

# FAMILY-TO-FAMILY HEALTH INFORMATION CENTERS

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

**FY2018  
DATA BRIEF**



March 2019

## WHAT ARE F2Fs?

**Family-to-Family Health Information Centers (F2Fs) are family-led centers that provide support to families of CYSHCN.** The Health Resources and Services Administration (HRSA) has funded F2Fs in **each state and the District of Columbia** since 2009. HRSA added new funding in 2018 for F2Fs in **American Samoa, Guam, Puerto Rico, Northern Mariana Islands, U.S. Virgin Islands**, as well as for three F2Fs serving **American Indians and Alaskan Natives**.

Each F2F is staffed by highly skilled, knowledgeable family members who have **first-hand experience and understand 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 the needs of, and serve, CYSHCN and their families.



## HOW DO F2Fs HELP FAMILIES?

Each F2F provides free, confidential 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
- Improve family/provider communication so families can partner in decision-making at all levels
- Advocate to ensure effective and cost-efficient care
- Connect with parent mentors and skill-building leadership opportunities

## 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.<sup>1</sup>

- 68% have 2 or more health conditions
- 46% have health conditions that affect their daily activities
- 36% saw a medical specialist in the last year; of those, 50% had problems accessing that care
- 33% received mental health care in the last year; of those, 42% had problems accessing that care

There are **13.8 MILLION CYSHCN**.<sup>2</sup>  
*19% of all children under 18.*

## FAMILIES OF CYSHCN

Parents are more likely to experience fair or poor overall health than parents of children without special health care needs.

- 15% stop or reduce work to care for their child
- 21% pay \$1000 or more per year for their child's health care
- 17% have problems paying medical bills

Families of children with more complex health needs are **3 times more likely** than families of children with less complex health needs to spend 11 or more hours/week providing health care at home, and they are **5 times more likely** to spend 1-4 hours/week coordinating their child's health care.



# WHY DO FAMILIES OF CYSHCN NEED SPECIAL HELP?

When a family learns their child has special health care needs, they need support, information, and help navigating complex systems of care that 84% of families say do not function well.<sup>2</sup> Many struggle to:

- **Obtain correct information** about programs, policies, eligibility, and application processes
- **Partner with their children's doctors** and understand treatment options
- **Coordinate care**, make multiple appointments, and manage medications and equipment
- **Pay out-of-pocket expenses** for deductibles, co-insurance, co-pays, and other uncovered medical expenses
- **Find new programs** that meet their children's changing needs
- **Make time** for their partners and other children

32% of families of CYSHCN report their health insurance is inadequate.<sup>2</sup> In FY2018, F2Fs helped families maximize their health insurance coverage, understand their options for Medicaid, SSI, and CHIP, access services and supports, and plan and manage transition points (into school, graduation, to adult services) in their children's lives.

## EXAMPLES OF ISSUES REPORTED TO F2Fs IN FY2018:

- Changes to Medicaid waivers
- Loss of continuity of care due to inadequate provider networks in MCOs
- Problems accessing mental and behavioral health services
- Lack of access to specialty care
- Lack of access to disability services due to state budget cuts
- Difficulty transitioning to adult care
- Costly out-of-pocket expenses for costs not covered by insurance, such as special nutrition and transportation



*"Finding Amy from the Ohio F2F literally changed our lives. For over a month, I had been attempting to resolve an insurance issue for my son, who has severe autism. He needed a specific insurance that would provide services that we desperately needed. No matter where I called or how often, I could not resolve the problem. I was referred to Amy and in ONE phone call I knew I wouldn't have to worry anymore. It was amazing what comfort can come from someone simply saying this isn't only your problem anymore, you have me now. Amy had the answers and in no time, helped us get the insurance that provided the in-home services we so desperately needed. Those services have been life changing. Just knowing there is a place to call when navigating this complicated world of special needs is an absolute relief. We aren't alone. Help really is a phone call away, and we are so grateful for that."*

- Parent

## FY2018 HIGHLIGHTS<sup>3</sup>



### F2Fs trained and assisted:

- 181,938 families and
- 83,859 professionals



### F2Fs reached and provided information to:

- Almost 1 million families and
- More than 374,000 professionals



<sup>2</sup> McPherson M, Arango P, Fox H, et al. "A new definition of children with special health care needs." Pediatrics, 1998; 102: 137 - 140.

<sup>2</sup> Child and Adolescent Health Measurement Initiative. 2016-2017 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by Cooperative Agreement U59MC27866 from the U.S. Department of Health and Human Services, Health Resources and Services Administration's Maternal and Child Health Bureau (HRSA MCHB). Retrieved 1/14/19 from [www.childhealthdata.org](http://www.childhealthdata.org). CAHMI: [www.cahmi.org](http://www.cahmi.org)

<sup>3</sup> Based on data collected from the Family-to-Family Health Information Centers



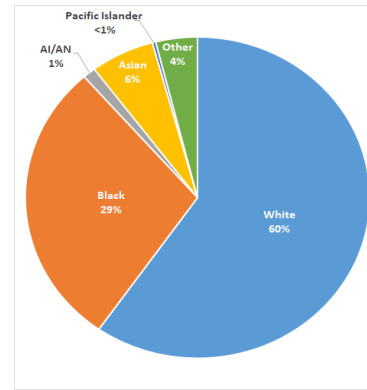
# FAMILIES OF DIVERSE RACIAL & ETHNIC BACKGROUNDS

The 2016-2017 National Survey of Children's Health reports that **more CYSHCN who are Hispanic (65%), Black (61%), and other races (56%) lack family-centered, coordinated care** within a medical home compared to White CYSHCN (52%).

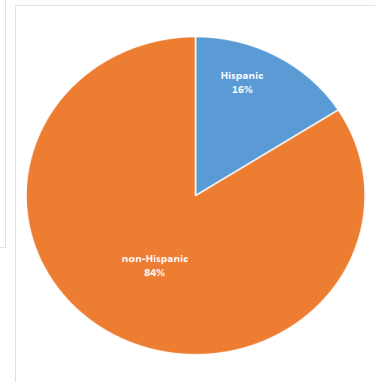
To serve families of diverse backgrounds, F2Fs employ bicultural and bilingual staff, host support groups and conferences in multiple languages, create culturally and linguistically competent materials, work with community liaisons, cultural brokers, and others to provide skill-building leadership opportunities and other types of support.

In FY2018 F2Fs reported that 16% of families served indicated they were Hispanic, and 40% of the families they served were from diverse racial populations.

RACE:



ETHNICITY:



## WHAT INFORMATION DO F2Fs PROVIDE?

F2Fs provide information on many topics to address the concerns of families. In FY2018, information was most frequently provided about:

1. Public health care financing programs (Medicaid, Medicaid Waivers, other public healthcare financing, public assistance)
2. Family Support (peer-to-peer, support groups, sibling support)
3. Communicating/partnering with their child's provider
4. Family collaboration with professionals
5. Family-centered care
6. Disability awareness
7. Community relationships and resources
8. Care coordination
9. Skill-building opportunities/support for leadership development to influence systems-change
10. Disability-specific information

*"South Dakota Parent Connection has helped me in so many ways. My daughter received a brain injury in April 2017. Until then, she was a normal child. Since her injury we have struggled financially and emotionally. We didn't know where to begin to research or how to go about everything we were now facing. SD Parent Connection (the SD F2F) helped reduce the overwhelming feeling to a manageable task. They gave us an organizer for all of our daughter's medical papers, which is a wonderful tool to keep everything in one place. I have called them numerous times. Without this organization, I would be overwhelmed and very frustrated."*

- Parent

## 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. Professionals most often request assistance about:

- Obtaining help for a patient/family
- Learning about family experiences
- Providing skill-building opportunities to help providers improve their ability to partner with families
- Partnering to address changes to state policies, programs, practices, and services

**160,785 requests received/addressed from professionals who work with families of CYSHCN**



# 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 and create systems change. In FY2018, F2Fs reported strong partnerships including:

- 92% partner with their State Title V and other MCHB-funded investments such as the Early Hearing Detection and Intervention (EHDI) programs, Regional Genetics Networks, University Centers for Excellence in Developmental Disabilities (UCEDDs), and LEND.
- 50% or more partner with: Departments of Education, the Centers for Disease Control and Prevention (CDC), state American Academy of Pediatrics (AAP) chapters, and private health insurers.



## FEDERAL INVESTMENT IN F2Fs LEADS TO PUBLIC/PRIVATE COLLABORATION

To expand their work, in addition to HRSA funding, 47 F2Fs reported attracting additional sources of funds through: support from state Title V programs (55%); private foundations (22%); Departments of Education (25%); and other federal grants (14%). 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.



### 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, gun violence, 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.

Alaska is a huge state and many families live in remote, hard-to-access, small communities with limited resources. **Stone Soup Group, the AK F2F**, in collaboration with the Alaska Autism Resource Center, used Facebook Live to conduct a "Steps to Growing a Support Group in your Community" training for families and professionals so they could create support groups locally. The Autism Resource Center hosted viewing locations in Fairbanks and Valdez, and other families, who routinely use Facebook, joined from their homes or other locations. It was a great way to engage and connect with more than 1100 individuals.

The **F2F in Mississippi** is partnering with Early Intervention to develop a plan to improve the health and education of young children and support education/day care centers across the state. The F2F also has a strong relationship with the state Title V program and provides education and technical assistance to Title V staff and the families they serve.

The **VT F2F** partners with the state Protection and Advocacy organization to improve compliance in high tech care for children, which has been impacted due to a nursing shortage. The F2F also provides 'Meet the Family' tours where attendees hear moving stories about family experiences with the Vermont Family Network (home to the F2F) - including accessing services, connecting to other families, and working successfully with professionals.

Staff at **Colorado Family Voices, the F2F**, chaired the state Medicaid Provider Rate Review Advisory committee and led the review of the 362 codes related to the HCBS Waiver programs. The F2F was instrumental in engaging more than 100 stakeholders in the in the rate review process.

The **F2F in TN** has hired a Youth Program Coordinator as part of their collaboration with their Title V to facilitate and sustain a TN Department of Health Youth Advisory Council.