August, 2015

Steven T. James
House Clerk
State House Room 145
Boston, MA 02133

William F. Welch
Senate Clerk
State House Room 335
Boston, MA 02133

Dear Mr. Clerk,

Pursuant to Section 16F of Chapter 6A of the Massachusetts General Laws, the attached plan details how the Department of Public Health intends to provide flexible supports to families and individuals with disabilities and chronic illnesses.

Sincerely,

Monica Bharel, MD, MPH
Commissioner
Department of Public Health
Massachusetts Department of Public Health
Annual Family Support Plan

A Plan to Support to Individuals with Disabilities and Their Families - Fiscal Year 2016

August 2015
Background

The Massachusetts Department of Public Health (DPH) promotes 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.

Within DPH, the Bureau of Family Health and Nutrition (BFHN), houses 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, which is on-going, 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

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, (OFI) 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 FY16, was gathered in a variety of ways. As a program funded by the MCHB Block Grant, the Title V program is mandated to conduct a comprehensive, state-wide Needs Assessment every five years. Most consultation for the FY16 Family Support Plan was gathered through this Needs Assessment process which consisted of multiple focus groups and an on-line survey. 569 families of children & youth with special health needs completed the survey which was available in English and Spanish. (Attached) In addition, five focus groups, two in English, two in Spanish and one in Vietnamese were conducted. 900 families attending the annual Federation for Children with Special Needs conference in March 2015 were offered the opportunity to complete the survey on-line on or paper. Links to the survey were disseminated broadly to stakeholders and organizations serving families of CYSHN. OFI staff met families at regional and local meetings, support groups and outreach events asking for their input. As parents of CYSHN themselves, they advise OFI as to; "where the families are, and how they access and give information," which informs distribution strategies. For FY16, the Needs Assessment survey was available on-line, mailed with a self-addressed stamped return envelope to 200 families and administered over the phone to families
calling our toll free lines. Other DCYSHN program staff 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. 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-directed way. They were also asked whether or not their children received care in a Medical Home, if they received information and support for health related transition, how they got information about community resources and parent-to-parent support opportunities and if they had made any preparations or wanted help in preparing for emergency situations. In addition, survey respondents rated their interest in a number of core public health issues.

66% of families said they had not heard of the Medical Home approach to care and 45% said their children did not receive care that met the definition provided. Disparities between white, non-Hispanic and Hispanic responders were pronounced, as illustrated by comments such as:

“I didn’t know it was okay to ask questions or not agree with my child’s doctor.”
“How can I get care like this for my family?”
“Where do I even find providers who speak my language and understand my culture?”
“Should my health care provider be helping me to find community resources?”

Another area where respondents identified gaps and needs was in planning for transition from the pediatric to adult health care system and in receiving support to assist their CYSHN to learn and practice, as developmentally appropriate, health self-management skills

“It’s like you need a treasure map to FIND these services. None of the providers we worked with knew about them.”
“I hear about programs or resources ONLY through other parents. I am ashamed to say that no doctor, social worker in our hospital, of which we spend a lot of time in has EVER suggested any type of resource.”
“Our son is 24 years old and still seeing his pediatrician.”
“Without me being present, our son’s medical needs would not be met. He has not learned how to ask or answer question. There should be a program that helps young adults learn these skills.”

An on-going theme that emerges from the substantial consultation activities is that children and families may need or receive services from 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 need to look at the whole child and family when planning services and supports.

As the recent recipient of a 3 year Maternal & Child Health Bureau Systems Integration Grant, the Department of Public Health is working to address this oft-stated request for coordination and integration. As part of the grant, DPH has
brought together a Steering Committee of stakeholders from a number of agencies and organizations to assist in making the system of care more coordinated and responsive. All members share information about family needs to identify and address integration opportunities.

**Focus Areas**

In response to the information obtained through substantial consultation, DPH will focus the FY16 Chapter 171 activities in two main areas: increasing knowledge of and access to care within a Medical Home, and supporting families, youth and providers around transition to adult health care, including acquisition of self-management skills. The two goals align with both our Systems Integration Grant aims and Maternal and Child Health Block Grant performance measures to:

- *Increase the % of children with and without special health care needs who receive services necessary to make transitions to adult health care.*
- *Increase the % of children with and without special health care needs having a medical home.*

Specific activities designed to raise awareness of and promote care within a Medical Home will be:

- **Development of a Medical Home website which will have information, links and resources for families and providers**
- **Inclusion of Medical Home Family Fact Sheets in Parent Information Packets distributed by the Universal Newborn Hearing Screening Program.**
- **Incorporation of information about the medical home approach to care by Family TIES in all their presentations and include Medical Home Family Fact sheets available in 6 languages in packets sent to callers.**
- **Targeting and strengthening relationships with CBOs that serve Spanish speaking families and share information about the medical home approach to care.**

Transition related activities planned for FY 16 include:

- **Developing stronger relationships with all DPH youth serving programs to ensure that the needs of CYSHN are represented**
- **Targeting Specialty Service Clinics at tertiary hospitals and sharing transition resources, parent and youth tip sheets and information about changes in public benefits and insurance when children become 18**
- **Identifying two to three youth with special health needs who will create digital stories that highlight transition issues, resources and successes.**

**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 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, all of whom 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 – run for the second time in 2015, the Institute offered 12 emerging family leaders a more intensive opportunity to grow skills that support them 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 Family to Family Health Information Center, PPAL and Mass Families Organizing for Change 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.
- Survey Primary Care Pediatricians to assess their knowledge of Title V resources and how often they refer to the program.
- Run another session of the Family Leadership Training Institute and target families from diverse communities as trainees.

**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, 94 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 315 trained support parents. DCYSHN direct service staff provide information about and referral to resources, public benefits and navigating the health care system. In response to an informational need articulated by families providing substantial consultation to the Chapter 171 Plan, a brochure, “A Bridge to Adult Health Coverage and Financial Benefits” (Attached) was developed, which explains changes in public benefits at age 18...

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 facilitate connections with these agencies.

BFHN maintains a toll free Community Support Line available to families of CYSHN and their providers. In FY 15, the Line received 861 calls of which 423 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 4000 calls from families in FY 15.
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 the families’ 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 25 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 MCH Block Grant priority, 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). In FY 15, $268,039.45 was allocated for respite and family support. To date, 580 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. In FY 15, the state-wide Early Intervention system was re-procured. Family members served on each review team to share their perspective.

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 2228 families whose children either did not pass or missed their initial hearing screening. Of 157 infants diagnosed with hearing loss, 120 or 76.4% 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 information about community and statewide resources. In FY15, 95,050 brochures in multiple languages, as well as 358 English and 49 Spanish Parent Information Kits were distributed to families and providers.

The UNHS Program has a strong focus on family support activities. In FY15, the Program hosted three in person events across the state which were attended by 46 families and their children, offered a conference call and provided financial support for 16 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 FY15, 408 children and their families received palliative care services including, pain and symptom management, case management, respite, complementary therapies and bereavement care. Digital stories created by families who used the PPCN were made available on-line, at PPCN provider meetings and at an ICC meeting.

Flexible Funding

In addition to these programs and services, the DPH makes 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 FY15 over 1000 children and families received close to $2,000,000 in funding from the Catastrophic Illness in Children Relief Fund (CICRF), Care Coordination Family Support, 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, in proposal reviews, as trainers, in community-based projects, attendance at
conferences and other skill building opportunities, and as participants in the Family Leadership Training Institute.

New Initiatives:

- Using data extracted from the National Center for Special Education Accountability and Monitoring Family Survey (NCSEAM) by DPH epidemiologists and an intern from the Harvard School of Public Health, DPH will engage stakeholders in identifying and implementing strategies to increase family participation in Survey returns.

- Extensive resources concerning health care and health related transition for youth with special health needs, their families and providers will be completed, approved and made available on the DPH website and disseminated to the public.

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. All staff present regularly at conferences and to community groups. The Universal Newborn Hearing Screening Program (423 likes), CYSHN Program (374 likes) and the EIPLP (367 likes) have active Facebook 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 FY15, 95 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 serves. Family TIES distributes over 2000 Resource Directories and 8000 project brochures in English, Spanish and Portuguese annually. Six editions, three hard copy and three 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 online 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:**

- Expand access to electronic resources through DPH and project web sites, publicizing Facebook pages and Twitter accounts.
- Pilot a texting program to EI Parent contacts
- Develop 2-3 “PSAs” as a recruitment tool for the Family Leadership Training Institute.
- Develop topic-specific digital stories and videos as awareness raising and outreach tools.
- Develop materials to raise awareness of the Individual Health Care Plan (IHCP) for children with special health needs.

**Culturally Competent Outreach & Support**

*Current and On-going Initiatives:*

Collaboration with the Office of Health Equity is on-going within the DCYSHN. OHE provides resources and technical advice on the application of the national CLAS (Culturally & Linguistically Appropriate Services) standards to ensure that programs are able to integrate and use the standards effectively  
(http://www.mass.gov/eohhs/docs/dph/health-equity/clas-intro.pdf). 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, including those fluent in American Sign Language. 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. In FY15, Family TIES staff began targeted outreach to under-served populations to share information about the Medical Home approach to care.
The NCSEAM Family Survey was made available in Haitian Creole, Portuguese and Vietnamese in addition to English and Spanish. In calendar year, 2014, close to 4000 Surveys were completed and returned. These included 778 in Spanish and 23 in the new languages available.

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 and Parent-to-Parent support are available in Spanish, Portuguese, Chinese and Vietnamese. The EIPLP newsletter parent articles 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 telephonic language lines provided by the department.

New Initiatives:

- Work with EI programs to increase distribution of the NCSEAM Family Survey in multiple languages.
- Develop a webinar about Cultural Competence for families.
- Recruit Family Advisors from diverse cultures by creating a climate and expectations that respect cultural norms.
- Develop an “each one, bring one” program as a family to family approach to growing a diverse group of advisors.

Interagency Collaboration

Current and On Going Activities:

- Implementation of a pilot project with EOE, DESE and the Federation for Children with Special Needs to assign SSAID numbers with parental consent at seven EI programs for data sharing to track and evaluate educational and developmental outcomes for children in Early Intervention and the public schools.
- Development of federally mandated State Systemic Improvement Plan (SSIP) for Early Intervention services.
- Completion of year one of a an MCHB State Systems Integration Grant for Enhancing the System of Services for Children with Special Health Care Needs, resulting in the formation of a 16 member Steering Committee with representation from multiple agencies and organizations including EOHHS, Mass Health, the Family-to-Family Health & Information Center at the Federation for Children with Special Needs, Mass Chapter of the AAP, League of Community Health Centers, Commonwealth Medicine at U Mass Medical Center and others.
- Receipt of an MCHB Workforce Development Grant that brings together stakeholders from multiple agencies to support pediatric primary care
practices to provide a continuum of care that includes integrating behavioral health

- Implementation of “Welcome Family,” a home visiting program to new mothers currently available in four communities.
- 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 for the purpose of combatting childhood obesity.
- Continued partnership with the 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:

- Next level of work on the State Systems Integration Grant to address three project aims: Cross Systems Care Coordination, policy level systems integration and development of a shared resource.
- Participation in the DaSy Center’s Family Data Institute in partnership with DPH, DESE and the Federation for Children with Special Needs.
- The Department of Public Health will continue to have a major leadership role in addressing the ongoing opiate epidemic in the Commonwealth through both intra-agency strategic (Bureau of Substance Abuse and Early Intervention) and inter-agency relationships (DCF) to address both infant and family issues.