

MA Department of Public Health Annual Family Support Plan - FY '05

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 Bureau of Family and Community Health (BFCH) within its Divisions of Perinatal and Early Childhood Health (DPECH) and Special Health Needs (DSHN) offer a number of programs providing services to individuals with disabilities and their families. Following the passage of **Chapter 171 of the Acts of 2002: An Act Providing Support to Individuals With Disabilities and Their Families**, BFCH 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.

Overview of Family Support

The BFCH 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 Bureau 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 BFCH initiatives include families/consumers in planning and monitoring activities
- Developing new and ongoing opportunities for family involvement within the Bureau
- Providing training, mentoring, financial and other supports to families partnering in planning, policy making and implementation
- Representing the Bureau and its commitment to family-centered services in interagency initiatives
- Representing the Bureau and its commitment to family-centered services with other organizations on the state and national level
- 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 Department 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 2004, approximately 1400 families accessed over \$3,500,000 through the Catastrophic Illness in Children Relief Fund (CICRF), Early Intervention Regional Consultation Program Respite Allocation, Care Coordination Flex funding and Special Medical Funds.

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

The DPH employed a variety of mechanisms to continue to gather information from families/consumers about their support needs. As described in our FY'04 Family Support Plan, efforts to facilitate regional conversations that included families, emergency personnel and other essential community members were initiated. During these conversations, families continued to give their input on systemic issues, roles for the DPH and community based needs. In addition, other families who could not take part in these conversations had the opportunity to offer their ideas and opinions through:

- Telephone surveys conducted by Family TIES (Together in Enhancing Support), a DPH funded statewide information and referral network for families whose children have special health care needs;
- Focus groups at scheduled statewide meetings;
- A survey distributed to over 500 families of children with special health needs at an annual conference;
- Individual conversations with families utilizing DPH programs and services;
- 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.

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 the Department. In addition, the following illustrate other ways the DPH promotes family participation in policy development and program planning within the BFCH.

- 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 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 critique the grant prior to submission to MCHB.

- With federal Individuals with Disabilities Education Act (IDEA), Part C (services to children 0-3) funding, the Bureau supports the Early Intervention Parent Leadership Project. This parent-designed and driven 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.

New Initiatives:

- Opportunities to advise the Department on Emergency Preparedness Planning
- Training and support to become Family TIES Associates
- Training and matching families to facilitate formal Parent to Parent supports
- Participation in the MECCS Advisory Committee

II Family Leadership

Current Activities:

The Bureau 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 (EIPLP), a parent-designed, parent-run project that offers information, training and supports to families whose children receive Early Intervention services that helps them to participate in partnership 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 advisory roles with health care and related organizations.
- 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 involved in the Family Advisory Network of the MassCare Project to grow their skills as partners and leaders.
- Families involved with DPH parent projects will have access to training in grant writing, facilitation and presentation skills and leadership development.

- Through its work for the Consortium for Children with Special Health Care Needs, the DPH will support families to partner with health plans, academic institutions and other members organizations through on-going leadership training.

III Family Support Resources and Funding

Current and On-Going Activities:

Information gathered from families/consumers regarding their flexible support needs in FY'04 clearly pointed to the need for assistance for their children with special health needs and themselves in the event of emergency situations or natural disasters. The DPH felt that this was an area in which public health could have a strong presence. The Department's new position, a Special Populations Coordinator funded through a HRSA grant for emergency and bio-terrorism planning offered a way to address these needs and concerns. The Coordinator would facilitate the formation of regional teams that included individuals with disabilities and their families, emergency personnel, physicians, pharmacists, health insurers and other community resources to assist families in emergency planning. Delays in the hiring process of the Special Populations Coordinator reduced the amount of regional team building for planning that could take place in the first year. Nonetheless, a large amount of information has been distributed to families, identifying regional resources, facilitating connections to local and regional emergency personnel and assisting with the development of individual and family Emergency Plans.

Over 250 individuals with disabilities and/or their family members have contributed to the DPH's knowledge of specific needs and current connections. In return these consumers have received person-to-person assistance to develop Emergency Health Plans. Families also received information and connection to the Disability Indicator Project, a method available in many communities in the Commonwealth whereby individuals connect with local emergency personnel, share their contact information and identify their current health care needs. In the event of an emergency, local personnel then know what specific emergency assistance will be needed.

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 FY' 05, the DPH Division of Perinatal and Early Childhood Health, will take the lead in planning a comprehensive, statewide system of services for children birth to five and their families as part of its Maternal and Child Health funded Massachusetts Early Childhood Comprehensive Systems grant (MECCS). MECCS will host a series of statewide forums bringing together families and providers across service systems to identify existing structures and resources and to develop best practices for family involvement in designing a coordinated, comprehensive service system. These

forums will assist in creating an infrastructure for effective partnership between families and providers.

- DSHN will fully develop its Community Support line, a toll free line, staffed by Resource Specialists who provide information and referral to families whose children have special health needs and disabilities. This connection will provide expanded information about public benefits, community resources and flexible funds. In addition, families who require additional assistance will be referred to DSHN Care Coordination services.
- The UNHS Program which currently focuses outreach and support efforts on families of newborns and newly diagnosed children with hearing loss will expand services to meet the resource and support needs of families whose children are three to five. This initiative will address the gap being reported by these families in their access to resources and family to family support so vital to successful functioning.

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 supports a listserv hosted 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 FY'05, The Early Intervention Parent Leadership Project (EIPLP) will be restructured. Staff will work 25 hours a week, allowing them much more time to meet with families in their communities to share information and resources. This increased contact will result in more parents receiving support and mentoring to grow leadership skills.
- All training offered through the MECCS project will be presented collaboratively by a parent and a professional to make it more accessible to families.
- The Department will contract with 13 community based primary care practices. DSHN Care Coordinators will work with a broad range of families whose children have a variety of special health needs and disabilities to disseminate information about resources and supports. In addition, work will begin to train and mentor families who receive care in these practices to provide peer to peer support.

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:

- DSHN has hired a Special Populations Coordinator who speaks Haitian Creole and Spanish. This individual will begin outreach to under-served groups in FY'05.
- **Directions: Resources for my Child's Care;** a manual for parents caring for children with special health needs has been developed and will be available in Spanish. The manual will be disseminated by health insurance plans and on the DPH web-site.
- EIPLP will hire an Outreach and Collaboration Coordinator. This person will forge connections with health centers and community organizations serving culturally, linguistically and ethnically diverse individuals to share information about resources and opportunities for families.

VI Interagency Collaboration

Current Activities:

- In collaboration with commissioners from the Department of Education (DOE) and the Office of Child Care Services (OCCS), Commission Ferguson took part in the legislatively mandated Early Care and Education Council. The Commissioners hosted forums throughout the state bringing together early childhood stakeholders including families and providers to ask questions, share concerns and offer strategies to develop a more responsive and cohesive service system. The DPH was charged with taking the lead in standardizing training and training credit for the three agencies to ensure the same level of high quality care for all children served in these systems. The DPH/EI Parent Leadership Project was cited by the Council as an example of an effective, family centered model.
- The DPH continues its work with DSS to implement the Massachusetts Early Childhood Linkage Project (MECLI). The Massachusetts project precedes the passage of the federal legislation, "Keeping Children and Families Safe Act of 2003" with its CAPTA provision requiring states to refer children 0-3 with substantiated DSS cases for evaluation by Early Intervention and will serve as a model for other states.
- 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.
- In partnership with the Massachusetts Health Quality Partners, the Department developed and disseminated an Asthma Action Plan, a care plan for families whose children have asthma to be shared with schools, childcare and recreational programs.
- 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 other EOHHS agencies to include consumers/families utilizing their services and who also have special health needs in regional emergency planning initiatives. Service providers will receive training and information about emergency personnel and resources. Families will be assisted to develop emergency health plans.
- Through the Office on Health and Disability (OHD) with the Division for Special Health Needs, outreach to organizations serving adults with disabilities will be conducted. Efforts to initiate collaborative information sharing and planning to facilitate emergency preparedness will take place with among others, with area Councils on Aging, the MS Society and the ALS Association.