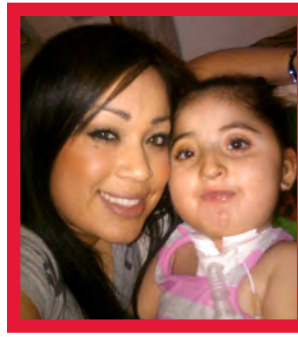




FAMILY-TO-FAMILY HEALTH INFORMATION CENTERS

Helping Families of CYSHCN &
the Professionals who Serve Them

Report on Activities, June 2011-May 2012



What are Family-to-Family Health Information Centers (F2F HICs)?

F2F HICs are statewide initiatives that assist families of children/youth with special health care needs or disabilities (CSHCN) and the professionals who serve them. F2F HICs are uniquely able to help families because they are staffed by family members of CSHCN, who have first-hand knowledge and training in navigating the maze of health care services, programs, and insurance coverage for these children. F2F HIC staff assist families in making informed decisions in order to promote appropriate, cost-effective care and achieve optimal health outcomes.

There is one F2F HIC in every state and the District of Columbia. Each receives a small but critical federal grant through the Maternal and Child Health Bureau.

“Being able to talk to someone that can provide, not only information and assistance as a professional, but in addition can offer love and emotional support, because they are parents, is something that cannot be found anywhere else.”¹

How do F2F HICs Help Families?

They provide:

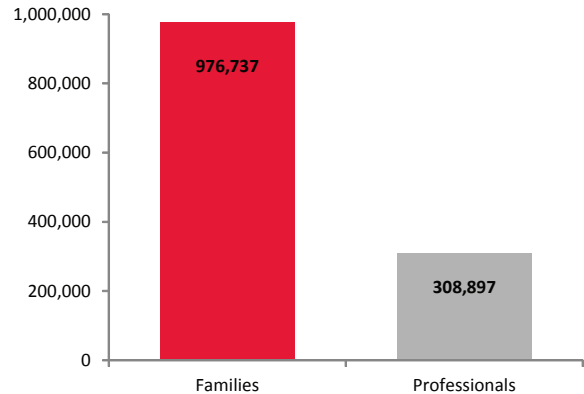
- One-to-one assistance in accessing health care and community-based services
- Information, education, training, support, and referral services for families and professionals
- Help in navigating public and private health programs
- Outreach to underserved / underrepresented populations
- Partnerships with state agencies and other stakeholder groups to guide health programs and policy
- Collaboration with other F2F HICs and family groups to share best practices

“As part of a recent redesign of the Title V CSHCN Program, newly identified families with CSHCN receive an initial home visit by a nurse, social worker, and either an F2F staffer member or a Parent Network Specialists. This new approach has been designed to improve care coordination, incorporate aspects and improve education related to the Medical Home model, and most of all, provides better services to families.”¹

What Does Data from F2F HICs Tell Us?

(Data Reported by F2F HICs from June 2011-May 2012)

People Served:



“After our recent state conference, “Joining Voices”, one policy maker said (this conference) has helped me to see there are families prepared to partner in a positive way.”¹

Information Provided to Families & Professionals— Top 3 Most Frequent Topics:

1. Public Health Care Financing Programs

Eligibility requirements of Medicaid/SCHIP, applying, knowing what services are covered, fighting denials

2. Family Support

Matching families with trained support parents, peer mentoring (youth), supporting/educating mentors

3. Family/Provider Communications

What families should ask providers, what they should share, being confident, cultural/linguistic barriers, medical home

Partnerships to Improve Care:

- On average, each F2F HIC partners with 16 statewide and 11 community-based organizations
- Initiatives that F2F HICs are most frequently involved in include Medicaid Waivers, Medical Home, Transition/ Youth Leadership, Family-Centered Care, Medicaid, and Provider Training

National Center for Family/Professional Partnerships • www.fv-ncfpp.org

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What is the Impact of F2F HICs?

As a result of services received by the F2F HIC¹:

- 94% of families are better able to partner in decision-making
- 93% of families are better able to navigate services
- 91% of families are more confident about getting health care services their child needs

*"Thank you for responding so quickly when I had a problem with homecare nursing. The contacts you gave me really worked out. It's reassuring to know there are people out there who support you in times of trouble."*¹

Conclusion of Independent Review of F2F HICs²:

"Ultimately, the FHICs' goal is to improve health and functional outcomes for families with CYSHCN. To the extent families understand what is available for their children and use services effectively, outcomes for their children will improve. These benefits go well beyond the children and families. Children whose outpatient needs are met and whose parents are able to meet their daily care needs are less likely to require hospital or emergency room care. Children who obtain home and community long-term care services are less likely to need costly institutional care."

Who are CSHCN?

Those who have or are at increased risk for a **chronic** physical, developmental, behavioral, or emotional condition and who also require **health and related services of a type or amount beyond that required by children generally.**³

- 11.2 million children ages 0-17⁴
- 23% of all US households with children⁴

What is the Impact on the Child?⁴

- 27.1% of CSHCN have health conditions that consistently and often greatly affect their daily activities
- 45.6 % of CSHCN experience 4 or more functional difficulties, such as problems with breathing, communicating, taking care of self, behavior, anxiety
- 15.5 % of CSHCN miss 11 or more days of school/year

*"Macy requires care for every aspect of her life. She is in a wheelchair, has very limited gross motor skills and is non-verbal. She receives diapers, medication and respite care through Medicaid. Because her needs are so extensive she requires many appointments to ensure that her needs are being met."*⁸

What is the Impact on the Family?

- 34.3% of CSHCN have insurance that is inadequate.⁴ In 2000, the average medical expense for children with SHCN was \$2,497.84, more than three times the average medical expense of \$803.12 for children without SHCN.⁵
- 25% of CSHCN families have cut back on work or stopped working.⁴ Parents of children with ongoing activity limitations (as a result of disabilities or other medical conditions) are at an increased risk for poor health and mental health outcomes and lost work time.⁶

*"IPUL (Idaho F2F) empowers parents and guides them to find, educate and apply for needed resources. In my opinion the best part of this is that IPUL doesn't just do the work for you, they teach families how to help themselves."*¹

What is the Impact on Health Care Systems?

- CSHCN account for 40% or more of medical expenditures for children overall⁷
- CSHCN have about 4 times as many hospitalizations and spend more than 7 times as many days in the hospital⁷
- 35.9% CSHCN have public health care (Medicaid/SCHIP)⁴

*"We (Louisiana F2F) uncovered a flaw in the new Medicaid managed care system for mental health and brought the issue to the attention of the behavioral health services contractor. We were able to make sure that the Multisystemic Therapy Services provider list was included in their system and we helped train staff in using this list."*¹

¹ Data submitted to NCFPP from 51 F2F HICs reporting activities from June 1, 2011 through May 31, 2012

² Activities and Accomplishments of the Family to Family Health Care Information and Education Center Grantees, RTI International, 2006.

³ McPherson M, Arango P, Fox H, et al. "A new definition of children with special health care needs," *Pediatrics*, 1998; 102: 137-140.

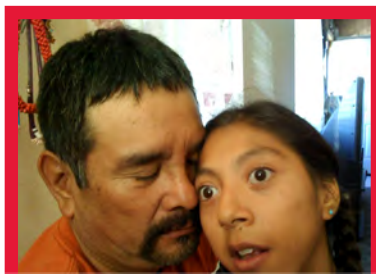
⁴ National Survey of Children with Special Health Care Needs, NS-CSHCN 2009/10 and National Survey of Children with Special Health Care Needs, NS-CSHCN 2005/06. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 01/28/2013 from www.childhealthdata.org.

⁵ Research Findings #24: Utilization and Expenditures for Children with Special Health Care Needs. January 2006. Agency for Healthcare Research and Quality, Rockville, MD. http://www.meps.ahrq.gov/data_files/publications/rt24.shtml

⁶ The Impact of Childhood Activity Limitations on Parental Health, Mental Health, and Workdays Lost in the United States, Whitney P. Witt, PhD, MPH et al. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2743933/>

⁷ Newacheck, PW & Kim, SE. A national profile of health care utilization and expenditures for children with special health care needs. *Archives of Pediatrics and Adolescent Medicine*. 2005;159:10-17.

⁸ North Dakota Family Stories Raising & Caring for Children and Youth with Special Health Needs: What's Working...What's Not...



keeping families at the center of children's health care