

**Massachusetts Department of Public Health
Annual Family Support Plan - Fiscal Year 2010**

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 to reduce the impact to 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) offers a number of programs providing services to individuals with disabilities and their families. Following the enactment of **Chapter 171 of the Acts of 2002: An Act Providing Support to Individuals With Disabilities and Their Families**, the Bureau actively examined existing programs to assess their level of meaningful family involvement. In addition, family/consumer input was sought to identify ideas about how programs and services could become more responsive and provide more flexible supports.

Overwhelmingly, individuals with disabilities and their families indicated their primary public health concern to be assistance with planning for and managing their complex medical and technological needs in the event of local, regional, statewide and/or national emergency. The Department response to this need formed the basis of our FY'04 Family Support Plan. In FY05, DPH conducted statewide Family Focus Groups that gave families whose children have special health care needs (CSHCN) the opportunity to share their concerns, hear what DPH was planning concerning emergency preparedness and gather resources to assist in developing emergency plans for their children and families.

FY06 activities that arose from the previous year's Family Focus Groups included development and publication of Frequently Asked Questions (FAQS) about emergency preparedness issues, dissemination of over 300 hundred packets of materials to support emergency planning and facilitation of community based disaster planning meetings. BFHN joined with other DPH programs working on emergency preparedness in developing plans to respond to pandemic flu and disseminated materials to families whose children have complex special health needs.

In response to substantial consultation gathered from consumers, FY07 work continued to offer support around emergency preparedness. This included facilitation of community based meetings bringing together local first responders, school departments, local health officials, ADA coordinators, families whose children have complex special health care needs and other community members to share information and begin a collaborative emergency planning process. In addition, the Family Initiatives program worked with other state agencies and programs to train staff around strategies to support families in their emergency planning efforts. PowerPoint presentations and materials were created and delivered to over 150 parents and professionals. In addition, 1000 packets of family friendly materials were created and disseminated.

Fiscal Year 08 work, based on input offered by families addressed issues of raising awareness of DPH resources and supports, disseminating up-to-date information about DPESCHN programs and collaborating with other DPH programs to embed knowledge of the needs of CYSHCN into these programs.

To better respond to family/consumer identified needs, in Fiscal Year 09, the Title V Children and Youth with Special Health Care Needs program (CYSHCN) embarked on a strategic planning process aimed in part at expanding outreach to ensure that all families whose children have special health needs were aware of and able to access our Public Health programs. New and more family-friendly outreach materials, better internal linkages to facilitate a single point of entry for services and an increased awareness of cultural competence make our programs more responsive to underserved populations, addressing family concerns and the DPH commitment to reducing health disparities.

Overview of Family Support

The DPH retains its long history of commitment to effective, collaborative partnerships with families and works to ensure that all programming is family-centered and responsive to family/consumer articulated needs. To ensure this strong focus on family-centered services, the BFHN supports a full-time position, Director of Family Initiatives. The incumbent'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;
- 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

In addition to the broad range of public health programs and services available to families throughout the Commonwealth, the DPH is able to make some flexible funding available to families to address medical and other health-related needs not covered by other sources. Special funds help eligible families purchase (among other things) hearing aids, medications, assistive technology, respite services, home and vehicle modification and reimbursement for travel expenses incurred for the care of their children with special health needs. Funds are disseminated through DPH vendors and in some cases, from DPH directly to families. In Fiscal Year 2009, approximately 1000 families received over \$2,600,000 in funding from the Catastrophic Illness in Children Relief Fund (CICRF), Early Intervention Regional Consultation Program Respite Allocation, Care Coordination Family Support funding, Epilepsy Drug program and the Hearing Aid Program for Children. Close to \$75,000 was allocated for family involvement activities across the Bureau including participation in focus groups, proposal reviews, as trainers, community-based projects and attendance at conferences and other skill building opportunities.

Process for obtaining "substantial consultation" from families regarding flexible support needs

DPH employed a variety of mechanisms to gather information from families/consumers about their support needs. In FY09, staff from Office of Family Initiatives projects attended conferences and regional and local meetings where families whose children have special health needs were gathered. Staff met families from Pittsfield to Nantucket to obtain a picture of the geographic diversity of need in the state. In addition, questionnaires were distributed and explained at community outreach visits and skill building sessions. Questionnaires were available in both English and Spanish. Requests for information were also made to Portuguese speaking callers to the Family TIES toll free 800 line. All families were asked about unmet/under-met health needs, experiences with DPH programs, knowledge of health care transition, need for support around emergency preparedness, how they obtain information about resources and supports and how best DPH could provide assistance. Every family interview included questions about how family-centered were the services received from BFHN programs and what could be done to make services more family friendly. The questionnaires allow families to indicate any other information they feel DPH needs to know in order to ensure that programs and services are flexible, family-directed and meet their needs.

Additional information was obtained through the following mechanisms:

- Questions on a survey disseminated at the annual Federation for Children with Special Needs conference; (800 participants 193 surveys returned)
- Questions included in calls received by the Family TIES project, the statewide Information and Referral and Parent-to-Parent program;
- Questions posted to the Family TIES and Early Intervention Parent Leadership Project websites;
- Survey questionnaires sent to over 100 families who indicated a desire to serve as advisors to BFHN and DPECSHN;
- Questions included in calls received by the DPH Community Support Line;
- Discussions between care coordinators and their client families; and
- Information gathered by the DPH Public Benefits Specialist during her talks and trainings with individuals and families statewide.

Face to face contact was made with over 150 families. Information from these families as well as an additional 200 who responded to questionnaires was used to develop our FY10 plan. Families continued to tell DPECSHN that their primary need was for reliable, accessible, knowledgeable and up-to-date information about resources, public programs and supports. As the year progressed, increasing numbers of families communicated with DPH about the effect of the economic downturn on their ability to care for their children with special health needs. Many of the issues that families raised in person, on the phone and on questionnaires go beyond the DPH purview, although most related to the on-going message families consistently share with DPH which is:

"Human Service agencies please provide coordinated, easy to access services that bypass individual agency eligibility criteria and recognize the whole child and whole family."

The following table illustrates needs expressed by families

Needs expressed by families for which DPH has primary responsibility ↓	Needs expressed by families outside DPH purview & resources ↓	Needs expressed by families for which multiple agencies are responsible ↓
Strategies to facilitate communication between primary and specialty health care providers	Behavior supports including ABA and biomedical therapies for children over three	Respite
Access to information and short term care coordination when needed	Speech, occupational and physical therapies for children on the Autism Spectrum beyond that provided by health insurance and public schools	Education for health care providers about low incidence disabilities and other health issues of CYSHCN
Information for primary care providers about DPH resources specific to CYSHCN	Funding for and connection to educational advocates	Independent living skills, health care self management
Inclusion of the needs of CYSHCN into core public health programs such as nutrition, physical activity and violence prevention	Expanded mental health resources	Support for transition from pediatric to adult health care system
Support for the purchase of hearing aids and cochlear implants	MCAS support	Support for alternative and complementary therapies such as hippo and message therapy
Oral health resources for CYSHCN	Therapeutic afterschool programming	Easier access to and funding for Durable Medical Equipment
	Community recreational opportunities	Planning for long term care needs of CYSHCN
	Food stamps and housing support	Expanded insurance coverage for specialized services
	Family Counseling	Turning 22 supports for youth with complex medical needs
	Availability of Personal Care attendants	

In FY10, DPH/DPECSHN will continue to pursue partnerships with agencies and organizations that can address these family articulated needs including but not limited to, the Department of Elementary and Secondary Education, Department of Developmental Services, the Mass Chapters of the American Academy of Pediatrics and Family Physicians, Massachusetts Developmental Disabilities Council and the LEND (Leadership Education in Neuro-developmental Disabilities) programs at the University Centers on Disabilities at U Mass.

Focus Areas

I Family Empowerment

Current and On-going Activities:

Programs within the Department of Public Health seek input from practitioners, academics, consumers/families and other stakeholders via Advisory Boards. Boards generally meet at least quarterly and transmit information regarding community and individual needs directly to DPH. In FY09, Commissioner Auerbach conducted another round of meetings statewide to gather information from the community about DPH programs and services, unmet needs, ideas for improvement and to introduce new initiatives such as Mass in Motion. In addition, the following illustrate other ways the DPH promotes family participation in policy development and program planning within the BFHN:

- The Bureau applies for and receives funding from the Federal Bureau of Maternal and Child Health (MCHB) that supports many programs for women and children. Federal regulations stipulate that 30% of the funding from this Block Grant is spent meeting the needs of children with special health care needs (CSHCN) and their families. To ensure responsive, family-centered, community-based services, families of CSHCN are invited to learn about the Block Grant, participate in needs assessment activities, offer information and suggestions based upon their individual family needs and review the application prior to submission to MCHB.
- With Federal Individuals with Disabilities Education Act (IDEA), Part C (services to children 0-3) funding, the DPECSHN supports the Early Intervention Parent Leadership Project (EIPLP). This parent-designed and run project reaches out to families whose children receive Early Intervention services and offers them opportunities for leadership and lifelong advocacy skills development. Parents are encouraged and supported to partner with their own EI programs at regional early childhood events; on the state level as advisors to the DPH; as members of the federally mandated Interagency Coordinating Council (ICC) and nationally to share information about Massachusetts and to learn and bring home information from other states about opportunities for families to impact and help define services systems. DPH EI staff conduct focused monitoring activities at the program level that includes input from families. In FY09, two family members began terms as tri-chairs of the ICC with an EI provider serving as the third tri-chair. These parents, as well as other ICC parent members received extensive skill building and mentoring from DPH to support them in carrying out their roles. The statewide Early Intervention program continued implementation of the Family Survey disseminated to all families enrolled in EI for at least six months. For calendar year 2009, over 3000 surveys have been returned allowing families to share broad feedback about their EI experience. This feedback is shared with EI programs and used to improve EI services and supports.
- Funding from both of the above sources supports Family TIES (Together in Enhancing Support) the statewide Information and Referral network for families of CYSHCN and their providers. Family TIES staff, who are all parents of children with special health needs are located in each of the DPH regional offices which gives them knowledge and familiarity with local resources. Family TIES also serves as the Massachusetts Parent-to-Parent program and 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. Mentoring and financial support is available to these families.

- Families are regularly surveyed about support needs and best uses of flexible funds through Office of Family Initiatives projects, 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:

- Active recruitment, training and support for family members to participate in federally mandated Maternal & Child Health 2010 needs assessment.
- Implementation of protocols to facilitate continuum of service and direct referrals among all division programs.
- Establishment of Advisory Councils for the Title V CYSHCN program and the Bureau of Family Health and Nutrition.

II Family Leadership

Current and On-going Activities:

DPH supports, directly or through contracts or stipends, a number of initiatives that help families to acquire leadership and advocacy skills. These include:

- Early Intervention Parent Leadership Project, a parent-designed, parent-run project that offers information, training and supports to families whose children receive Early Intervention services to assist them to partner with providers within the Early Intervention system.
- Early Intervention Hausslein Leadership Awards offer small grants to families enrolled in EI to design and implement inclusive projects that connect their children and families to their communities.
- Family TIES, a statewide information and referral network, offers parent-to-parent support and training to families of CYSHCN and their health care providers. Families learn how to navigate the public and private service system and partner with health care and related organizations that impact policy development
- Navigating the Maze, collaboration between Family TIES and DPH Care Coordination program brings together families and service providers statewide to learn about and share information on public programs, eligibility requirements and "who to call."
- Collaboration with other family organizations such as 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.
- Maintaining the skill building and networking aspects of the Family- Professional Partners Institute. The Institute funded by DPH at New England Serve created a model of partnership between families and health care organizations. Federal funding for this initiative ended in April 2008. DPH continues to provide support to existing partnerships.
- On-going opportunities to indicate desired skill building training through surveys and questionnaires disseminated at conferences and workshops and at Family Initiatives projects' web sites, followed by development and dissemination of desired training.
- Positions for two family members as Advisors to the Catastrophic Illness in Children Relief Fund.
- Contracts with nine Community Health Centers and community-based primary care practices to implement Medical Home activities. A requirement of each contract was the establishment of Practice Improvement Teams that include family members who receive a stipend for their participation.

New Initiatives:

- Partnership with Children's LEND program to develop and deliver in-person and on-line Parent Leadership training.
- Collaboration with the DPH Early Intervention Training Center to develop skill building opportunities for families such as "Understanding Family Rights" and "You and Your IFSP."
- Development of "Train the Trainer" model for self-identified Family Advisors to disseminate information about the CYSHCN program. These Advisors will meet small groups of families to share and collect information for use in the MCH 2010 Needs Assessment, on-going Chapter 171 information gathering and to help evaluate and improve DPECSHN programs and services.

III Family Support Resources and Funding

Current and On-Going Activities:

Family support activities in FY09 have focused on skill building at the community level, identification of resources to produce and disseminate materials, assistance in development of local support groups and expanding the statewide Parent-to-Parent program. Through the CYSHCN strategic planning process, we continue to identify and share state and community resources, improve coordination among DPH programs and develop effective mechanisms to share information about resources with each other and with families. This effort has resulted in improved ease of access to information and support. A priority for DPH direct service programs including Family TIES, Community Support Unit and Care Coordination has been this improved communication and knowledge sharing and a commitment to assisting all families who contact DPH connect to appropriate resources. Information about and referral to resources, public benefits and navigating the health care system are provided by these three programs. Staff helps families to identify which agency would have primary responsibility for their presenting issue and facilitate connections with these agencies. A focus of program strategic planning has been to identify resources and supports needed by families whose children have complex special health needs experiencing critical life/health events.

DPECSHN supported efforts led by the Consortium for Children with Special Health Care Needs to include legislation about access to durable medical equipment (DME) into the FY10 Massachusetts State Budget.

A continued focus is the promotion of the Medical Home concept within community-based pediatric practices. DPH Care Coordinators are currently placed in nine Community Health Centers and private practices across the state where they provide information and support to families and train staff in aspects of Medical Home. The Division collaborates with EOHHS and other state and national efforts to promote and implement Medical Home for children and adults.

Over 50% of families indicated that Emergency Preparedness remains an important issue for them. Staff offers small group training for families and makes information and technical assistance available on project websites. As requested, DPH, MEMA and HHS information about H1N1 and pandemic flu is given to families. The Director of Family Initiatives supported an effort by the E.K. Shriver Center to obtain funding to provide

individualized consultation to families to assist with the development of emergency plans.

The Director of Family Initiatives serves as the family representative to the state Emergency Medical Services for Children Program. In this role, she helps to make connections between EMS and families that facilitate effective emergency response. She provides input to the program about the needs of families whose children have complex medical issues that would require individualized responses in the event of emergency or disaster.

Other DPH family support initiatives within the Bureau are provided by Early Intervention Regional Consultation Programs (RCPs). Six programs statewide provide support to families of young children with complex medical needs that facilitate inclusion in community settings of family choice. Over 1000 families whose children are enrolled in Early Intervention and eligible for RCP services accessed family support, networking opportunities, equipment loans and respite funding through the program. DPH maintains a toll free Community Support Line available to families of CYSHCN and their providers. In FY09, the line received close to 1400 calls, of which more than 50% were from families, and added an additional Resource Specialist.

Through the Bureau of Family Health and Nutrition Universal Newborn Hearing Screening Program (UNHS), the Department has provided support and information to approximately 1200 families whose children either did not pass or missed their initial hearing screening. Of these, 650 families who missed their diagnostic appointment, were in the process of achieving a diagnosis or had received a diagnosis of hearing loss were contacted. Follow-up efforts are made to reach every family either by phone, mail or through family-identified pediatrician. Some on-going case management was provided to these families by the Department. Additional supports are available through the Mass Commission for the Deaf and Hard of Hearing (MCDHH), with whom DPH has an agreement to share information, with family permission, facilitating early referral to the Commission.

The program employs a parent of a young child with hearing loss as a parent consultant. This consultant makes personal contact with every family whose child receives a diagnosis of hearing loss to offer family-to-family support and community and statewide resources. 360 English and 125 Spanish Parent Information Kits were distributed to families. 44,000 brochures in multiple languages were distributed

Family TIES continued its focus on outreach and support to culturally and linguistically underserved populations. Training about organizing complex and multiple records, emergency preparedness and building community were translated into Spanish, Portuguese and Chinese. In all, over 1200 parents accessed training and skill building opportunities offered by Family Initiatives programs. These included leadership development, building community, emergency preparedness, facilitation and presentation skills and providing parent-to-parent support.

New Initiatives:

- Development and distribution of Medical Home Fact Sheets for Families and Providers
- Collaboration with EOHHS around initiatives to promote and seek funding for Medical Home activities.
- Identification of Division staff to collaborate with other core DPH programs to embed understanding of the similarities and differences of issues of CYSHCN.

IV Accessing Services and Supports

Current and On-going Activities:

The Department supports a variety of efforts to educate families/consumers about availability of and access to services. Some of these include public service announcements, Early Intervention Child Find, program specific newsletters such as EIPLP's **Parent Perspective** and the MassCare newsletter. CICRF, Community Support Line, Family TIES and Care Coordination staff outreach to hospitals, schools and community settings where individuals with disabilities and their families receive services. The DPH Public Benefits Specialist provides training across the state and offers technical assistance through a toll free number and at in-person trainings. In FY 09, 100 parents received personalized TA and training from this Specialist. Staff from Care Coordination, Community Support Unit and Family TIES continued their collaboration on a series of statewide public benefits and informational meetings for families and professionals to disseminate information about available services and supports. Family TIES and EIPLP both maintain toll free numbers. In FY09, over 3000 families called these lines for information, referral, Parent-to-Parent matches, training and skill building opportunities. These projects also host web-sites and list serves. To date, 1000 Family TIES Resource Directories, 4000 project brochures in English, Spanish and Portuguese and six editions of the **Parent Perspective** have been distributed to families and professionals. These materials are also available electronically. DPECSHN program information, including the Family Support Plan is available on-line at www.mass.gov/dph. There is interactive capability on the DPH website and on DPECSHN project sites for families to offer feedback and suggestions.

New Initiatives:

- New CYSHCN program brochure and services guide will be widely distributed.
- Family Initiatives staff will support EI Parent Contacts and Family Advisors to implement activities for grass roots information sharing.
- As part of the CYSHCN program strategic planning process, stakeholder and constituency building activities will facilitate broader dissemination of information.

V Culturally Competent Outreach & Support

Current and On-going Initiatives:

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/or access to interpreters. The Department hires and/or contracts with individuals who are bilingual, bicultural and familiar with the culture and customs of families who utilize our programs. Outreach initiatives take place collaboratively with community-based organizations where ethnically, linguistically and culturally diverse individuals and families receive services and are comfortable. These include community health centers, WIC offices and family organizations. The Family TIES Project contracts with native Spanish and Portuguese speakers to respond to requests for information and referral, and Parent-to-Parent matches. In FY09, Family TIES hired a parent coordinator from Eritrea who has made a number of new connections with community based organizations. Information about the availability of flexible family supports is disseminated to organizations where ethnically, culturally and

linguistically diverse individuals and families gather and receive services. Project training is available in Spanish and Portuguese. Family TIES continues its focus on expanded outreach to linguistically and culturally diverse populations. In FY09, partnerships with an additional 9 community-based organizations were established. Coordinators shared materials, worked collaboratively on translation and offered skill building sessions to families whose children have special health care needs. Bilingual/bicultural staff worked with Spanish speaking families to provide input into the FY 10 Family Support Plan. The EIPLP newsletter lead article and updates on the EI Family Survey continue to be translated into Spanish in each of six editions. TTYs are in place in all DPH regional offices to ensure access for individuals who are deaf or hard of hearing. DPECSHN programs continued to utilize the Office of Health Equity telephonic interpreter services line.

As part of the CYSHCN program strategic planning process, a work group focusing on health disparities and cultural competence was formed. This group has done a literature search of relevant materials, sought technical assistance from the National Center on Cultural Competence at Georgetown University and connected with the DPH Office of Health Equity to gather data on regional disparities. They have begun to share information with staff of the CYSHCN program.

New Initiatives:

- Development and dissemination of Resource Binders with information to address health disparities and cultural competence for all DPH Regional Offices.
- Viewing and facilitated discussion of the video "Unnatural Causes" at Regional Offices.
- Work group members will mentor staff to increase understanding and develop effective strategies to expand services to underserved populations.

VI Interagency Collaboration

Current and On-Going Activities:

- Continuing collaboration between DPH and Department of Early Education and Care (EEC) around transition requirements for children leaving Early Intervention.
- Collaboration between DPH, EEC, ACF/Head Start and community agencies to expand training and support for inclusive community-based options for children.
- Participation on Birth-to-Three Task Force formed by EEC. DPH staff participates on all task force committees to represent health and family involvement issues.
- DPH Public Benefits Specialist represents BFHN on the State Special Education Advisory Board to share information about children with special health needs in public schools.
- Interagency Coordinating Council, A federally mandated council that advises and assists the DPH as lead agency for the MA Early Intervention System in planning, implementation and evaluation of EI services. The ICC is made up of family members of children who receive or have received EI, representatives from state agencies, early intervention programs, higher education, and other interested organizations serving young children and their families.
- Collaboration with the Mass Commission for the Deaf and Hard of Hearing to share contact information of families whose children are diagnosed with hearing loss with their permission to facilitate early referrals.
- Active participation in EOHHS Medical Home initiatives.

New Initiatives:

- If funded DPH will work collaboratively with the Boston Public Health Commission to support Boston Medical Center and three Community Health Centers to implement medical homes for children from families that have substance abuse issues.
- DPH will collaborate with EEC to offer on-line transition training (from EI) for providers and families
- DPH will participate in 3-to-5 EEC Task Force
- Investment of Maternal & Child Health Block Grant funds into EOHHS Medical Home activities
- Possible collaboration with EEC to maintain funding for Regional Consultation Programs (RCPs)