

FAMILY-TO-FAMILY HEALTH INFORMATION CENTERS DATA REPORT:

Helping Families of Children & Youth with Special Health Care Needs & the Professionals who Serve Them



2014-2015

Family-to-Family Health Information Centers (F2Fs) provide critical, specialized support and assistance to families. F2Fs particularly help families with complex needs and those from diverse communities.

Data aggregated from reports submitted by all 51 F2Fs summarizing their work from June 1, 2014 through May 31, 2015 (FY2015) demonstrate their:

Direct Support to:

- **155,950 Families**
- **74,225 Professionals**

Estimated Overall Outreach to:

- **928,225 Families**
- **350,960 Professionals**

Impact on:

- **92% of Families Better Able to Partner with Providers & Navigate Systems**

F2Fs impact systems of care by working with community, state, and federal partners. F2Fs ensure that families are engaged in shared decision making at all levels of health care.

1 in 5 families has at least one child with special health care needs.



Approximately 8.8 million families in the US have a least one child under the age of 18 with a special health care need.* Of these, about 3 million families report not being able to easily access community-based services due to eligibility issues, services not available, problems getting appointments, costs of services, lack of information and other difficulties.*

Direct Support:

F2Fs exist in every state and the District of Columbia to provide assistance to help families and professionals address these issues. F2Fs are staffed by family members who have first-hand knowledge and training in navigating the maze of health care services for children and youth with special health care needs (CYSHCN).

F2Fs provide direct support through free one-to-one assistance and training. From June 1, 2014 through May 31, 2015, F2Fs **assisted and trained 155,950 families (unduplicated) and 74,225 professionals (unduplicated)** across the country.

FAMILY VOICES... keeping families at the center of children's health care

Requests for Assistance Received/Answered



Requests for Assistance:

Families contact an F2F for help in determining their eligibility for a health care financing program, applying for programs, dealing with healthcare denials, getting referrals, identifying and accessing community support programs, connecting with peer support and many other issues. A parent who received help from Family Ties of Nevada exemplifies the value of support from an F2F:

"Beth struggled to learn more about her son's diagnosis of autism and how best to help him. She connected with Family TIES and was provided support, information, and connections to other parents. Through this support, Beth learned about the Autism Treatment Assistance Program (ATAP) which has provided her son with Applied Behavior Analysis (ABA) therapy. Beth credits ABA therapy with significant advances in Mike's development: talking, potty training, listening, social skills, and handling noise and crowded situations. 'It has helped us be a family.'"

In FY2015 F2Fs responded to **236,982 requests for assistance from families and 87,787 requests from professionals.**

Trainings:

F2Fs provide trainings through in-person workshops, online courses, webinar trainings and other media. Frequent topics of trainings included the Affordable Care Act, Autism and Family Supports, Medicaid Programs, and Mental Health Issues for Children/Youth. In FY2015 F2Fs provided **11,013 trainings.**

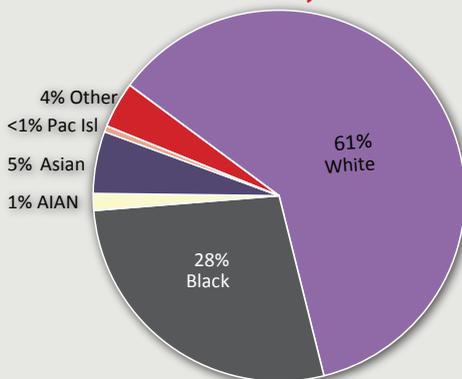
Serving Families of Diverse Backgrounds

National surveys indicate that more Hispanic (66.9%), Black (66.2%), and Asian (67.1%) families lack coordinated, ongoing, comprehensive care within a medical home compared to White families (51.2%).* 72% of White CYSHCN received family-centered care while only 56% of Hispanic and 52% of African American CYSHCN receive this comprehensive care.* F2Fs reach families of diverse backgrounds—hosting support groups and leadership conferences for Spanish-speaking participants, facilitating focus groups to create culturally competent materials, participating in community meetings serving diverse communities, and partnering with community brokers. F2Fs help develop the leadership skills of diverse families. The F2F Director in Iowa (ASK Resource Center) noted the impact of Family Voices' Polly Arango initiative:

"The Polly Arango grant greatly enhanced our ability to outreach to Hispanic families. ASK's Family-to-Family Mentoring Network is robust among other groups, but not with the Hispanic families in Iowa. Knowing the cost-savings that natural, family-to-family-support provides, our goal is to build the infrastructure needed to sustain outreach efforts within these communities to increase both the mentoring and leadership capacities of Hispanic families."

In FY2015 F2Fs reported, on average, that about 35% of the families they served were from diverse racial populations when the family self-identifies (about

Families Served by Race



11.2 Million Children with

67% of families who were provided direct support self-identify.) This represents approximately the same racial distribution as reported in the 2009-2010 National Survey of CSHCN which indicates that non-white families make up 40% of families who have CYSHCN. Of those families who self-identify to the F2F, **29% indicated they are Hispanic.**

Information Dissemination

F2Fs play an important role in disseminating information to the broader public, such as news about changes to programs and policies, opportunities to provide public comments, announcements on upcoming events, and stories reflecting family experiences. Last year F2Fs reported dissemination of information by:

- Listservs: reaching **173,078 families and 76,854 professionals**
- Newsletters: reaching **409,897 families and 154,638 professionals**
- Handouts and other publications: distributing over **5 million materials**

Some F2Fs use partner and public channels to get messages out, such as the F2F in Michigan at the Michigan Public Health Institute:

"We have written articles for partner organizations reaching approximately 800 professionals through the MI Chapter of the American Academy of Pediatrics and 9,223 families through the Ludington Daily News."

Utilizing Social Media

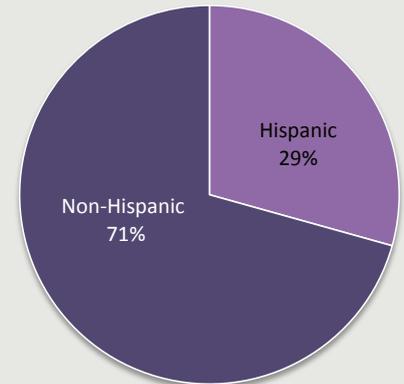
Many F2Fs are increasingly serving families and professionals using Facebook, Twitter, and other social media tools. Data collection standards for tracking this reach were newly implemented this year. Data submitted for FY2015 includes:

- Facebook Likes: **12,360** (reported by 10 F2Fs)
- Facebook Organic Reach (total number of unique people who were shown a post): **1.4 million individuals** (reported by 11 F2Fs)
- Facebook Average (monthly) # of People Talking About Page (actual number of people who are 'engaged' and interacting with that Facebook Page): **43,046 individuals** (reported by 10 F2Fs)
- Twitter followers: **3,272 people** (reported by 4 F2Fs)
- Highest Adjust Reach of any Tweet: **7,896 people** (reported by 4 F2Fs)

Total Estimated Overall Reach

In FY2015 F2Fs reached an **estimated 928,225 families and 350,960 professionals** through one-to-one assistance, trainings, information dissemination, and social media.**

Families Served by Ethnicity



Social Media (Twitter) Reach



Special Health Care Needs*

Partnerships to Improve Care

F2Fs help families partner at the **direct care level** by giving them information & advice, bolstering their confidence, and providing tools to help them communicate with their child’s providers. At the **organization level**, F2Fs work with pediatric practices and many F2Fs serve as family faculty to nursing and medical students—helping these providers understand the value of the family as a partner. Many F2F staff also partner with health clinics and serve on hospital advisory boards to help implement family-centered care. Finally, every F2F partners at the **system level** to ensure policies effectively meet the needs of families. The F2F in Virginia summarized their efforts of the past year:

“Our biggest impact has been the over 400 hours of technical assistance provided by F2F director and staff to state Medicaid and DD agency staff on the redesign of three current Medicaid waivers that serve unique populations. In the new design, everyone, regardless of disability label, would be served under an independence, support, or comprehensive waiver depending upon level of need. This is huge for our state which historically only served people with ID and served them in large congregate care facilities.”

Partner	% of F2Fs Involved
Medicaid Agency	100
Early Intervention	100
Developmental Disability Program	100
Mental Health Agency	100
State Title V	98
Protection & Advocacy Agencies	98
Health Care Advocacy Groups	98
Children’s Hospitals/Pediatric Units	98
Youth Advisory Groups	96
State Chapter AAP	94

- Examples of F2F Partnerships:**
- AR F2F & University of Arkansas for Medical Sciences
 - CO F2F & CO Department of Health Care Policy and Financing
 - CT F2F & US Department of Transportation National EMS Advisory Council
 - DE F2F & Title V Needs Assessment
 - FL F2F & AAP FL Medical Home Project
 - ID F2F & Idaho State University Traumatic Brain Injury project
 - NJ F2F & Centers for Independent Living/Vocational Rehabilitation Agency
 - NM F2F & Native American Communities
 - NV F2F & Hispanic Community Partners Group
 - OK F2F & Integris Baptist Medical Center NICU Discharge Team
 - RI F2F & New England Genetics Collaborative
 - SC F2F & Emergency./disaster support for families during the flooding
 - WY F2F & Medicaid Waiver Redesign Committee

Impact on Families

Of the families served by the F2Fs, the following percent of families reported the service received as useful, very useful or extremely useful in:

- helping them partner in **decision-making: 92%**
- helping them find/learn about **community services: 92%**
- helping them feel more **confident** about getting needed health care services for their child: **90%**

Impact on Programs & Policies

F2Fs self-reported their impact in specific policy areas in their communities. The greatest area of impact was in **promoting community based services, supporting transitions, and ensuring partnerships at the individual care level.**

Last year, of the families served by F2Fs, 14% reported they participated in committees, task forces, advisory boards, or other levels of program/policy. Of those families, **88% reported that the assistance/training they received from the F2F was useful, very useful, or extremely useful** in helping them represent CYSHCN. The F2F in Louisiana (Bayou Lands Families Helping Families) noted their work in developing new family leaders:

“We are the only agency training families regarding Medicaid Managed Care in Long-term Supports and Services (MLTSS) so they can participate in stake-holder meetings and serve on plan oversight committees. We are spearheading discussions among a number of agencies regarding MLTSS and representation for families on stakeholder groups.”

F2F Impact on Policy (self-rated)

