

Massachusetts Department of Public Health Annual Family Support Plan - Fiscal Year 09

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 has 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.

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 is 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 2008, approximately 1000 families received over \$2,000,000 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.

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. During FY08, staff from the Department's Family Initiatives projects attended conferences and regional and local meetings where families whose children have special health needs might be found. 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; (750 participants)
- 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 60 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 100 families. An additional 150 responded to questionnaires. Families continued to tell DPECSHN that their primary unmet public health needs remained the need for reliable, accessible, knowledgeable and up-to-date information about resources, public programs and supports. They continued to comment on the issues of lack of coordination of services provided by multiple human services agencies. Other strong themes that emerged from this substantial consultation were difficulty in finding at-home nursing care, lack of access to durable medical equipment (DME) and responsiveness from DME vendors and the need for health care provider education to better support children and youth with complex medical needs around core public health issues such as nutrition, physical activity, sexuality, etc. Families also wanted DPECSHN to know that there are times in their families' lives when they need short-term, intensive assistance. They asked that we make this type of support available and broadly publicize its availability

Focus Areas

I Family Empowerment

Current 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 FY07, Commissioner Auerbach conducted meetings statewide to gather information from the community about DPH programs and services, unmet needs and ideas for improvement. Follow-up regional meetings to ensure that information about needs remains current have been ongoing. 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 grant 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 FY08, the statewide Early Intervention program implemented a Family Survey disseminated to all families enrolled in EI for at least six months. To date close to 1800 surveys have been returned allowing families to share broad feedback about their EI experience.
- Funding from both of the above sources supports Family TIES (Together in Enhancing Support) our statewide Information and Referral network for families of CSHCN 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 as well as offering training and support to interested families to take on roles within DPH programs and other public policy venues.
- Families are regularly surveyed about support needs and best uses of flexible funds through 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:

- All DPECSHN programs will expand efforts to identify opportunities for family involvement in policy and program development.
- Collaborative training sessions provided by Community Support, Care Coordination, and Family Initiatives staff statewide.
- Creation of Family Advisory Group for CICRF

II Family Leadership

Current 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 that offer small grants to families enrolled in EI to design and implement inclusive projects that connect their children and families to the their communities.
- Family TIES, a statewide information and referral network, offers parent-to-parent support and training to families of CSHCN and their health care providers. Families learn how to navigate the public and private service system and take on roles with health care and related organizations that impact policy development
- Navigating the Maze, a 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 Mass ARC, Mass Families Organizing for Change and Mass Family to Family Health and Information Center to share training and skill building opportunities.
- The Family- Professional Partners Institute, funded by DPH at New England Serve identifies opportunities for family members to take on a variety of roles with health care organizations. Family and organizational partners receive training, mentoring and support to work together effectively. Support for families to attend national and statewide conferences where they can access information and skill development activities.
- 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.
- A family member whose child has special health needs serves as an advisor to the CICRF.

New Initiatives:

- Expanded outreach and training for family members to be co-trainers, facilitators and participants within the Early Intervention Training Center (EITC) now housed at DPH.
- The **Parent Perspective**, newsletter of EIPLP will have "growing leaders from the ground up" as its theme for FY09 and will focus on publicizing opportunities for leadership development at the community level.
- Over 100 family members have indicated an interest in providing input to DPH on a regular basis. These Advisors as well as EI Parent Contacts and Liaisons and Family Partners will come together regionally and at the community level for skill building, leadership development and provision of community and family perspective on unmet needs.

III Family Support Resources and Funding

Current and On-Going Activities:

Throughout FY08, the focus of family support activities has been to address issues raised by families as part of our annual needs assessment and substantial consultation activities. Family Initiatives staff worked with the Department of Early

Education and Care, the Mass Consortium for Children with Special Needs and other division staff to look at issues of transition both at the early childhood and adolescent/young adult level.

DPH and EEC finalized and published a transition guide for families whose children are leaving Early Intervention. The Director of Family Initiatives, Assistant Director for Early Childhood Programs and 619 Coordinator at EEC presented information about individual agency mandates and strategies for collaboration between EI and public schools at an EI stakeholders retreat. This was followed by two regional meetings and individual technical assistance to programs.

As part of a Maternal and Child Health state implementation grant, DPECSHN staff supported the development of transition training for young adults. The training was offered three times state wide and was open to care coordinators, case managers and families.

Families placed a strong emphasis on the need to know what resources were available, how to access these resources and where to get help in managing short term crisis situations. In response to these articulated needs, DPECSHN has updated and broadly disseminated information about division programs and continued to publicize the availability of support from our Community Support Line, Public Benefits Specialist, Family TIES and EI Parent Leadership Projects, Care Coordination program, Catastrophic Illness in Children Relief Fund and Pediatric Palliative Care program. Efforts to enhance collaboration among other DPH programs have been instituted. DPECSHN staff has worked with DPH offices of Adolescent Health, Violence Prevention and Nutrition to raise awareness of the needs of children and youth with special health care needs that are the same or similar to those of their typically developing peers.

Although it no longer emerged as families' top priority for support from DPH, most families continued to express a need for assistance with emergency planning. The Director of Family Initiatives served on a state wide committee looking at personal preparedness for individuals with disabilities and their families and participated in development of a set of recommendations. Emergency Preparedness information is posted on the Family TIES website and technical assistance for families is available from staff.

The Director of Family Initiatives continues to work with the Emergency Medical Services for Children Program 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. Within DPECSHN, programs serving children with special health needs and their families work to improve the coordination of services and supports to ensure that families have what they need to manage complex life situations.

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. In addition, RCPs disseminated over \$200,000 of respite and family support funding for families whose children are enrolled in Early Intervention and eligible for RCP services. DPH Care Coordination and Community Support Line programs provide additional support to families in accessing resources, navigating the health care system and obtaining information about public benefits.

DPH maintains a toll free Community Support Line available to families of CSHCN and their providers. In FY08, the line received over 1600 calls of which more than 1000 were

from families. Callers receive information, technical assistance, referral and support from two dedicated Resource Specialists.

Through the Bureau of Family Health and Nutrition's Office of Specialty Services and Universal Newborn Hearing Screening Program (UNHS), the Department has provided support and information to approximately 1500 families whose children have either not passed or missed their initial hearing screening. Of these, 800 families who missed their diagnostic appointment, were in the process of achieving a diagnosis or had received a diagnosis of hearing loss were contacted. Approximately 225 children were diagnosed with hearing loss. Some on-going case management was provided to these families. DPH signed an agreement with MCDHH to share this information, with family permission, to facilitate 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. The program partnered with Family TIES to host a training for mentor parents as part of our state wide Parent to Parent program bringing in a number of new parents willing to offer parent to parent support to families whose children have hearing loss. 270 Parent Information Kits were distributed to English speaking families. This year the Kit was translated into Spanish. 160 were distributed. In FY 08 75,000, brochures in English, Spanish, Portuguese, Russian and Haitian Creole 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 650 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:

- Materials developed for the transition training will be synthesized into a "family friendly" packet including checklists and timelines. These materials will be disseminated to interested families through DPH family projects.
- DPECSHN Transition Coordinator will conduct key informant interviews with families and other collaborators including the Department of Elementary and Secondary Education and the Federation for Children with Special Needs to identify best practices and strategies for embedding health goals for CYSHCN within Individual Education Plans.
- Collaboration with the Consortium for Children with Special Needs to raise awareness of service and resource needs of families whose children have complex special health needs and build capacity to articulate these needs and educate their communities about them.
- Outreach to health care provider community to raise awareness of the importance of wellness instruction and activities for children and youth with special health care needs as part of community based primary pediatric care.

IV Accessing Services and Supports

Current 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. In FY08, 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. These meetings were well attended and appreciated by the community. Family TIES and EIPLP both maintain toll free numbers. In FY08 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 servs. 1500 Family TIES Resource Directories, 6000 project brochures in English, Spanish and Portuguese and six editions of the **Parent Perspective** were distributed to families and professionals. DPECSHN web liaison worked with the EOHHS web team to expedite availability of the most up-to-date information about programs and services. Emergency preparedness information and the FY 08 DPH Family Support Plan are available on line. In December 07, DPH worked collaboratively with the Massachusetts Family to Family Health and Information Center, a project of the Federation for Children with Special Needs to provide information about the Maternal and Child Health Block Grant and to offer strategies for family input.

New Initiatives:

- Office of Family Initiatives and other DPECSHN staff will work with the Consortium for Children with Special Needs and families to build awareness and community capacity to both access services and supports and grow resources.
- DPECSHN staff will participate in EOHHS working group looking at ways to improve practices in meeting family needs through the Chapter 171 process.
- Ongoing outreach to referral sources will continue.

V Culturally Competent Outreach & Support

Current 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. 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. A focus of work for Family TIES has been expanded outreach to linguistically and culturally diverse populations. In FY 08, Family TIES staff began building partnerships with over 20 new community based organizations. Coordinators shared materials, worked collaboratively on translation and offered skill building sessions to families whose children have special health care needs. The Family TIES annual Resource Directory continued to expand Spanish and Portuguese pages. DPH funded the attendance of three parents from the Haitian community at the annual "Joining Voices" conference. As part of the Family-Professional Partners Institute, a networking meeting for families and professionals that focused on cultural perceptions of disability was held. Bilingual/bicultural staff worked with Spanish families to provide input into the FY 09 Family Support Plan. The EIPLP newsletter lead article on paths to leadership and updates on the EI Family Survey was 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 Multicultural Health telephonic interpreter services line.

New Initiatives:

- DPECSHN will incorporate CLAS standards into all RFRs and contracts.
- Family TIES training materials will be translated into Chinese.

VI Interagency Collaboration

Current Activities:

- The MECCS Executive Committee applied for and was granted affiliate status with the Strengthening Families National Network (SFNN). MECCS partnered with the Children's Trust Fund, the Department of Early Education and Care, the Head Start State Collaboration Office, Mass Head Start Association, Department of Social Services, and the Department of Education to host a meeting with the Strengthening Families Initiative (SFI) for one hundred and fifty participants.
- MECCS continues to work with UWMB&MV to identify strategies to enhance home visiting models for health and mental health services.
- MECCS has been involved in a project with EEC, DSS, and HSSCO and Mass Head Start Association to survey programs providing Supportive Child Care. Survey results and analysis will inform EEC and DSS's future procurement of supportive services, decisions about mental health and transportation services and policy issues.
- DPH continues work with EEC, DOE, Head Start, EOHHS and ACF to update and implement an interagency Early Childhood Transition Agreement.
- The Department continues its active participation in the Consortium for Children with Special Health Care Needs; a group convened by New England Serve, a 23-year-old health policy and planning organization. The Consortium has a broad membership consisting of families of children with special health needs, primary care providers, academic physicians and researchers, representatives of health insurance plans and state agencies who come together to improve systems of care for CSHCN through the exchange of information, strategic thinking, and collaboration to address gaps

and barriers in service systems. The DPECSHN division director serves a member of the Consortium Steering and Executive Committees.

- 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.
- A Helping Hand: Mother to Mother project, a collaboration among DPH, DSS, the Federation for Children with Special Needs and Community Health Link established a second site in Fitchburg.
- DPH joined EEC, ACF and other community organizations to Special Quest a program with a focus on expanding the inclusion of young children with special health needs into Massachusetts. The MA team focus will be on cross systems professional development to facilitate inclusion of young children with special needs into community based settings.
- DPH and EEC have collaboratively produced and disseminated a Guide for Families about transition from Early Intervention.
- DPH and MCDHH agreed to a collaboration in which contact information of families whose children are diagnosed with hearing loss will be shared, with family permission to facilitate early referrals.

New Initiatives:

- MECCS and the SFI collaboration plan focus groups to follow up on the momentum of the SFI event and determine strategies for moving forward, such as supporting early childhood programs in using the SFI self-assessment tool and using the results to support enhancement of their family support practices. MECCS will link with United Way of Mass Bay and Merrimack Valley (UWMBMV) on their Partnering with Families Initiative, which involves learning communities who are using self-assessment tools.
- MECCS has applied for a SAMHSA funded Project LAUNCH grant with the Boston Public Health Commission. If funded, BPHC will pilot an enhanced version of the Nurse Family Partnership home visiting model, as well as Family Nurturing programs.
- MECCS plans to partner with CTF in doing a more detailed inventory of family support training opportunities, as well as family support policies and practices at the state agency level.
- DPH will collaborate with EEC to offer on-line transition training (from EI) for providers and families.