



For many of the 8.8 million families of children with special health care needs in the US, having adequate financing to pay for health care services and being able to navigate a myriad of community resources needed by their children is an ongoing struggle. Family-to-Family Health Information Centers in every state address this critical need by assisting families and the professionals who serve them in a variety of ways.



Family-to-Family Health Information Centers

Family-to-Family Health Information Centers (F2F HICs) are nonprofit, family-staffed organizations that provide support, information, resources, and training to families of children and youth with special health care needs (CYSHCN) and the professionals who serve them. Established by the Family Opportunity/Deficit Reduction Act of 2005, funding for F2F HICs was recently extended through 2012 by the Affordable Care Act.

F2F HICs are uniquely qualified to help families because they are staffed by family members who have first-hand experience navigating the maze of health care services and programs for CYSHCN. F2F HIC staff understand the issues that families face and help families make informed decisions.

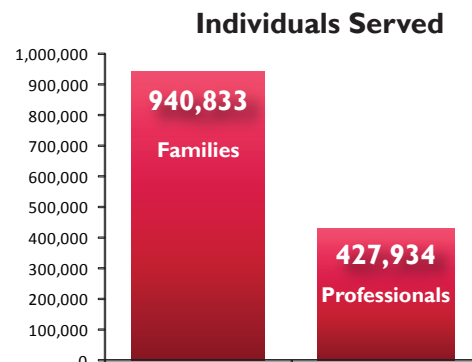
All F2F HICs provide:

- Assistance to families and professionals in navigating health care systems;
- Information, education, training, support and referral services;
- Outreach to underserved / underrepresented populations;
- Guidance on health programs and policy;
- Collaboration with other F2F HICs, family groups, and professionals to improve services for CYSHCN; and
- Evaluation and outcome assessment

This report summarizes data reported by F2F HICs in 50 states and the District of Columbia from June 2009 through May 2010.

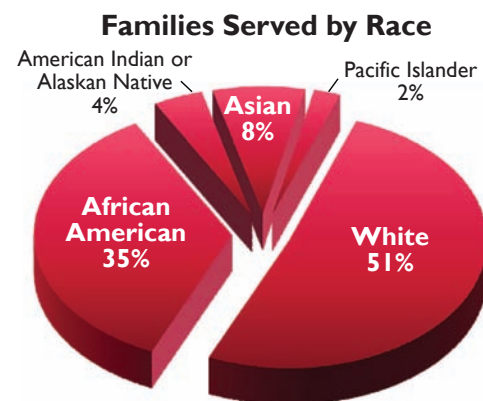
Who do F2F HICs help?

F2F HICs serve both families and professionals.



Of all people served by F2F HICs, 69% were family members and 31% were professionals.

F2Fs outreach to and serve families with CYSHCN in their communities. The chart below shows average percents of families served by race when the family self-identifies.



Of families served, 20% were of Hispanic, Latino, or other Spanish origin.

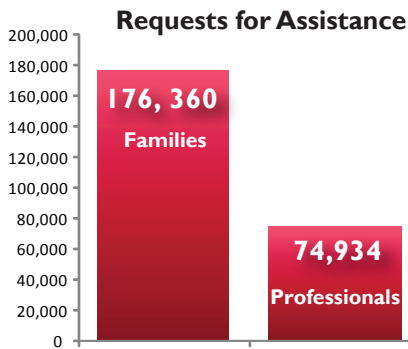
"We did go for a hearing with the Human Services Judge and, because of learning the system and understanding the eligibility requirements, I was able to successfully argue our case. She overturned the denial and we now receive TEFRA . . . It was a scary process, being alone with a Judge and having to prove to a panel of doctors that they made a bad decision. I constantly think of others who do not have experience navigating the system and am very grateful to have learned about the F2F HIC. I could not have done it without you!"

- a parent in Minnesota

How do F2F HICs help?

I-I Assistance

Families find it critically important to talk with someone who understands what they are going through and who can provide support and information. The experienced family leaders staffing F2F HICs provide this individualized assistance, both to families and professionals who may contact the F2F HIC on behalf of a family.

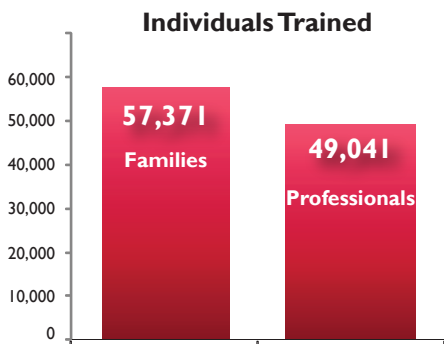


On average, each family made 2.12 requests for assistance, while each professional contacted the F2F HIC 1.98 times for help.

Training

F2F HICs conduct workshops and conferences and are frequently asked to provide trainings at events run by other family and professional organizations.

During this reporting period, F2F HICs trained over 100,000 individuals in 4,263 trainings.



Broad Outreach

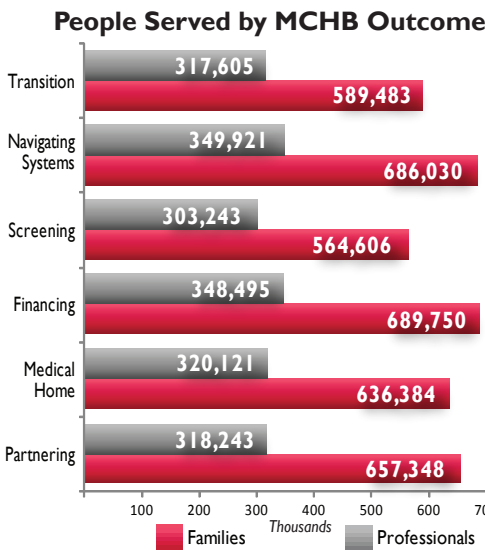
In addition to I-I assistance and training, F2F HICs provide information through a variety of venues to reach many people and to reach people multiple times. These mechanisms include: listservs, newsletters and other materials, community fairs, radio and cable TV shows, and online social networking sites, such as blogs, Twitter and Facebook.

Data indicate that F2F HICs:

- Participated in 11,391 meetings;
- Recorded over 19 million web hits;
- Distributed 1,274,199 fact sheets and other materials;
- Communicated with 329,586 people by listserv;
- Distributed newsletters to 709,255 people; and
- Collaborated in each state, on average, with 16 state-based and 11 community-based organizations to improve services for CSHCN.

What information do F2F HICs provide?

F2F HICs provide families and professionals with a variety of information and resources tailored to their needs.

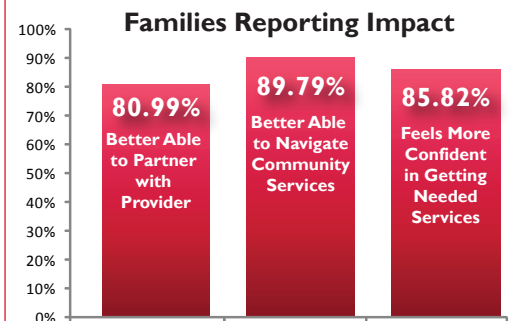


The top 10 topic areas on which information was most frequently provided through I-I assistance and training were:

- **Public Health Care Financing** - accessing Medicaid, SCHIP, Title V, SSI, other public health programs
- **Family Support** - seeking, obtaining, and/or providing family support, such as family-to-family, peer-to-peer, or sibling support.
- **Communicating with providers** - improving the quality of the family-provider relationship.
- **Cultural Competence** - understanding or promoting the family perspective of all cultural/linguistic populations.
- **Care Coordination** - understanding roles of multiple providers & facilitating communication
- **School-based financing** - working with schools regarding financing health-related services
- **Schools** - resolving school issues other than financing
- **Mentoring** - sharing knowledge and experiences with other families
- **Advancing Knowledge** - identifying opportunities to increase skills or knowledge
- **Disability Awareness** - discussing abilities/disabilities, discrimination, attitudinal barriers, civil rights

What is the impact of F2F HICs?

Families report that the assistance and training they received has made a difference:



Family-to-Family Health Information Centers: Helping to ensure family-centered, community-based, culturally competent health care for all



Through the F2F involvement with Boys Town Institute for Child Health Improvement (BTI) ten pediatric practices are progressing through medical home certification. The practices have been learning the value of parent input in the workings of the practice. As a result of this work, BTI is providing funds to pilot Professional Parent Consultants (PPC) in Medical Homes. In the coming year, two PPCs will be placed in two pediatric practices to assist families in their needs, other than medical, for CYSCHCN.

- PTI Nebraska (F2F HIC)

