

FAMILY-TO-FAMILY HEALTH INFORMATION CENTERS

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

FY2017
DATA BRIEF



November 2017

WHAT ARE F2Fs?

Family-to-Family Health Information Centers (F2Fs) are family-led centers funded by the Health Resources and Services Administration (HRSA). There is **one F2F in each state and in the District of Columbia**. Each F2F is staffed by highly-skilled, knowledgeable family members who have **first-hand experience and understanding of the challenges faced by families of CYSHCN**. These uniquely qualified staff provide critical **support to families caring for CYSHCN**, particularly families of **children with complex needs** and those from **diverse communities**.

F2Fs also **assist providers, state and federal agencies, legislators, and other stakeholders to better understand and serve CYSHCN and their families**.

FY2017 HIGHLIGHTS⁴



F2Fs trained and assisted:

- 184,002 families and
- 85,556 professionals



F2Fs reached and provided information to:

- Almost 1 million families and
- More than 341,000 professionals

WHO ARE CYSHCN?

Children/Youth who have a chronic, physical, developmental, behavioral, or emotional condition *and who also require* health and related services beyond that required by children generally.¹

- ➔ 68% have 2 or more health conditions
- ➔ 45.5% have health conditions that affect their daily activities
- ➔ 37.5% require specialty medical care
- ➔ 33.2% require mental health care
- ➔ 47.2% needed mental/behavioral health care but did not receive it

There are **14.2 MILLION CYSHCN**.²
19.4% of all children under 18.

FAMILIES OF CYSHCN

- ➔ Are more likely to have difficulty coping with the daily demands of raising children than parents of children without special health care needs
- ➔ Families of children with more complex health needs are 4 times more likely than families of children with less complex health needs to spend 1-4 hours/week coordinating care
- ➔ 14.5% stop or reduce work to care for their child
- ➔ 15.8% had problems paying health care bills
- ➔ 22.5% spend 5+ hours/week providing care

Families annually provide about
1.5 BILLION HOURS WORTH OF CARE

to approximately 5.6 million CYSHCN,
at an estimated value of

\$35.7 BILLION OR \$6400 PER CHILD PER YEAR.³



WHY DO FAMILIES OF CYSHCN NEED SPECIAL HELP?

When a family learns their child has special health care needs, they face frightening prognoses and complex challenges:

- **A maze of programs** with different eligibility requirements, policies, and procedures
- **Demands of providing home health care** for their child, dispensing medications, managing equipment, and carrying out therapies
- **Extraordinary expenses** for deductibles, co-pays, and un-covered medical expenses
- **Lost Income** from the need to cut back work hours to care for their child
- **Re-navigating** new programs as a child's needs change

33.9% of families of CYSHCN report their health insurance is inadequate.² In FY2017 F2Fs helped families increase access to services and maximize their health insurance coverage, understand their options for Medicaid, SSI, and CHIP, and connected them to school-based care and other programs.

EXAMPLES OF ISSUES REPORTED TO F2Fs IN FY2017:

- Lack of care coordination
- Loss of services due to state budget cuts
- Denial of coverage for medications under private insurance
- Inadequate provider networks
- Lack of transportation in rural areas
- Medical debt for privately insured families due to high deductibles and out-of-pocket expenses
- Problems accessing mental health services
- Language barriers
- Primary and specialty provider shortages, requiring travel to out-of-state facilities
- Denials of durable medical equipment
- Unavailable long-term services and supports



HOW DO F2Fs HELP FAMILIES?

Each F2F provides free, 1:1 assistance to families, helping them:

- Find appropriate care and services
- Apply for Medicaid, CHIP or private insurance
- Get referrals to providers
- Address insurance denials
- Identify and access community support programs
- Advocate to ensure effective and cost-efficient care
- Connect with parent mentors



The staff at the F2F in Nebraska helps families prepare to transition their youth to adult systems of care and support. A parent shared how the F2F in NE helped when her daughter with Down Syndrome turned 18. The F2F provided a checklist that included crucial tips on what to expect, how to prepare, and what to say when meeting with representatives of the Social Security Administration and the state Department of Developmental Disabilities. This information helped the family successfully navigate the maze of services and support.

When another family was planning for their son's future, the staff at the F2F in NE provided step-by-step guidance, explained the differences in each program and the supports available for their son. Staff also provided referrals to attorneys so the family could learn about guardianship. The parents shared that they, "certainly would not have known where to begin without the assistance of the F2F."



249,161 requests from families (received/addressed)



184,003 individual families served (unduplicated)

"Thank you--all of you [at the F2F Network of Virginia]--for being such a good resource for us, for enabling us to be effective advocates for [our son], for helping us find a way to lower as many of the barriers in his path as we possibly can. How fortunate we are! Between his red glasses and the device you helped us advocate for at school, we feel like [our child] has a fantastic shot at being able to pursue his natural intellectual curiosity with very little holding him back."
- Parent

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

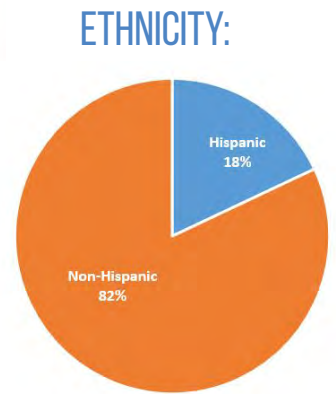
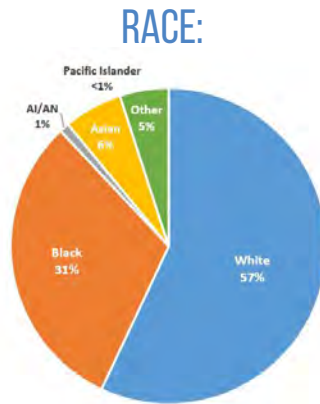
² Child and Adolescent Health Measurement Initiative. Data Resource Center for Child and Adolescent Health. 2016 National Survey of Children's Health (NSCH) data query. Retrieved 11/17/2017 from www.childhealthdata.org. CAHMI: www.cahmi.org.

FAMILIES OF DIVERSE RACIAL & ETHNIC BACKGROUNDS

The 2016 National Survey of Children's Health reports that **more Hispanic (63.7%), Black (61.1%), and Asian (54.6%) CYSHCN lack coordinated, ongoing, comprehensive care** within a medical home compared to White CYSHCN (52%).

To serve families of diverse backgrounds, F2Fs host support groups and conferences in multiple languages, create culturally and linguistically competent materials, work with community liaisons, and provide leadership training and support.

In FY2017 F2Fs reported that 43% of the families they served were from diverse racial populations; 18% indicated they were Hispanic.



WHAT INFORMATION DO F2Fs PROVIDE?

F2Fs provide information on many topics to address the concerns of families. In FY2017, information was most frequently provided about:

1. Public health care financing programs (CHIP, Medicaid, other public healthcare financing, public assistance)
2. Family Support (peer-to-peer, support groups, sibling support)
3. Communicating/partnering with child's provider
4. Family collaboration with professionals
5. Family-centered care
6. Disability awareness
7. Community relationships and resources
8. Care coordination
9. Learning opportunities/advancing knowledge
10. Disability-specific information

175,257 requests received/addressed from professionals who work with families of CYSHCN

HOW DO F2Fs HELP PROVIDERS AND SYSTEMS?

F2Fs also work with health care professionals, hospitals, and public agencies to help them better meet the needs of CYSHCN and their families. They most often request assistance for:

- Obtaining help for a patient/family
- Addressing changes to state policies and programs
- Learning about family experiences, and
- Partnering to improve services.

"At times, I have been very frustrated with 'the system'. The Raising Special Kids staff [AZ F2F] have been extremely patient, provided the information I so desperately needed, and explained how to resolve my issues. I felt so comfortable knowing you cared and really wanted to help me and my family."

- Parent



"The F2F at Family Voices Colorado has continued to make great use of our partners serving as cultural brokers to provide culturally competent materials and communicate information in a way that addresses the needs of Colorado's diverse population."

-F2F CO

PARTNERSHIPS

F2Fs' learned experience of the needs of families is vital to shaping effective programs and policies. F2Fs actively seek partnerships to bring the perspective of families to the table. In FY2017, F2Fs rated strong partnerships with:

- 75% or more F2Fs: State Title V, Developmental Disability programs, children's hospitals, Protection & Advocacy organizations
- 50% or more F2Fs: Mental Health Agencies, Lend Programs, Adults with Disabilities Agencies, Vocational Rehabilitation Agencies, Independent Living Centers, and Regional MCH Leadership Collaboratives

FEDERAL INVESTMENT IN F2Fs LEADS TO PUBLIC/PRIVATE COLLABORATION

To expand their work, in addition to HRSA funding, 46 F2Fs reported attracting additional sources of funds through: support from state Title V programs (59%); private foundations (20%); Departments of Education (22%); and other federal grants (22%). Additional sources of funding come from partnerships with state Medicaid programs, other state agencies, UCEDDs, LEND programs, children's hospitals, Bar Associations, and individual fundraising efforts and donations. Several F2Fs also receive in-kind donations for meeting space and printing of materials.



The **F2F in Ohio** established relationships with healthcare navigators and facilitated sessions on the health insurance marketplace; one session focused on helping the Bhutanese refugee community access Medicaid coverage.

The **Oklahoma Family Network** (F2F) provided leadership institutes for families, agency staff, community members, legislators, and others in 2 very rural regions of the state. The participants learned how to develop partnerships to ensure better services and supports for individuals with disabilities and special health care needs including behavioral health and the child welfare system.

In Idaho, families could only receive therapeutic foster care services if their child was removed from their home. **Idaho Parents Unlimited (IPUL)** was instrumental in establishing this evidence-based treatment option as part of the services families can receive without having their child removed from the home.

The **MI F2F** gives presentations to Speech and Language and Human Ecology undergraduate and graduate students at Michigan State University. The information they share about real life experiences of families with CYSHCN and the importance of family/professional partnerships helps build the capacity of the future workforce.

After more than a decade of work, **FV Wisconsin** and other advocates worked to eliminate the waiting list for Children's Long-Term Supports, providing needed services to approximately 2,500 children statewide.



OTHER PURPOSES OF F2Fs OUTREACH/PUBLIC EDUCATION

F2Fs play an important role in disseminating information to the broader public, such as

- Alerts about changes to programs and policies
- Opportunities to provide public comments
- Announcements on upcoming events
- Important news about public health issues, such as the opioid crisis, increase in mental health issues, public water contamination, Zika virus, and disasters & emergencies.



F2Fs MAKE A DIFFERENCE

Overall, the F2Fs expanded partnerships with professionals, community-based organizations, state agencies, and other organizations to share data, identify issues, propose solutions, maximize resources, and ensure diverse and underserved families have access to the information they need to navigate the healthcare system for their CYSHCN. These efforts increased access to public benefits and services, and improved the capacity of the system of care.