

FAMILY-TO-FAMILY HEALTH INFORMATION CENTERS

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

FY2016
DATA BRIEF



March, 2017

WHAT ARE F2Fs?

Family-to-Family Health Information Centers (F2Fs) provide critical support to families caring for CYSHCN, particularly families of children with complex needs and those from diverse communities.

There is one F2F in each state and the District of Columbia.

Each F2F is staffed by trained families with first-hand understanding of the challenges faced by families of CYSHCN, making them uniquely qualified to help. In addition, F2Fs help providers and government agencies to better serve CYSHCN and their families.

FY2016 HIGHLIGHTS:



F2Fs trained and assisted:

- 169,232 families and
- 73,759 professionals



F2Fs reached out and provided information to:

- Almost 1 million families and
- 350+ thousand professionals



F2Fs made a difference:

- 91% of families helped by the F2Fs are better able to communicate with providers
- With state and community partners, F2Fs helped improve health policies and programs.

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

- ➔ 86% depend on prescriptions
- ➔ 48% require specialty medical care
- ➔ 28% require mental health care
- ➔ 24% have at least one unmet need for services²

There are between
11.2³ and 14.6 MILLION CYSHCN⁴

- ➔ 20% of all children under 18 years⁴
- ➔ 23% of families with children³

FAMILIES OF CYSHCN

- ➔ 25% stop or reduce work to care for their child³
- ➔ 22% experience financial problems³
- ➔ 13% spend 11+ hours/week providing care³
- ➔ More than twice as likely to report feeling stress as parents of non-CYSHCN.⁴
- ➔ Non-Hispanic Black and Hispanic children twice as likely to not receive family-centered care than non-Hispanic White children.³

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.⁵



WHY DO FAMILIES OF CSHCN 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, and
- **Re-navigating** new programs as a child's needs change.

In FY2016 F2Fs helped families with many health financing issues—around accessing services or coverage through Medicaid, SSI, CHIP, other public programs, private insurance, and school-based care.

EXAMPLES OF ISSUES REPORTED TO F2Fs IN FY2016:

- 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 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, and
- Unavailable long-term services and supports.



Sadiatou is the mother of a 21 year old daughter, Binta, born with multiple disabilities. Binta has up to five seizures a day, and as many as 40 if she is sick. She does not speak, and requires two people to lift her from bed to wheelchair and to the bathroom.

When she turned 21, the state drastically reduced her in-home nursing care and insurance would no longer cover her treatment in a children's hospital, leaving her mother with a large bill.

Family Voices of Tennessee supported Sadiatou to participate in a Tennessee Disabilities conference where she connected with others, and these connections helped her daughter receive a waiver for additional home care.



HOW DO F2Fs HELP FAMILIES?

Each F2F provides families with free one-on-one assistance in:

- Finding appropriate care and services,
- Applying for Medicaid, CHIP or private insurance,
- Getting referrals to providers,
- Addressing insurance denials,
- Identifying and accessing community support programs,
- Advocating to ensure effective and cost-efficient care, and
- Connecting with parent mentors.



265,548 requests received/addressed from families



169,232 individual families served (unduplicated)

"Idaho Parents Unlimited (IPUL) has been such an amazing help. When my son was diagnosed with autism, I had no idea where to start and IPUL was able to tell me what steps I needed to take and how to do it. Without IPUL, I don't think I could have done it."
- a Parent

¹ 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 2. U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. *The National Survey of Children with Special Health Care Needs Chartbook 2009–2010*. Rockville, Maryland: U.S. Department of Health and Human Services, 2013.

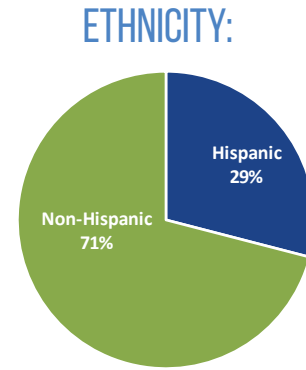
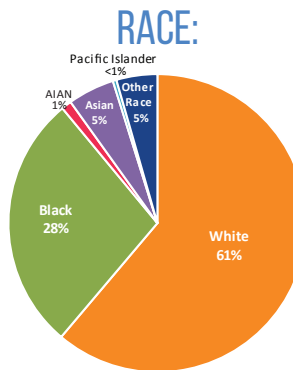
³ 3. National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved [02/01/2017] from www.childhealthdata.org.

FAMILIES OF DIVERSE RACIAL & ETHNIC BACKGROUND

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%).³

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

In FY2016 F2Fs reported that 31% of the families they served who self identify were from diverse racial populations (72% of families self-identify.) 29% indicated they were Hispanic.



"I'm the mother of a child with special needs who has benefitted from the ECAC's (F2F in NC) programs. I want to thank every single person who makes it possible for this organization to exist. I especially want to thank ECAC staff who guide us in our native language."

- Parent

WHAT INFORMATION DO F2Fs PROVIDE?

F2Fs provide information on many topics to address the concerns of families. The 10 most frequently provided topics in FY2016 were:

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



86,100 requests received/addressed from professionals



73,759 individual professionals served (unduplicated)

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.

"We have helped to reduce inappropriate referrals for psychiatric evaluations by successfully advocating for our state's Primary Care-Child Psychiatrist Consultation program. The program helps primary care providers get immediate consultation from an appropriate psychiatrist about a child with mental health challenges in their care."

- NJ F2F

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 FY2016, F2Fs rated strong partnerships with

- 75% or more F2Fs: State Title V, Developmental Disability programs, children's hospitals, Protection & Advocacy,
- 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 F2F work, 41 F2Fs reported attracting many additional sources of funds through: community fundraising (54%), private foundations (43%), and United Way (20%). Over 1/3 of F2Fs receive contracts and funding from universities. One quarter of F2Fs generate income via fee for service reimbursement. Well over a third of F2Fs receive monies from state sources such as public health, Parent-to-Parent and others. Over half receive additional and varied Federal monies from MCHB, Title V Block Grants, HHS, LEND/UCEDD/DDRC.

"Being in the school counseling profession for 22 years, I reach out to many different resources in the community. Over the years, my go to resource is the F2F, South Dakota Parent Connection. It provides a wealth of resources from workshops, training, and materials for both families and myself as a professional. I value the South Dakota Parent Connection so much that, as an instructor in the SD State University Counseling Department, I use the information and materials that it has made available in the graduate level classroom!"

- a Professional



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, and
- Important news about public health issues, such as opioid crisis, increase in mental health issues, public water contamination, Zika virus, and disasters & emergencies.

Through trainings, listservs, newsletters, and social media, F2Fs reach an estimated:

**995,246 FAMILIES &
353,687 PROFESSIONALS**



F2Fs MAKE A DIFFERENCE

- 91% of families reported that the F2F helped them partner in decision-making
- 90% of families indicated that the F2F helped them find/learn about community services and feel more confident about getting needed health care services for their child.

92% of F2Fs rated their organization's work as having meaningful to significant impact on creating improvements at the individual, program, or policy level for CYSHCN.

About 1/3 of F2Fs served families with children/youth affected by opioid abuse:

- *The F2F in Idaho works with foster care, child protection, and mental health agencies to assist families whose children were exposed to drugs and alcohol in utero.*
- *The F2F in Washington works with youth who are in active recovery with a grant from SAMHSA.*
- *The F2F in New Hampshire assists grandparents who suddenly gain custody of their grandchildren and are simultaneously coping with their own children's addictions.*