

Family Participation Work Group

“Develop and support an expanded network of informed and engaged families working to monitor and improve health care financing systems for CSHCN in the Commonwealth.”

Source: Massachusetts Initiative to Address Adequate Health Care Financing for CSHCN”, a 4 year project supported through a grant from the Maternal & Child Health Bureau, 2002-2006

Goals for the Family Partners Initiative (FPI)

- To demonstrate sustainable partnership roles for family members in health care organizations
- To develop a detailed understanding of the key factors for building successful partnerships

FPI: “Not built in a day”

- Culmination of 2+ years of preparation
 - Interviews with Consortium family members
 - Needs assessment with family organizations across the state
 - Survey and interviews with Consortium members about family roles in their own organizations
 - Presentation at June 2003 Consortium meeting and Resource Fair

Critical Aspects of the FPI

- A pilot
- Demonstrated a variety of potential roles for family members
- Worked with a range of health-related organizations
- Developed sustainable partnerships

Critical Aspects of the FPI cont.

- Expanded on existing knowledge and experience with partnerships
- Built in collaboration with family leaders and organizations in MA
- Family members involved in improving *systems* of care for CSHCN while representing and speaking for many families

Developing the FPI Pilots

- Recruited and screened organizations
- Identified and refined potential family partner role
- Developed set of specific objectives and timeline
- Recruited family partners

Developing the FPI Pilots cont

- Identified mentors for each family partner
- Oriented family partners (2 half-days)
- Monitored progress
- Provided technical assistance to organizations
- Supported family partners
- Assisted with transition when pilot completed
- Evaluated accomplishments, challenges, lessons learned

6 Pilot Sites

- Affiliated Pediatric Practices
 - Developed practice-wide Parent Advisory Council
- BU School of Public Health
 - Created family educator/advisor role in MCH Dept to identify strategies for increasing family participation
- Children's Hospital, CCS
 - Established Parent Advisory Group

6 Pilot Sites cont

- Harvard Pilgrim Health Care
 - Developed a curriculum and trained Member Service Reps about CSHCN, family needs and resources available
- Mass Hospital School
 - Developed and implemented a family component for monthly new employee orientation sessions
- UMass Memorial Health Center
 - Organized a Parent Advisory Group for Pediatric Primary Care Clinic

FPI: Was it successful?

- Each site and each family partner would like to continue/grow the role
- Concrete outcomes include:
 - Changed attitudes; excitement about possibilities
 - Establishment of PAGs; commitment to continuing
 - Publications and resources developed
 - Ideas for, and implementation of, new ways to partner with families