

# National Center for Family/Professional Partnerships

Family-to-Family Health Information Center Data Brief on Activities from July 2007 – June 2008



Helping families of children and youth with special health care needs partner in decision making at all levels

## The National Picture:

### 22% of U.S. households with children have at least one child with special health care needs<sup>1</sup>.

Family-to-Family Health Information Centers (F2F HICs) help families of children and youth with special health care needs (CYSHCN) and the professionals who serve them. As parents themselves, staffs at F2F HICs understand the issues that families face, and offer a multitude of resources and supports that help families navigate complex systems and CYSHCN receive quality health care.

In one year (July 2007 - June 2008), 29 F2F HICs:

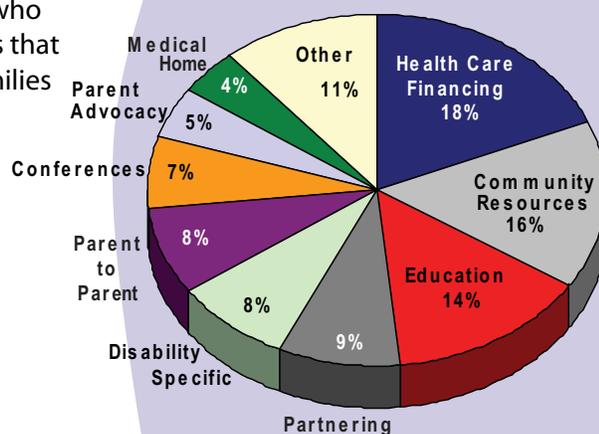
#### Responded to over 206,000 requests for individualized assistance:

- 65% requests from families; 35% requests from professionals;
- Helped families and professionals who serve families navigate **Health Care Financing systems**;
- Provided connections to **Community Resources**; and
- Worked with families and providers to develop **partnerships** that improve communication, care, and access to a **"Medical Home."**

#### Provided training and information to many families and professionals, often collaborating with Title V, American Academy of Pediatrics and other organizations in their state:

- Participated in over **9,600 meetings** attended by almost **240 thousand families and professionals**;
- Disseminated over **1.5 million newsletters**;
- Disseminated almost **400 thousand fact sheets, guidebooks, brochures, and other materials**;
- Exchanged information with over **340 thousand individuals** by listserv;
- Recorded over **24.5 million webhits**; and
- Reached **families from underserved communities (45% of all families served)**

## Information Provided



## Outreach to Families



*"We spoke in mid-September when among other wonderful assistance, you (Mass Family Voices F2F HIC) provided me information on resources families could use to more effectively partner with their children's providers. I've spent a few hours this afternoon looking through information I've gathered from the websites & just wanted to send a big THANK YOU!!!! This has been an amazing treasure of information you lead me to & I know I'll have many opportunities in working with families to help guide parents! Thanks again for all your help!"*

## State by State Solutions:

- AZ:** Raising Special Kids trains physicians in pediatrics and family practice residency programs in **family-centered care** through home visits with trained Family Faculty, ensuring that new health care practitioners will better understand the complexities and context of everyday life for CYSHCN and their families.
- CA:** Family Voices of CA promotes **family-centered care** for families, including **families of diverse backgrounds**, with a questionnaire to help families identify needed post-hospital care. This tool is used throughout the state by the Family Voices of CA's Parent Health Liaison Network, the 47 Family Resource Centers and can be downloaded by families and professionals. By obtaining critical information before their child leaves the hospital, the questionnaire reduces the likelihood that parents will need to call or visit their providers because of misunderstandings, mistakes or confusion and greatly reduces the families' anxiety and stress.
- DC:** Family Voices of DC is actively involved in a **family-professional partnership** with the DC Title V Department of Health/Community Health Administration (DOH/CHA) to develop a Medicaid Waiver or amendment, which is expected to help about 4,000 families access additional medically necessary services and supports for their child that are not covered by existing public and private plans.
- HI:** Hilopa'a Family to Family Health Information Center serves as the state's first Medicaid Ombudsman for QExA (QUEST Expanded Access) and assists that agency in improving the efficiency and effectiveness of its services and policies, demonstrating a **family-professional partnership**.
- IL:** Family Voices of IL provides training to providers through the IL Medical Home Project and the Medical Home Autism Project Seminars, resulting in helping providers to understand family perspectives and to implement **Family-Centered Care and Medical Homes**.
- MD:** Parents Place of Maryland has an active **family-professional partnership** with the MD Medicaid Office in which a PPMD staff member works in the Medicaid office one day a week, reviewing materials and providing guidance on policy. This work has resulted in a change to the instructions on the Medicaid card, resulting in streamlined communication with families and improved use of Medicaid staff resources.
- ND:** Family Voices of North Dakota, Inc. educated legislators about family needs, resulting in a new FOA Medicaid Buy-In program. Executive Director Donene Feist was awarded the prestigious 2008 RWJ Community Health Leaders Award for her service to families of CYSHCN, including **families of diverse backgrounds** in rural areas and Native American Tribes.
- NJ:** Statewide Parent Advocacy Network (SPAN) assists **families of diverse backgrounds** (immigrant, limited English proficient, and African-American families) through monthly support group meetings, accompanying families to a variety of meetings, connecting them to other immigrant parents for ongoing emotional support, and/or helping them access a "**Medical Home**."
- MS:** The Institute for Disability Studies @ USM provides **family support** to low income families of CYSHCN who utilize the Children's Medical Program's at the Jackson Medical Mall location. Co-location at the First Steps Early Intervention Resource Library at the Mall creates a **partnership** that ensures high level of coordination in the provision of services to families, resulting in assisting 233 families during the first year of the project.
- PA:** The Parent Education & Advocacy Leadership Center (PEAL), is active in a **family-professional partnership**, Every Child Deserves a Home and Family, an effort to address the fragmentation and gaps in services for PA CYSHCN and their families. The group identified barriers to coordinated and accessible services and presented recommended changes to state program administrators, that promise to benefit over 200,000 children in PA. Many of these changes would be of little or no cost to taxpayers.
- RI:** Family Voices @ the RI Parent Network (RIPIN) Resource Specialist provides **family support** to inmates at the Women's Prison through workshops and pre-release services, such as providing focus groups and locating basic resources, including food, clothing, vital records, housing, and parenting information.
- SD:** South Dakota Parent Connection focuses on **family support** and **family-professional partnerships** in working with Augustana College, USD Center for Disabilities at Sanford School of Medicine, SD Council on Developmental Disabilities (CDD) and other agencies to provide "Lighting The Way," an annual conference about Autism, in which hundreds of families and professionals from across South Dakota and neighboring states share resources to improve community systems.
- TX:** Texas Parent-to-Parent promotes **family-centered care** by having family faculty provide training to pediatric and family practice residents. They recently received a grant from the Centene Foundation to expand this Medical Education Program.
- WI:** Family Voices of Wisconsin has trained over 400 families on the fundamentals of health care and community supports through its ten-hour, five module "Did You Know? Now You Know!" training program. This training is delivered in a variety of formats and has been adapted to meet the needs of **families of diverse backgrounds**, including participants from the African American, Latino, Native American and rural Wisconsin communities.

## Problems:

- **Low-income families experience greater financial burdens** than higher income families
- **33% of insured CYSHCN have inadequate coverage**<sup>1</sup>
- **20% of families with CYSHCN pay \$1,000 or more in out of pocket expenses**<sup>1</sup>
- **24% of families of CYSHCN cut back or stop working** because of their child's health conditions<sup>1</sup>
- **Quality declines** when a culture gap exists between providers and patients
- **Ethnic/culturally/racially diverse populations are less likely to have access** to health care and health insurance

## Solutions:

### Family-Professional Partnerships:

- Identify unmet needs,
- Improve systems,
- Improve efficiency and effectiveness in use of health care resources

### Family-Centered Care:

- Helps professionals understand family needs
- Improves clinical decision making
- Improves follow-through

### Medical Homes

- Reduce hospitalizations
- Reduce length of stay in hospital
- Reduce ER Utilization

### Family Support:

- Increases confidence and problem-solving
- Helps families utilize services
- Decreases parental anxiety in caring for children

### Reaching Families of Diverse Backgrounds:

- Helps families most in need learn about and access services
- Helps reduce unnecessary expenditures and emergency room utilization
- Helps to address inequities

<sup>1</sup> U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. *The National Survey of Children with Special Health Care Needs Chartbook 2005-2006*. Rockville, Maryland: U.S. Department of Health and Human Services, 2007.