

MA Department of Public Health Annual Family Support Plan - FY '06

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 Center for Community Health's (the Center) 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**, CCH 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 FY'05, 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 doing around emergency preparedness and gather resources to assist in developing emergency plans for their children.

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 Center 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 Center 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 implementation;
- Representing the Center and its commitment to family-centered services in interagency initiatives;

- Representing the Center 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 Center 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 small amounts of 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. Funds are disseminated through DPH vendors and in some cases, from DPH directly to families. In Fiscal Year 2005, approximately 1100 families received over \$2,500,000 in funding from the Catastrophic Illness in Children Relief Fund (CICRF), Early Intervention Regional Consultation Program Respite Allocation, Care Coordination Flex 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 FY'05, staff from the Department's Family projects, Family Initiatives and Family TIES, worked with the Center for Emergency Preparedness to conduct statewide Family Focus Groups. Close to 100 family members attended these groups and offered compelling information about their personal readiness plans as well as their knowledge of community resources.

Additional information was obtained through the following mechanisms:

- Questions on a survey disseminated at the annual Federation for Children with Special Needs conference;
- Questions about emergency preparedness were included in all calls received by the Family TIES project, the statewide Information and Referral and Parent-to-Parent program;
- 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.

All these sources yielded similar information: in general, families are still not prepared for disaster, emergency or terrorism events. Approximately 10% of families reached through the above mechanisms stated that they had Emergency Plans in place. Fewer knew their local first responders.

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 addition, the following illustrate other ways the DPH promotes family participation in policy development and program planning within the Center:

- The Center 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 are 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 parent-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.
- 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. In addition, Family TIES serves as our state 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 public policy venues.
- Through its Federal Early Childhood Comprehensive Systems Planning Grant (MECCS), the DPECSHN has recruited families to take part in the development of a seamless, comprehensive system of services for families of children birth to six.

New Initiatives:

- 3 year MCHB State Implementation Grant, that will support in collaboration with the Consortium for Children with Special health Care Needs the development of a Family Professional Partners Institute
- Additional advisory roles for families on the Massachusetts Newborn Screening Advisory Committee
- Participation in the MECCS Family Sub-Committee, designed to expand family support and involvement in development of family centered service systems

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
- Mass Family Voices, a grass roots network of families of CSHCN that provides a variety of training and supports to help families learn advocacy, partnering and leadership skills. The Mass Family Voices listserv which serves as forum for information exchange and policy dissemination.
- The Family Participation Working Group of the Consortium for Children with Special Health Care Needs, co-chaired by the DPH Director of Family Initiatives, assesses the status of current family-centered activities of member organizations and offers leadership training, financial support, and mentoring to family members wishing to join this policy organization.

New Initiatives:

- Support for families to take on leadership roles and influence policy development by participation at conferences, on task forces and meetings such the Prematurity Summit and the Early Childhood Mental Health Working Group
- New training and leadership skill building opportunities including Understanding the Legislative Process, grant writing, facilitation and presentation skills
- Train the Trainer models at the new Early Intervention Training Center to prepare families as co-trainers to the Early Intervention community
- Support for an expanded network of Family Leaders who will advise and mentor, new family members to take on leadership roles in health care policy and planning

III Family Support Resources and Funding

Current and On-Going Activities:

In response to information gathered from families/consumers through out FY'04 and '05, the Department of Public Health has continued to focus flexible family supports on assisting families whose children have special health care needs to access information and resources around preparedness in the event of emergency situations or natural disasters. DPH through its Center for Emergency Preparedness facilitates a Special Populations Working Group. Members are DPH staff as well as representatives from sister agencies. The Federal definition of Special Populations includes individuals with mental health needs, special health care needs, non-English speakers, pregnant women, immigrants and refugees and the elderly. The Special Populations Nursing Coordinator from the CEP has worked closely with the Director of Family Initiatives to connect with families of CSHCN and assess level of preparedness, identify specific assistance individual families will need and gather information and resources to support these families.

Feedback from families has given DPH the following information:

- Fewer than 10% of families have an emergency plan in place
- While most families whose children have SHN know what to do in the case of a personal emergency, fewer than 20% know whom to contact in the event of a natural disaster or act of terrorism

- Community-based first responders do not know which families would require special assistance
- Public schools and community venues may have disaster plans in place, but very few of them have special provisions for children with SHN and other disabilities
- 75% of families said they need assistance in developing emergency plans, connecting with local first responders, accessing medication and assistive equipment and in general keeping their child with SHN safe and well in the event of an emergency.

Other DPH family supports within the Center include Early Intervention Regional Consultation Programs (RCPs). In FY'05, seven programs statewide provided support to families of young children with complex medical needs that facilitated inclusion in community settings of family choice. In addition, RCPs disseminate over \$300,000 of respite funding for families whose children are enrolled in Early Intervention. Care Coordination and Community Resource Line programs, provide additional support to families in accessing resources, navigating the health care system and obtaining information about public benefits.

Through its Universal Newborn Hearing Screening Program (UNHS), the Department has provided support and information to over 1000 families whose children have either not passed their initial hearing screening or have been diagnosed with hearing loss. The program employs a parent of two children with severe 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 has developed a Parent Information Kit that is distributed to these families.

New Initiatives:

- In response to information obtained through regional Emergency Preparedness Family focus groups, DPH will continue to work to forge ongoing community based collaborations involving families, first responders, public schools, local physicians and pharmacists, health insurers, representatives from other state agencies serving CSHCN as well as any relevant community members.
- As part of a new MCHB State Implementation grant, DPECSHN will partner with the Federation for Children with Special Needs, through the Family TIES project to fully develop a continuum of services and supports for families of CSHCN receiving their primary care within community based pediatric practices where DPH Care Coordinators are placed.
- The Catastrophic Illness in Children Relief Fund (CICRF) will recruit a parent of a child/ren with special health care needs to become a member of the Commission to ensure that meaningful family experience informs decisions.
- The RCPs will conduct a statewide Family Needs Assessment to obtain current and complete information about family support needs and develop programs and resources to address these needs.

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, Child Find, program specific newsletters such as EIPLP's **Parent**

Perspective and the MassCare newsletter. CICRF and Care Coordination 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. Family TIES and EIPLP both maintain toll free numbers. These projects also host web-sites and list servs. UNHS distributed over 100,000 brochures in five languages to birth hospitals and birthing centers as well as over 800 Parent Information Kits. The Department provides partial support for a listserv moderated by Massachusetts Family Voices that gives families an opportunity to gain information and share concerns. Professionals are invited to participate in this on-going forum. Training for families around medical transition for youth with special health care needs from the pediatric to the adult health care system has been delivered at workshops and conferences throughout the fiscal year. The Early Intervention Training Center (EITC) includes families in all its offerings to the EI field.

New Initiatives:

- In collaboration with New England Serve, DPH will develop and widely disseminate "Lessons Learned" from a pilot project pairing family members with health care organizations interested in partnering to become more family centered
- Responses to "Frequently asked questions and concerns" that arose from the Emergency Preparedness Family Focus groups will be developed and disseminated to the community.
- Additional printing of "**Directions: Resources for My Child's Care**" a manual to support families of CSHCN participate in their child's care will occur. In addition, the manual currently available in English, Spanish will be available in Portuguese.
- All training offered through the MECCS project will be presented collaboratively by a parent and a professional to make it more accessible to families and to model the DPH commitment to family-professional partnership

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. 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. Core Project training is available in Spanish. The EIPLP generic newsletter is available in Spanish and disseminated to Spanish speaking families by Early Intervention Service Coordinators. TTYs are in place in all DPH regional offices.

New Initiatives:

- Strategic planning for the Family TIES project has identified outreach to diverse and under-served populations as a critical project goal for FY'06. Project staff will work in collaboration with the Office of Minority Health to explore the development of plans to address the disparities found among culturally, linguistically and ethnically diverse populations with regard to Emergency Preparedness
- All materials developed for the Family Focus groups will be translated into Spanish. Materials will be disseminated through Family TIES, Care Coordination, EI programs and community venues where Spanish speaking families go for services and supports
- Through its new MCHB State Implementation grant, DPECSHN staff will receive technical assistance and support from the National Center on Cultural Competence

VI Interagency Collaboration

Current Activities:

- Through its Early Childhood Comprehensive Systems grant, DPH works collaboratively with DOE, OCCS, Head Start, the Juvenile Courts, DMH, families and other partners to identify elements of a family centered, easily accessible, family centered service system for families children six and under.
- DPH participates on the steering committee of the EOHHS Planning and Review Teams. DPH staff participated in development of training for members of these teams and in selection of Family Consultants to support families utilizing the teams.
- The Department is an active presence in the Consortium for Children with Special Health Care Needs; a group convened by New England Serve, a 20-year-old health policy and planning organization. The Consortium consists 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.
- 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. 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.
- DPH convened a task force comprised of families, representatives from a number of state agencies and the Mass Dental Society to address issues around Oral Health for CSHCN
- The DPH participates in the Chapter 171 working group convened by DMR to share information about agency Family Support plans and implementation activities.

New Initiatives:

- The Department will work with the new Department of Early Education and Care, continuing its long standing collaboration with the former OCCS and DOE Early Learning Service. Collaborative work to explore the inclusion of early childhood core competencies including a competency for family involvement and support will occur
- DPH will write a collaborative grant with DSS and Brandeis University to develop systems to better identify children involved with the child welfare system and better support families at risk

- The Early Childhood Mental Health committee, co-chaired by the DMH Children's Services Coordinator will develop a state plan with a focus on healthy social and emotional development for young children
- MECCS Family Involvement committee will model public-private partnership through joint chairs from DPH and United Way of Mass Bay