



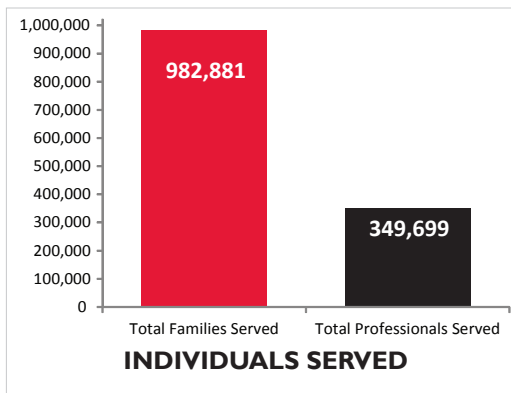
2012-2013 Report of Activities of Family-to-Family Health Information Centers

What are Family-to-Family Health Information Centers?

Family-to-Family Health Information Centers (F2F HICs) are statewide initiatives that assist the families of more than 11.2 million children/youth with special health care needs or disabilities (CYSHCN)¹ and the professionals who serve them. F2F HICs are uniquely able to help families because they are staffed by family members of CYSHCN 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. By partnering with professionals and sharing family perspectives about what is working for families and what is not, F2F HICs play a critical role in shaping programs and policies across the nation.

Who do F2Fs serve?

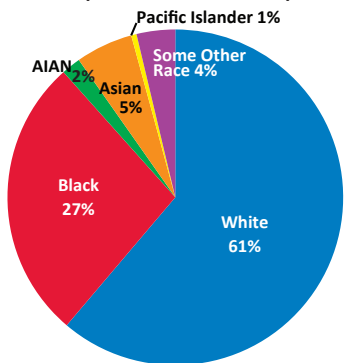
Over the last year 982 thousand families and 349 thousand professionals were provided information, assisted, or trained by the 51 F2F HICs across the country (each state plus the District of Columbia). Information about each F2F may be found at: <http://www.fv-ncfpp.org/f2fhic/find-a-f2f-hic/>.



“Over the years, I have called PTI Nebraska (F2F HIC) for input and advice. I have always received wonderful assistance and think they provide a critical service to parents and children/young adults with various special needs.”

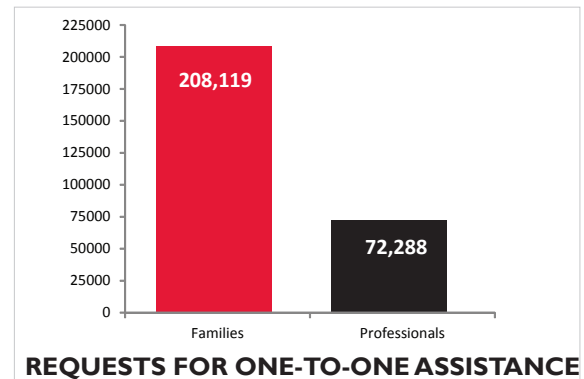
- anonymous survey respondent

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 (about 10% of families served). Of those families who did self-identify 25% indicated they were Hispanic.

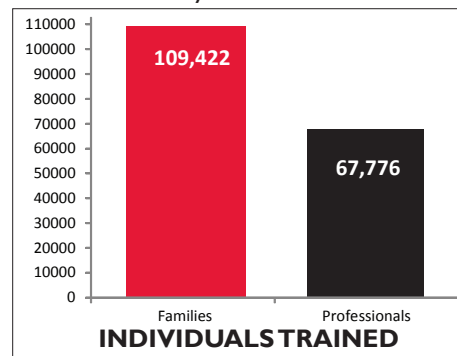


How do F2Fs help families and professionals?

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



Teaching families how to access services and understand new programs like the ACA is an important part of the work. F2F HICs are frequently asked to train professionals about partnering with families. In the last year F2F HICs conducted almost 8 thousand workshops, conferences and trainings across the country.



“Your presentations (SPAN of NJ) were wonderful. The manner in which you set up the slides bilingually and your resources were well thought-out and very user-friendly.”

- Tanya Pagan Raggio-Ashley, MD MPH FAAP,
US DHHS HRSA NY Regional Office

What other ways do F2Fs provide information?

- **By Listserv** - reaching 192,829 families and 96,094 professionals
- **By Newsletter** - reaching 488,500 families and 154,457 professionals
- **By Handouts** and other publications - disseminating 4.5 million materials

What kind of information do F2Fs provide?

F2F HICS provide families and professionals with a variety of information and resources tailored to their needs. The 10 topic areas on which information was most frequently provided through one-to-one 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.
- **Care Coordination** - understanding roles of multiple providers & facilitating communication
- **Advancing Knowledge** - providing information or identifying opportunities to develop family leadership skills
- **Disability Awareness** - discussing abilities disabilities, discrimination, attitudinal barriers, civil rights
- **School-based financing** - working with schools regarding financing health-related services
- **Cultural Competence** - understanding or promoting the family perspective of all cultural/linguistic populations.
- **Schools** - resolving school issues other than financing
- **Systems Involvement** - providing information and mentoring on involvement at a systems level

"In the aftermath of Hurricane Sandy, Parent to Parent of New York State (F2F HIC) provided critical support to families. Working with Office for People With Developmental Disabilities, we arranged for gas deliveries and repair services to keep generators running for families of children dependent on medical technology. Families told us we were the only organization who reached out to them." -NYS F2F Director

Have F2F HICs helped families of CYSHCN?

91% of families report that the assistance and training they received has made them better able to partner in decision-making, better able to navigate services, and more confident about getting the health care services their child needs.

What are the partnership activities of F2Fs?

F2F HICs are engaged in a number of initiatives to address the needs of families in their community. Across the country many of the F2F HICs work on:

INITIATIVE	% F2F HICs Involved
Medicaid Waivers	88%
Medical Home	88%
Transition/Youth Leadership	88%
Family-Centered Care	84%
Medicaid	84%
Provider Training	82%
Autism	73%
ACA Implementation	69%
Title V Block Grant	69%
Title V Needs Assessment	69%
SCHIP	59%
Assistive Technology	57%
Cultural Competence	57%
Disaster/Emergency	57%
Immigrant Families of Diverse Culture	57%
Medicaid Managed Care	57%
Voc Rehab	55%
EPSDT	53%
Mental/Behavioral Health	53%
Respite	51%

The F2F HIC work on these initiatives is accomplished by building partnerships with many community, state, and national/federal organizations, such as:

PARTNER	Average Rating (0= No Partnership to 5=Significant)
Other parent led organizations	4.63
Parent Training and Information programs	4.57
State Title V Programs	4.57
Developmental Disability Agency/Program	4.45
Early Intervention	4.39
Parent-to-Parent programs)	4.30
Department of Education / Schools	4.27
Lend Program or /University Center on Disability program	4.16
Children's Hospital/s or Pediatric Units in Hospitals	4.16
Disability Specific Organizations	4.16
Universities	4.12
Child Advocacy Organizations	4.04
Protection and Advocacy Agencies	4.04
Medicaid Agency	4.00

What is the evidence that family-to-family support helps families?

Peer support is recognized as an important component of family-centered care, which in turn, is associated with higher family and provider satisfaction and with improved cost effectiveness. The AAP recommends that "pediatricians should encourage and facilitate peer-to-peer support and networking, particularly with children and families of similar cultural and linguistic backgrounds or with the same type of medical condition."² Studies indicate that linking parents of children with disabilities to appropriate family organizations and peer support has been shown to positively affect both parents and children.³ "Parents value the opportunity to talk with other parents in the same situation as themselves to share knowledge, experiences and feel reassured. This is viewed as one way of counterbalancing the information received from official sources such as health professionals, which is often perceived as supporting a particular course of action."⁴

What is the evidence that family-run organizations improve systems?

Although this topic has not been widely researched, studies in the mental health field show that "statewide family advocacy organizations are an important catalyst in the system reform efforts in children's mental health. They increase the support, information, and advocacy of families of children with serious emotional disorders, as well as increase family member participation in the promotion of an improved child mental health system of care."⁵ Other research asserts that F2F HICs "are well positioned to help expand access to medical homes where partnerships are built between families and health care professionals."⁶



As the National Center for Family / Professional Partnerships, Family Voices provides technical assistance, training, and connections among F2F HICs and partnering organizations.



1 National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 01-14-2014 from www.childhealthdata.org.
 2 Patient- and Family-Centered Care and the Pediatrician's Role. Committee On Hospital Care And Institute For Patient- And Family-Centered Care, Pediatrics 2012; 129:394; originally published online January 30, 2012.
 3 Parent-Provider-Community Partnerships: Optimizing Outcomes for Children With Disabilities. Nancy A. Murphy, MD, Paul S. Carbone, MD, and the Council On Children With Disabilities, www.pediatrics.org/cgi/doi/10.1542/peds.2011-1467, doi:10.1542/peds.2011-1467
 4 Jackson, C., Cheater, F.H., & Reid, I. (2008). A systematic review of decision support needs of parents making child health decisions. Health Expectations An International Journal of Public Participation in Health Care And Health Policy, 11(3), 232-251.
 5 Obrochta, C., Anthony, B., Armstrong, M., Kallal, J., Hutz, J., & Kernan, J. (2011). Issue brief: Family-to-family peer support: Models and evaluation. Atlanta, GA: ICF Macro, Outcomes Roundtable for Children and Families.
 6 Assessing Family-Provider Partnerships and Satisfaction With Care Among US Children With Special Health Care Needs Mary Kay Kenney, PhD; Diana Denboba, BS; Bonnie Strickland, PhD; Paul W. Newacheck, DrPH. Academic Pediatrics 2011; 11:144-151