

Department of Public Health  
Department of Public  
Health Annual Family Support Plan – FY '04

**Background**

The mission of the Massachusetts Department of Public Health is to promote healthy people, healthy families, healthy communities and healthy environments for the people of Massachusetts. DPH programs and services respond to the articulated needs of individuals, families and communities and seek to promote high quality, comprehensive, community-based, family-centered systems of care throughout the Commonwealth.

The Department takes a leadership role in creating and maintaining public health promotion and education initiatives designed to prevent disease and disability and to reduce the impact to both individuals and society of preventable health conditions and secondary effects.

Department initiatives are designed to reach a broad range of individuals with a variety of abilities. All programming is planned to accommodate individual needs and based on substantial consumer input. However, several bureaus within the Department have specific programs to meet the needs of individuals with disabilities and their families. These programs are found primarily within the Bureau of Family and Community Health (BFCH), Bureau of Substance Abuse (BSAS) and the AIDS Bureau.

Within BFCH, the divisions for Special Health Needs (DSHN) and Perinatal and Early Childhood Health (DPECH) maintain a number of programs providing services to individuals with disabilities and their families. Many of these programs are able to offer flexible supports based on family/consumer identified areas of need.

**Overview of Family Support**

The BFCH has a 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<sup>a</sup> 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 <sup>B</sup> Representing the Bureau and its commitment to family-centered services in interagency initiatives <sup>a</sup> Representing the Bureau and its commitment to family-centered services with other organizations on the state and national level <sup>o</sup> 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 travel expenses. Funds are disseminated through DPH vendors and in some cases, from DPH directly to families. In Fiscal Year 2003, approximately 1300 families accessed over \$1,500,000 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 used a variety of approaches to gather input from family members on current family supports and on the development of this Annual Family Support Plan. Detailed information about family/consumer

responses is available in a separate report and will be used to guide all planning and implementation. Approaches included:

- Regional meetings with families who are staff and consultants to DSHN and DPECH programs;

- " Telephone surveys to families who have called Family TIES, a statewide information

- and referral network for families whose children have special health care needs;

- " Focus groups at scheduled statewide meetings and conferences;

- Individual conversations with families utilizing DPH programs and services;

- Survey questions discussed between care coordinators and their client families, and " Information gathered by the DPH Public

Benefits Specialist during hertalks 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 we promote 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 suggestion? 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:*

' Monthly meetings to discuss MCH Block grant planning

<sup>B</sup> A Family Advisory Council for the Catastrophic Illness in Children Relief Commission

" Regional family meetings to discuss uses of Early Intervention Regional Consultation

Program respite funds " Development of Family Advisory

Councils at Medical Home community-based practice sites " Personal calls

from Family TIES coordinators to randomly selected families who have used

the project to ask for information about unmet/under-met health needs and strategies to address these needs. " Regular mailings of Family Support Survey to randomly selected clients of care coordination and Family TIES

## **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. » Family TIES, a statewide information and referral network offers, parent-t&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 play advisory roles with health care and related organizations. <sup>a</sup> 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 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:*

The Department will convene and facilitate a Leadership Institute for representatives of a variety of family advocacy and support organizations statewide. This Institute will bring together experienced family leaders to identify challenges and solutions and to provide opportunities for support, training, networking and collaboration. Within the Department, a series of information and training opportunities for new parent staff and emerging leaders will be provided. Topics such as understanding the legislative process, balancing work, family and advocacy, conflict resolution, effective communication skills, opportunities for involvement, etc. will be offered. Additionally, the Department will increase funding for families to attend conferences, meetings and presentations that will develop and enhance their leadership skills.

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

### *Current Activities:*

Within the BFCH, families are offered training in the development of leadership and advocacy skills, DSHN and DPECH fund training workshops for families on the legislative process, policy making and presentation, facilitation and communication skills that enable family members to feel prepared and comfortable participating in policy activities. Families are offered opportunities to attend local, regional, state and national conferences with their professional partners. Their expenses are covered by the DPH, with support and mentoring before, during and after all meetings.

- Family and Community Support – Staff work with families of CSHCN to help them access community-based services, collaborate with educational, social service and medical providers in order to minimize fragmentation in service delivery and to advocate for the development of comprehensive, coordinated, community based systems of care for children and adolescents with complicated health needs.

Available services include:

- Reimbursement for a broad range of expenses for goods and services related to raising a child with SHN, including insurance co-pays, respite care, supplies, equipment or assistive technology, camperships, advocacy

costs and household expenses. " Care coordination operated out of DPH regional offices and out-stationed in medical home practices that administers flexible funds

available to families once a year. " Special Medical Fund that helps families pay for expenses related to their child's special health care needs including PKU, epilepsy, and hearing aids.

° CICRF – a fund established by the Massachusetts legislature to help families bear financial burdens associated with the care of children with special health care needs and disabilities. The Fund is overseen by an independent, multidisciplinary Commission and offers (based upon eligibility determination and Commission policies) the following:

<sup>a</sup> Financial assistance to families whose children are under age 19 with medical

and related expenses totaling more than 10% of gross family income. <sup>B</sup> Examples of assistance include travel, lodging and per diem for medical care, home and vehicle modifications, medication and insurance co-pays, household expenses.

<sup>B</sup> Early Intervention Regional Consultation

Programs – regional multidisciplinary teams that provide expert consultation to Early Intervention and child care providers in order

to ensure availability of high quality, community-based services for CSHCN and their families. Program includes:

<sup>B</sup> Collaboration with Office of Child Care Services (OCCS) for day care vouchers for children served by RCPs

<sup>0</sup> Respite dollars up to \$600 per eligible family annually. <sup>a</sup> Family activities such as museum

outings, community swim and music programs, infant massage, etc. <sup>8</sup> Training opportunities

such as CPR and managing sibling issues and medically complex children  
" MassCARE – Massachusetts Community AIDS Resource

Enhancement. Program is designed to ensure access to comprehensive, family-centered, culturally and linguistically competent services

for individuals living with, or caring for others, with HIV. Family Support initiatives include:

" Family Advisory Network

- Fathers' groups

- Peer support and advocacy " Education and training

- Family Initiatives – Ensures multiple and varied opportunities for families to participate in the development, implementation and monitoring of program policies, procedures and practices including:

- " Stipends for child care and transportation that facilitate parent involvement in educational, leadership and social opportunities

- Parent-to-parent support » Mentoring to enhance parent and family participation in policy and planning activities of the divisions " Multiple pathways to actively participate including meetings, conference calls, email, regional coffees, etc.

" MASSTART – Massachusetts Technology Assistance Resource Team which provides assistance to families and schools re: the health and safety needs of children and adolescents with special health needs, especially those assisted by medical technology.

*New Initiatives:*

Families responding to surveys, face-to-face meetings and telephone interviews designed to obtain "substantial" consultation regarding their support needs have identified specific concerns to be: access to medications, supplies, technology; and general assistance for themselves and or their children in emergency situations or natural disasters. The Department will be addressing these concerns by allocating

resources from our joint HRSA/CDC grant for emergency and bio-terrorism planning which calls for the hiring of a Special Populations Coordinator who will collaboratively plan for the needs of individuals with special health care needs in case of emergency. The Public Health Nursing Advisor hired for this position will work regionally in collaboration with DPH-designated community-based, Medical Home primary care practices.

The incumbent will bring together teams comprised of individuals with disabilities, their families, physicians, pharmacists, emergency personnel, including fire, police and hospitals, insurers and other community members to identify-resources and develop communication strategies. These groups will address individual concerns, such as the ability to fill prescriptions for longer than one month, loss of electricity, etc., and assist with the development of individualized plans for families of CSHCN to be activated in case of emergency conditions with community assistance as needed.

A second new initiative is the formation of a working group of DPH staff, external experts and families to gather information on current research and thinking about mitochondrial diseases. The group will develop recommendations and assistance for families as they advocate for consistent supports from public and private insurers. A final area of flexible support will be mechanisms to solicit family input into the policies and procedures developed for the disbursement of funds through the Catastrophic Illness in Children Relief Fund.

#### **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. Our Public Benefits Specialist provides training across the state and offers technical assistance through a toll free number. Family TIES and E1PLP both maintain toll free numbers. These projects also host web-sites and list servs. The Early Intervention Training Center (EITC) includes families in all its offerings to the EI field.

##### *New Initiatives:*

In the coming year, the Department will support regionally-based training for families whose children are transitioning out of Early Intervention to provide information about community-based resources and supports. We will convene regional family forums to communicate,

action steps and activities of our family support plan and to solicit ongoing input into the formulation of future plans. Training is being designed and will be disseminated around medical transition from the pediatric to the adult health care system. The Public Benefits Specialist will collaborate with Early Intervention programs and with medical home practice sites to share information and communicate directly with families.

## **V. Culturally Competent Outreach & Support**

Current Initiatives:

Materials about our 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 native speakers, 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.

New Initiatives:

<sup>B</sup> The Department will implement a toll free line for Spanish-speaking families through the Family TIES project. Family TIES parent coordinators will conduct targeted regional outreach to key representatives of community groups and organizations where ethnically, culturally and linguistically diverse individuals and families gather and receive services to facilitate the flow of information regarding the availability of flexible family supports.

<sup>a</sup> The Individualized Family Support Plan (IFSP) Guidance Document will be translated and available in Spanish.

<sup>B</sup> TTYs will be installed in all regional DPH offices with a dedicated line answered by the Special Populations Coordinator, who will also conduct outreach to the Deaf and Hard of Hearing community with assistance from culturally competent community-based individuals.

## **VI. Interagency Collaboration**

Current Activities:

- The Department of Public Health has an ongoing collaborative relationship with the Office of Child Care Services (OCCS) designed

to increase the capacity of childcare providers to care for children with disabilities and special health care needs. Planning and shared funding has supported training for providers and subsidies for families.

.” DPH collaborates with the Department of Education to provide training for early care and education professionals to meet the needs of children with disabilities and special health care needs (CSHCN) in the community.

- The DPH is working with the Department of Social Services (DSS) in a pilot project in four sites statewide, the Massachusetts Early Childhood Linkage Initiative (MECLI). This initiative triggers an automatic referral to Early Intervention for children within the state child welfare system where there is a positive DSS finding.

New Initiatives:

- DPH will participate in a working group of EOHHS agencies to work collaboratively on development, implementation and evaluation of agency Family Support plans. ” In addition, we will take part in jointly-sponsored cross-agency forums in the spring of 2004 to get feedback on first year activities and direction for future planning. ” The Department will support the development of “one-stop” family centers for health information proposed by Mass Family Voices and DMR.

- With collaboration from DMH and DMR, the Department will develop partnering relationships among family organizations supported by sister agencies to increase opportunities for leadership development.

- The Department participates routinely in EOHHS led committees and work groups that seek to improve access and services for families.