

## MA Department of Public Health

### Annual Family Support Plan - FY '08

#### ***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 and Community Health (BFCH), 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 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 planning concerning emergency preparedness and gather resources to assist in developing emergency plans for their children and families.

FY'06 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. BFCH 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, FY'07 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, Family Initiatives program worked with other state agencies and programs to train staff around strategies to support families in their emergency planning efforts. Over 1000 packets of family friendly materials were created and disseminated.

## ***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 BFCH 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 BFCH and its commitment to family-centered services in interagency initiatives;
- Representing BFCH 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. Funds are disseminated through DPH vendors and in some cases, from DPH directly to families. In Fiscal Year 2007, approximately 1000 families received over \$1,500,000 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 FY'07 , staff from the Department's Family Initiatives projects attended conferences, regional and local meetings and conducted focus groups and community outreach visits to share and gather information from families. 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 BFCH programs and what could be done to make services more family friendly.

Additional information was obtained through the following mechanisms:

- Questions on a survey disseminated at the annual Federation for Children with Special Needs conference;
- 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;
- 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.

Over 100 families attended focus groups and regional family meetings. An additional 150 responded to questionnaires. Of great interest to DPECSHN was the fact that although many families have not yet developed emergency plans and all identified the importance of preparedness, this was no longer their primary request for assistance. Instead, families told us that they needed reliable, accessible, knowledgeable and up-to-date information about resources, public programs and supports. They expressed a need for better coordination of service delivery from multiple agencies, help in addressing general public health issues such as obesity and access to available, short term care coordination during times of crisis and transition.

### ***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 FY'07, Commissioner Auerbach conducted meetings statewide to gather information from the community about DPH programs and services, unmet needs and ideas for improvement. 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 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.

- 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 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:*

- Continued expansion of opportunities for family involvement in policy and program development.
- Creation of opportunities for family involvement within community based health care organizations.
- Collaborative training sessions provided by Community Support, Care Coordination, Family Initiatives staff statewide.

## **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
- Collaboration with other family organizations such as Mass ARC and Mass Families Organizing for Change to share training 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.
- Participation in leadership training through MECCS community projects.
- A family member whose child has special health needs has become an advisor to the CICRF.

*New Initiatives:*

- Expanded outreach and training for family members to be co-trainers, facilitators at all Early Intervention Training Center (EITC) offerings.
- The **Parent Perspective**, newsletter of EIPLP will have "paths to leadership" as its focus for FY'08 and will define and identify a variety of methods to grow leadership skills.
- Continued "Alumni" mentoring and training activities for family members participating in Family-Professional Partners Institute activities.
- Regular community based meetings for family members who have indicated an interest in advising DPH.

### **III Family Support Resources and Funding**

*Current and On-Going Activities:*

Throughout FY'07, the focus of family support activities has been to continue initiatives related to emergency preparedness. The Director of Family Initiatives, as well as the Director of OHD and other DPH staff took part in a statewide Emergency Preparedness Task Force in January '07 and are members of working groups that grew out of that meeting. Family Initiatives staff has provided training to community organizations, consumer boards and DMR Family Support workers on best practices and strategies for assisting families to develop their emergency plans. 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 an emergency or disaster. Materials, presentations and technical assistance regarding the special support needs of individuals with disabilities are made available. 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 \$ 250,000 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 FY'07, the line received 1810 calls of which 977 were from families. Callers receive information, technical assistance, referral and support from two dedicated Resource Specialists.

Through its Office of Specialty Services and 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. In FY'07, 50,000 brochures in five languages were distributed. A new initiative, Partnering for the Success of Children with Hearing Loss, brought together families, providers and other community members to identify strategies to maximize the linguistic, communicative and literacy development of children who are deaf or hard of hearing.

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:*

In response to information gathered from families/consumers throughout FY'07, DPECSH will work to develop a number of new collaborations with internal and external partners. Our goal will be to embed an awareness of the unique needs of children with special health care needs and their families within DPH and other agency programs that already think about children and families such as Nutrition, Obesity, Physical Activity, Adolescent Health, Violence Prevention and School Health Services.

Families also told us that they needed expanded access to information, referral, resources, support and Parent to Parent connections. To address these articulated needs, we will:

- Maintain and broadly disseminate up-to-date program descriptions. This will be available in hard copy and on websites in English and Spanish. Efforts to work with agency and organizational partners to make this information available to health care providers as well as families will be made.
- Develop and disseminate information about transition from Early Intervention to special education and community settings and to the adult health care system. Families' requests for guidelines, timelines and check lists will be honored.

- Identify and utilize resources and strategies to broaden Parent to Parent supports for families whose children are birth to 22.

#### **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 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. In FY'07, 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 FY'07 over 3000 families called these lines for information, referral, Parent to Parent matches and training opportunities. These projects also host web-sites and list serves. 1000 Family TIES Resource Directories, 5500 project brochures in English, Spanish and Portuguese and six editions of the **Parent Perspective** were distributed. Portalizing of the DPECSHN program websites made information about programs and services more accessible to the public. FAQs about emergency preparedness and the FY'07 Family Support Plan were made available on-line. **Growing Up Healthy, a Child Health Diary**, which includes information about special health needs and emergency preparedness as well as "**Directions: Resources for My Child's Care**" a manual to support families of CSHCN to participate in their child's care is available to families whose children have special health needs.

##### *New Initiatives:*

- Family Initiatives staff will expand collaboration with the Massachusetts Family to Family Health and Information Center, a project of the Federation for Children with Special Needs to increase access to information for families.
- Possible collaboration between DPH and DOE to increase understanding of health related issues within special education services will be explored.
- Family Initiatives and FPPI staff will identify opportunities to present information on Institute activities and lessons learned.

#### **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. Ten new community based organizations were identified and relationships established that will foster connections with diverse individuals. A training session about resources within state agencies and the community was offered to individuals from the Haitian, Chinese and Eritrean communities. In FY'07 information gathering for the Family Support Plan, bilingual/bicultural staff facilitated focus groups with two groups of Spanish speaking families. 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. In FY'07, the Office of Multicultural Health instituted a telephonic interpreter services line. This has greatly increased staff ability to communicate with individuals speaking languages other than English.

*New Initiatives:*

- **Parent Perspective** newsletter of the Early Intervention Parent Leadership Project will incorporate Spanish translations of lead articles in each addition.
- Family Initiatives will provide some financial support to Mass Families Organizing for Change leadership development initiatives to expand the participation of Spanish and Cambodian speaking families.

## **VI Interagency Collaboration**

*Current Activities:*

- The Massachusetts Early Childhood Comprehensive Systems Project (MECCS) , sited at DPH, has established a Commissioner-level Interagency Steering committee to work towards better coordination of services for young children.
- MECCS partners with Department of Mental Health, institutions of higher education, community organizations, families and United Way of Mass Bay and Merrimack Valley to address early childhood mental health issues.
- DPH is working 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 22-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 and the Federation for Children with Special Needs was implemented with a pilot site in Cambridge-Somerville.
- DPH participates in the Chapter 171 working group convened by DMR to share information about agency Family Support plans and implementation activities.
  - DPECSHN Transition Coordinator works closely with the Department of Education to incorporate information about health care transition for adolescents and young adults.
  - DPH and EEC have collaboratively produced a Guide for Families about transition from Early Intervention.

*New Initiatives:*

- DPH and EEC will develop a dissemination plan for the Family Transition Guide to support families transitioning from Early Intervention to public school or community based programs.
  - A Helping Hand will expand to two additional sites in the central and western parts of the state.
  - DPECSHN staff will collaborate with Department of Early Education and Care on workforce development, expansion and retention.