with the EIPLP, the Program recruited and supported three families who use the PPCN to create digital stories describing their experiences.

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 FY14 over 1000 children and families received approximately \$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. \$100,000 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:

- In depth analysis of data obtained from the National Center for Special Education Accountability and Monitoring Family Survey (NCSEAM) will be used to improve family outcomes and satisfaction with Early Intervention services.
- Families will participate in proposal review for the Early Intervention re-procurement process
- Pediatric Palliative Care Program will recruit, mentor and stipend families to serve in advisory roles
- Extensive resources concerning health care and health related transition for youth with special health needs, their families and providers will be added to the DPH website.

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 (337 likes), CYSHN Program (162 likes) and the EIPLP (292 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. These programs work together regionally to ensure that family needs are met. 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 FY14, 49 parents received personalized TA and training from this Specialist. Community Support Line, Family TIES and EIPLP all maintain toll free numbers. Family TIES and EIPLP also host web-sites and list servs. Family TIES distributes over 2000 Resource Directories, 7500 project brochures in English, Spanish and Portuguese annually. Eight editions - four hard copy and four electronic of the ***Parent Perspective*** have been distributed to over 11,000 families and professionals. These materials are available for down-load on Project websites.

DCYSHN program information, including the Family Support Plan is available on-line at www.mass.gov/dph/specialhealthneeds CYSHN Program brochures and magnets are widely disseminated and available in English, Portuguese and Spanish.

There is interactive capability on the DPH website and on BFHN project sites for families to offer feedback and suggestions.

New Initiatives:

- Collaborate with EOHHS and DPH to offer the Family Leadership Training Institute to emerging family leaders.
- Develop and disseminate new informational materials such as a one page description of the MCH Block Grant
- Development of additional digital stories and videos to assist families around youth transition and emergency preparedness

Culturally Competent Outreach & Support

Current and On-going Initiatives:

Collaboration with the Office of Health Equity is on-going within the DCYSHN. 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, MAPS serving Portuguese speaking families and the 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. The Project has a strong focus on recruiting families 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. DCYSHN programs continued to utilize the Office of Health Equity telephonic interpreter services line.

New Initiatives:

- The NCSEAM Family Survey will be available in Portuguese, Haitian Creole and Vietnamese
- On-going work to ensure culturally appropriate opportunities for participation for families from culturally and linguistically diverse communities.
- Collaboration with Health & Disability Program at DPH around transition activities for youth with special health needs.

Interagency Collaboration

Current and On Going Activities:

- Implementation of a pilot project with EOE, DESE and the Federation for Children with Special Needs for data sharing to track and evaluate educational and developmental outcomes for children in Early Intervention and the public schools.
- Implementation of Massachusetts Home Visiting Initiative efforts in collaboration with 6 state agencies, including “ **Welcome Family**” in two pilot communities offering home visits to new parents.
- 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 the Office of Refuge and Immigrant Health to support children and youth with special health needs from culturally and linguistically underserved populations.
- 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.
- Participation in an Oral Health Task Force, to provide information about the oral health needs of CYSHCN.
- 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
- Participation in Special Quest- an early childhood inclusion initiative and Act Early, the state's autism awareness team
- Support for the Autism Insurance Resource Center at the Shriver Center
- Regular collaboration with the Coordinated Case Management Program

New Initiatives:

- Continuing work with EOE and DESE to bring SSAID pilot, currently in place at 7 Early Intervention Programs to scale. This effort, based upon Governor Patrick's approval of FY 15 budget will be funded at \$400,000.
- Submission of a ***State Implementation Grant for Enhancing the System of Services for Children with Special Health Care Needs through Systems Integration*** to the Maternal & Child Health Bureau in partnership with EOHHS, Mass Health, the Family-to-Family Health & Information Center at the Federation for Children with Special Needs, Mass Chapter of the AAP, Commonwealth Medicine at U Mass Medical Center and others.
- The Department of Public Health has played a major leadership role in addressing the ongoing opiate epidemic in the Commonwealth. Within this context, significant growth has occurred in the number of women giving birth to infants who are drug exposed in utero and must go through detoxification process. These infants are generally classified as falling within the Neonatal Abstinence Syndrome (NAS). DPH has identified both intra-agency strategic (Bureau of Substance Abuse and Early Intervention) and inter-agency relationships (DCF) to address both infant and family issues.

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. 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 |
| <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*

2. 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____
3. 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.

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

6. [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.**

7. Has your child's primary care provider talked to you and your child about Health Transition?
Yes____ No____ Not Sure____
8. Has your child begun to learn how to manage her/his health needs? Yes____
No____
9. 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.

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

Anything else?

12. 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!