



AMCHP Conference -Leadership  
Education in Neurodevelopmental &  
Related Disabilities

Maternal and Child Health Bureau

Parent Partnerships:  
Family-to-Family Health Information  
Centers:  
We Are All Part of the Process

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# Why It Began – Shared Vision

Maternal and Child Health Bureau



Family Voices Web-site 2006



# Levels of Partnerships

Maternal and Child Health Bureau

- Policy
- Program
- Practice





# Why Partnerships -Mission of MCHB

- To provide national leadership, in partnership with key stakeholders, to improve the physical and mental health, safety and well-being of the maternal and child health (MCH) population which includes all of the nation's women, infants, children, adolescents, and their families, including fathers and children with special health care needs.



# Why Parent Partnerships- MCHB

- Provide Services and Supports
  - Building Leadership
  - Improving Performance
  - Assuring Accountability



# Family Centered Care Is ...

Maternal and Child Health Bureau

- The Standard of Practice in Pediatrics
- The Model for Consumer Driven Health Care
- Based on Family/Professional Partnerships, Integrates Cultural and Linguistic Competence





# Family-to-Family Health Information Centers

## Why Important?

### ■ National Survey for CSHCN

- Only 57% of families with CSHCN report they participate in decision making and are satisfied with services they receive
- 1/2+ poor families report receiving care lacking at least one component of family centered care; 47% of Hispanic & 43% of non-Hispanic Black families

### ■ Research – Brandeis Study

- Families prefer hearing/getting support from those who have been there
- Lack of information from providers on resources



# Family-to-Family Health Information Centers

- **Why Important? NFI-Delivering On The Promise**
- **Identified access barriers to:**
  - Comprehensive, family-centered care
  - Affordable insurance
  - Early and continuous screening for special health care needs
  - Transition services to adulthood
- **Also addressed issues for families:**
  - Complexity and organization of services resulting from fragmentation and multiple funding streams
  - Need for family satisfaction






# Family-to-Family Health Information Centers

## Maternal and Child Health Bureau

- State-wide, family run grants
- Promote family-centered care that is culturally competent and involves meaningful family/professional partnerships
- Promote the inclusion of all families as decision makers at the family and systems levels-policy, program and practice
- Promote mentoring and training of family leaders
- Advocate for community systems on behalf of other's rights and honor



# Family-to-Family Health Information Centers

## Maternal and Child Health Bureau

- Develop and disseminate needed health care and related information to families, providers and policy-makers
- Provide education and training opportunities for families *and* providers
- Collect and analyze data related to project activities, family and system impact and the Healthy People 2010 agenda for CYSHCN
- Help families navigate systems
- Will be a community of learners by linking with community and state partners, Family Voices and CMS F2F Centers (29)



# Family-to-Family Health Information Centers

- **MCHB State Implementation Grants**
  - \$2.5 million past 4 years
  - F2F Health Information and Education Centers (FL, IL, ME, MN, TN, VT/ CA, IA)

# Family-to-Family Health Information Centers



Maternal and Child Health Bureau

- ♥ In 2006 35 states had F2F HICs through funding from MCHB and CMS
- ♥ Family Voices, through an MCHB funded National Center on Family/Professional Partnerships and sub contracts with CMS grantees, provided TA and a variety of communication vehicles/opportunities to connect these F2F HICs in a national network of peer support



# Family Opportunity Act

## Maternal and Child Health Bureau

- Appropriations for the Maternal and Child Health Bureau, Division for Services for Children with Special Health Care Needs to develop **Family-to-Family Health Information Centers** in each one of the fifty states & DC
- \$3,000,000 for fiscal year 2007 for not less than 25 states;
- \$4,000,000 for fiscal year 2008, for not less than 40 states (15 additional); and
- \$5,000,000 for fiscal year 2009 and each fiscal year thereafter, in all states



# Family Opportunity Act

## Maternal and Child Health Bureau

- Assist families of CSHCN make informed choices about health care in order to promote good treatment decisions, cost effectiveness and improved health outcomes;
- Provide information regarding the health care needs of and resources available for CSHCN
- Identify successful health delivery models
- Develop with representatives of health care providers, managed care organization, health care purchasers, and appropriate State agencies, a model for collaboration between families of CSHCN and health professionals;



# Family Opportunity Act

## Maternal and Child Health Bureau

- Provide training and guidance regarding the care of CSHCN
- Conduct outreach activities to families, health professionals, schools and other appropriate entities; and
- Be staffed by such families who have expertise in Federal and State public and private health care systems and health providers.



# Family Voices: Connecting F2F Centers

## ■ F2F Centers:

- Increase of families in, policy and advocacy committees – training & mentoring
- Increase in obtaining services – information, peer navigators, parent liaisons, contacts
- Increase in emotional support – support groups, social worker
- Increase in outreach to geographically & racially diverse populations, translated materials
- Bridge to agencies, organizations





# Family Voices: Connecting F2F Centers

- Information and Assistance Provided
  - F2F HICs report receiving the most requests for information and assistance on health care financing and community services, as well as requests on parent to parent support, specific disability, transition, partnerships, advocacy, etc.
  - F2F HICs estimate that approximately 36% of all families they serve are from underserved communities including socially and economically diverse communities and underserved geographic areas



# From Data to Policy

Maternal and Child Health Bureau

*“The families that are reporting problems with Medicaid are reporting a number of issues...We are finding that families are being denied a number of services...when they would have been provided those services a year ago....”*

VT F2F HIC



# Family Voices: Connecting F2F Centers

- Family leaders report impact of their activities within their states
  - ♥ Family leaders working with a Medicaid Agency identified streamlined way for parents to share information about their primary care provider when MCOs in the state changed
  - ♥ Family activism helped stave off cuts to Title V programs
  - ♥ Family leadership helped to involve Chinese speaking families in program and policy activities
  - ♥ Family leaders impacted the development of waivers, immigrant eligibility for programs, assessment tools for Medicaid long term care
  - ♥ Families' e-mails and letters had a significant impact on proposals to charge hefty premiums for Medicaid waivers



# From Data to Policy

**Maternal and Child Health Bureau**

*“Families have received referrals for complex oral health needs and prenatal care for young adults with behavioral issues, among many other topics. Policy Makers have received information about family care giving issues and the need for our state to apply for a Medicaid waiver for children with developmental disabilities.”*



## Partner with a F2F HIC

- Connect family leaders – share educational opportunities
- F2F HIC families can participate in your training of professionals and you with their trainings
- List serves, newsletters
- Expand diversity
- What are your ideas?



# Building Partnerships



***Partner:*** one who shares with another or others for a mutual benefit

***Essential Components:***

- ✓ Building trust, nurturing trust
- ✓ Actively listening & engaging
  - open & honest
- ✓ Open to new opportunities for learning, sharing power and moving forward
- ✓ Establishing clear expectations, roles & responsibilities
- ✓ Acknowledging mutual respect for each others' cultures, values and traditions
- ✓ Commitment





# Contact

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