

Family-to-Family Health Information Centers



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 the parent of a child with disabilities can be a very isolating experience, when, ironically, what you need most is contact with other parents and their various networks of support.”⁶

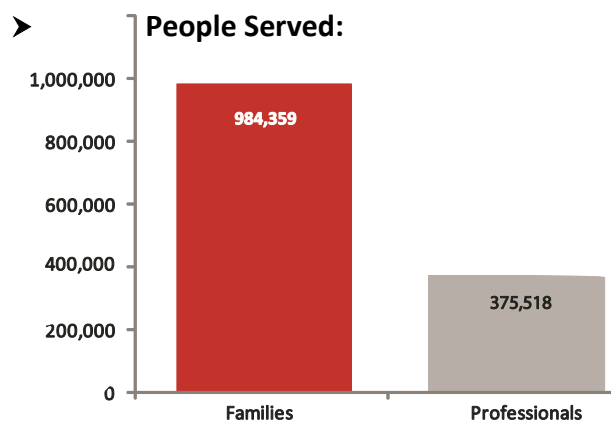
How do F2F HICs Help Families? They provide:

- One-to-one assistance in accessing health care and community-based services
- Information, education, training, support, and referral services for families and professionals
- Assistance in navigating public and private health insurance
- 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

“Quite honestly, I found the Medicaid system to be very difficult to manage, overwhelming, intimidating, and frustrating. Without your assistance and guidance, I likely would not have completed the Medicaid application process. I am so grateful that the MA F2F HIC is run by someone who has gone through the Medicaid application process themselves, understands the difficulties, and is sensitive to the emotions of parents.”⁶

What Does Data from F2F HICs Tell Us?

Data Reported by F2F HICs from June 2010-May 2011⁶



“As an RN Case Manager I know that families with children who have disabilities need to know what services are available and how to obtain those services; they need the support of others, especially of those who are in similar situations. No single organization can offer as much and do it as well as Delaware Family Voices (F2F HIC).”⁶

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

1. Family-Provider Communications

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

2. Public Health Care Financing Programs

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

3. Family Support

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

➤ 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 Family-Centered Care, Autism, Medical Home

February, 2012

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

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This report was developed with funding from the Health Resources and Services Administration (HRSA)/Maternal and Child Health Bureau (MCHB)/Division of Services for Children with Special Health Needs (DSCSHN), through cooperative agreement# U40MC0014980.

keeping families at the center of children's health care



What is the Impact of F2F HICs?

▶ As a result of services received by the F2F HIC⁶:

- 86% of families are better able to partner in decision-making
- 93% of families are better able to navigate services
- 93% of families are more confident about getting health care services their child needs

▶ Conclusion of 2006 Independent Review of F2F HICs⁷:

"Through their work to promote family-centered, culturally competent, and linguistically appropriate care and medical homes for CSHCN, FHICs are contributing to improvements in the quality of health care. By helping families to provide a consumer perspective on program and policy issues, FHICs enable states to develop more effective ways to assist families with CSHCN."

"Losing my insurance turned out to be a blessing in disguise. My 13 year old with Down syndrome and autism gained 40-50 pounds as a result of medications. I contacted SPAN (F2F HIC in NJ) and worked with them and the Federally Qualified Health Center to wean him off the medications and to develop a positive behavior plan. My son is now a totally different kid. He lost 30 pounds in 6 months and his overall health and behavior has significantly improved."⁶

Who are Children/Youth with Special Health Care Needs?

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**¹

- 11.2 million children ages 0-17²
- 23% of all US households with children²

What is the Impact on the Child?²

- 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, anxiety²
- 15.5 % of CSHCN miss 11 or more days of school/year

At 4 months [Anna] had heart surgery at a Children's Hospital in another state, the first of many surgeries and procedures. Now on a breathing machine and needing a heart transplant, her family refinanced their home twice to pay for expenses and they are no longer able to work because of the amount of care that [Anna] requires.³

What is the Impact on the Family?²

- 34.3% of CSHCN have insurance that is inadequate
- 21.6% of CSHCN families have financial problems caused by their child's condition
- 25% of CSHCN families have cut back on work or stopped working

"I cannot imagine going one single moment through Emma's life without Medicaid as her secondary insurance. At times her medical and pharmaceutical bills could easily put our family of six on the street. It's hard enough to raise a family in this day and age, but imagine what it's like to live with children affected by life-long special healthcare needs."⁵

What is the Impact on Health Care Systems?²

- CSHCN account for 40% or more of medical expenditures for children overall⁴
- CSHCN have about 4 times as many hospitalizations and spend more than 7 times as many days in the hospital⁴
- 35.9% CSHCN have public health care (Medicaid/SCHIP)²

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

2 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 01/29/2012 from www.childhealthdata.org.

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

4 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.

5 Children's Health Policy Blog, Georgetown University Center for Children and Families,. Retrieved 01-30-2012 from <http://thecccblog.org/>.

6 Data submitted to NCFPP from 50 F2F HICs reporting activities from June 1, 2010 through May 31, 2011.

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