



National Center for Family/Professional Partnerships

a project of
 Family Voices

As the National Center for Family/Professional Partnerships, Family Voices provides technical assistance to families, F2Fs and other family-led organizations, as well as professionals to address the following goals:

- ▲ Increase capacity of families, Title V, and others to partner in implementing ACA;
- ▲ Strengthen primary care workforce through family/professional learning opportunities; and
- ▲ Improve access to quality care through innovation in family-centered care, cultural & linguistic competence, and shared decision-making.

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2013-2014 Data Report of Activities of Family-to-Family Health Information Centers

Key Messages

Family-to-Family Health Information Centers (F2Fs) provide critical, specialized support and assistance to families of children and youth with special health care needs (SHCN), particularly those with complex needs and those from diverse backgrounds. These families experience significant challenges in caring for their children, paying for health services, and coping with disparities in health care.

Families report the positive impact of the assistance and training provided by F2Fs in helping them become more confident, better able to navigate systems of care, and better able to partner with providers in shared decision making. F2Fs also help families to become leaders advocating at the systems level.

F2Fs play a key role in sharing family experiences collaboratively with partners to develop more effective systems of care.

Children & Youth with Special Health Care Needs

There are an estimated 11 million (15%)¹ to 15 million (20%)² children/youth with SHCN in the United States. Children/youth with SHCN, by definition, have more intensive needs than children without special needs. This is reflected in their utilization of health care:³

- About four times the number of hospitalizations and seven times as many days receiving hospital care;
- Seven times as many annual visits to non-physician health care providers;
- Five times as many prescribed medications; and
- Four times the average health care expenditure.

Identifying and accessing health care financing programs, providers, and care settings is challenging for families. "Lack of communication among providers, limited access to pediatric subspecialists, inconsistent eligibility criteria for special services, and lack of quality standards all contribute to tremendous strain on families, adverse health outcomes for children, and increased costs both for families and for the health care system."⁴

Family-to-Family Health Information Centers

Family-to-Family Health Information Centers are statewide initiatives that assist families of children/youth with SHCN and the professionals who serve them. F2Fs are uniquely able to help families because they are staffed by family members who have first-hand knowledge and training in navigating the maze of health care services, programs, and insurance coverage for children and youth with SHCN.

The F2F grant program was established in all States and the District of Columbia by authorization of the Family Opportunity Act (part of the Deficit Reduction Act, 2005) and funding has been extended by subsequent laws through the first half of federal FY2015. Grants are administered through a competitive grant process by the Health Resources and Services Administration, Maternal and Child Health Bureau, Division of Children with Special Health Care Needs. Each F2F is awarded \$95,700 annually.

"I have an 11-year-old son who has been diagnosed with Asperger's Disorder, ADHD, and learning disabilities. I tried to enroll my son in children's services through Health and Welfare. Trying to navigate systems is like trying to find your way through a labyrinth.

I contacted Idaho Parents Unlimited (IPUL), the F2F, and they gave me information on the appeal process for SSI. They also contacted the Care Coordinator at my child's doctor's office. By the end of that day, my son had an appointment for the next afternoon.

Without IPUL I still wouldn't know what to do. The relationship IPUL has with the Care Coordinators at various medical specialty offices is crucial to helping special needs children receive all the services they need."
- a parent from Idaho



"As a first time mom in a new country, I was unaware of how to navigate the different systems such as health insurance, health care, etc., and felt very intimidated by my new surroundings.

I contacted the Statewide Parent Advocacy Network (SPAN), the F2F in New Jersey, and the help I received was phenomenal. They helped me with my son and opened the doors to many more opportunities/trainings to educate myself.

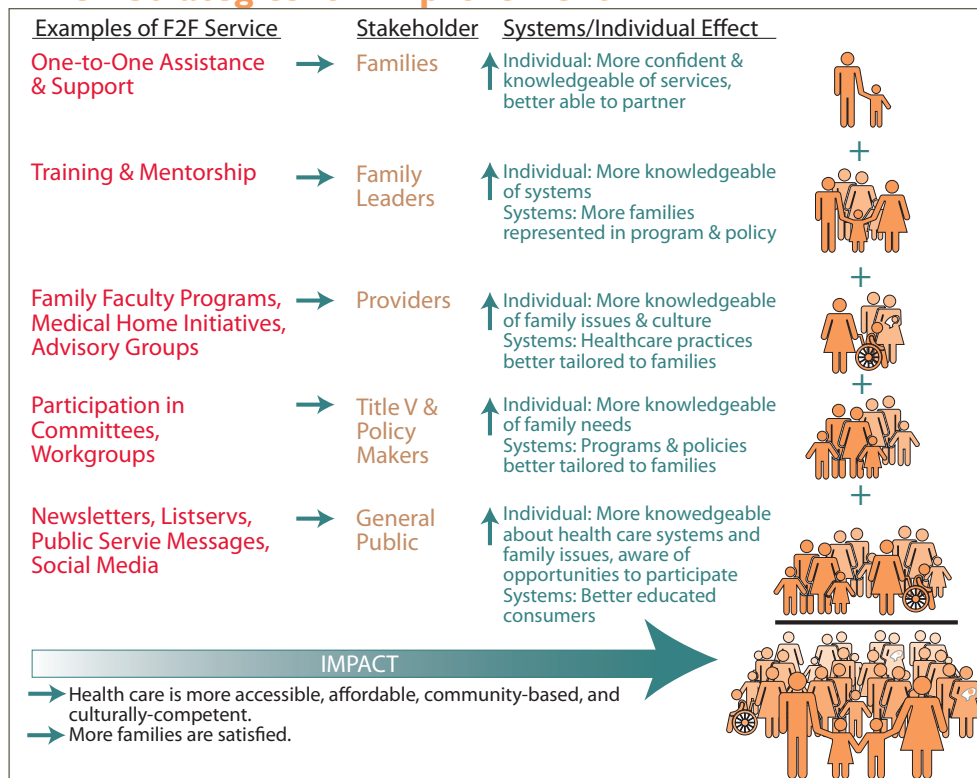
Because of their trainings I became an advocate not only for my son but for better outcomes for all children with special needs. I have presented at Medical Home Learning Sessions to help pediatric practices learn to become an effective Medical Home."

- a parent from New Jersey

How do F2Fs Improve Services for Families?

- F2Fs assist families to make informed choices about health care to promote good treatment decisions, cost effectiveness and improved health outcomes;
- F2Fs provide information regarding the health care needs of and resources available for children/youth with SHCN;
- F2Fs identify successful health delivery models for children/youth with SHCN;
- F2Fs work with representatives of health care providers, managed care organizations, health care purchasers, and appropriate State agencies to develop models of collaboration between families and health professionals;
- F2Fs provide training and guidance regarding the care of children/youth with SHCN; and
- F2Fs conduct outreach activities to families of children/youth with SHCN, health professionals, schools and other appropriate entities.

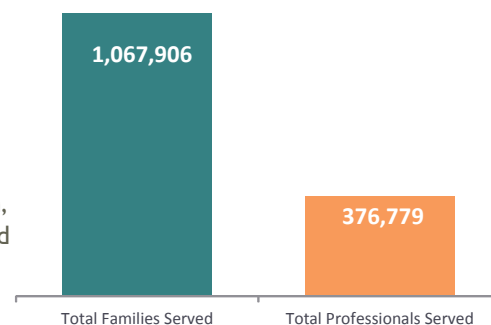
F2Fs - Strategies for Improvement



Data Reported by F2Fs from June 1, 2013 - May 31, 2014 Families and Professionals Served

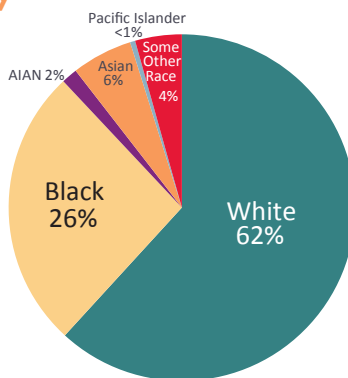
F2Fs reported serving over 1 million families and 376 thousand professionals last year. F2Fs assist families and professionals through consultation, training, information dissemination, social media, and partnership activities. Specific information, including contact information, project goals, examples of activities, shared materials, as well as data on assistance, outreach, and impact for each F2F may be found at:

<http://www.fv-ncfpp.org/f2fhic/find-a-f2f-hic/>.



Families Served by Race & Ethnicity

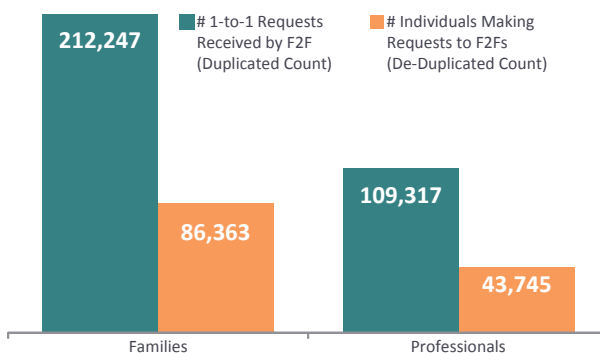
F2Fs outreach to and serve families with children/youth with SHCN in their communities. Last year, F2Fs reported serving, on average, about 38% families from diverse racial populations when the family self-identifies (about 11% of families served). This represents approximately the same racial distribution as reported in the 2009-2010 National Survey of CSHCN which indicates that non-white families make up 40% of CSHCN.¹



Of those families who did self-identify, 28% indicated they were Hispanic.

Requests for One-to-One Assistance

Individualized help is often the best way to meet the needs of a family. Professionals also contact the F2F either in support of a family or to seek the family perspective. F2Fs reported that 33% of all requests for one-to-one assistance were from professionals last year.



Often the issues facing families are complex and require time to discuss and resolve. F2F services that are more intensive include: emotional support, cultural issues, understanding eligibility and completing applications, identifying appropriate peer support, and multi-system issues. Examples of multi-system issues reported last year include:

- transitions in foster care for youth with complex medical and behavioral needs;
- medically-fragile/technology dependent youth and waiver services;
- psychiatric crises for families living in rural areas;
- loss of Medicaid coverage and redetermination processes; and
- children and families involved in Child Protective Services.

On average, families made 2.5 contacts with the F2F to address a need last year. On average the F2F spent about 1.3 hours on each family.

Trainings

F2Fs conducted many trainings last year to help families access services and understand new programs like the ACA. Other topics of training included: Navigating Systems, Leadership Development, Care Coordination, Transition to Adult Services, and Family/Professional Partnerships.

In the last year F2Fs conducted over 10 thousand workshops, conferences, and trainings across the country.

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 on proposed changes, upcoming trainings, and stories reflecting the experiences of families. Last year F2Fs reported dissemination of information by:

- Listserv - reaching 302,041 families and 94,141 professionals
- Newsletter - reaching 415,128 families and 157,376 professionals
- Handouts and other publications - disseminating 6.2 million materials

“The F2F in Montana, Parents, Let’s Unite for Kids (PLUK), blended funding from Substance Abuse and Mental Health Services Administration (SAMHSA) and the U.S. Department of Education in order to provide care coordination to the most needy Native American families on and near reservations who have children with emotional-behavioral disorders. PLUK trained the wraparound teams and state coordinators to work with families.”

- The Montana F2F Project Director

“The need for grass-roots, community-based solutions to address the mental health needs of children in these communities is clear. The wraparound process brings a community’s cultural, familial, and programmatic resources together to support the well-being of children.”

- Denise Juneau, State Superintendent
Montana Office of Public Instruction

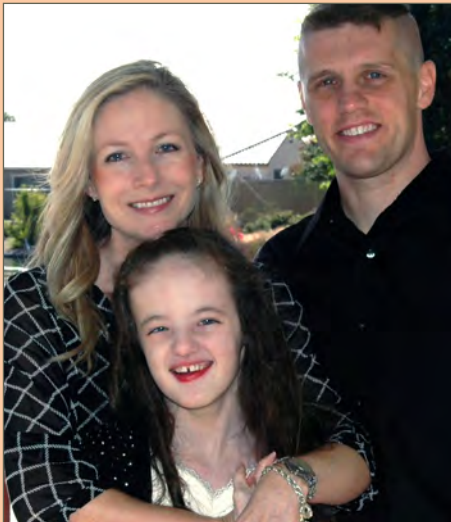


“I am so thankful for all the help that New Hampshire Family Voices, the F2F, provided. Their advice and encouragement made the difference. The information packet they provided allowed me to understand the eligibility criteria for a program needed by my child. I was glad to have all the references for the rules and regulations. With a better understanding of the criteria, I now have a clearer idea of the details required for application for services.”

- a parent in New Hampshire

“Bayou Land Families Helping Families, the F2F in Louisiana, is the only agency training families regarding Medicaid Managed Care in Long-term Supports and Services (MLTSS) so they can participate in stakeholder meetings and serve on plan oversight committees. We are spearheading discussions among a number of agencies and have developed a detailed recommendation to the state with our recommendations for best practices in MLTSS. We provided technical assistance regarding MLTSS and the need for highly-specialized care coordination, Medicaid Purchase Plan, and the ACA to the La Developmental Disabilities Council.”

- The Louisiana F2F Project Director



“Family Connection, the F2F in South Carolina, partnered with PASOs, a state-wide, non-profit organization, helping the Latino community and service providers to develop the Family Connection Asthma Program, Project Breathe Easy. This award winning state-wide program, provides emotional and informational support to parents who have children with asthma, to be more culturally and linguistically appropriate within the Latino population.”

-The South Carolina F2F Project Director

Partnering at the Systems Level

Given their direct involvement with families, F2Fs play a key role in working with policy makers to design policies and programs that meet the needs of families. Last year F2Fs worked with different partners to accomplish goals around specific initiatives.

| Groups Specified by at least half of all F2Fs as Involving Significant Partnership | # F2Fs | Initiatives in which more than 50% of F2Fs are involved | % F2Fs |
|--|--------|---|--------|
| State Title V Programs | 46 | Family-Centered Care | 90% |
| Other Family Support Organizations | 44 | Transition/Youth Leadership | 86% |
| DD (Developmental Disability) Agency/Program | 44 | ACA Implementation | 82% |
| Disability Specific Organizations | 42 | Medical Home | 82% |
| Early Intervention | 41 | Autism | 78% |
| Department of Education / Schools | 41 | Title V Block Grant | 75% |
| Protection and Advocacy Agencies | 38 | Medicaid | 73% |
| Children's Hospitals or Pediatric Units in Hospitals | 38 | Mental/Behavioral Health | 71% |
| Medicaid Agency | 37 | Title V Needs Assessment | 67% |
| Universities | 36 | Medicaid Waivers | 65% |
| University Center on Disability program | 36 | Cultural & Linguistic Competence | 65% |
| Mental Health Agency | 35 | Provider Training | 65% |
| Head Start / Early Childhood Programs | 33 | Medicaid Managed care | 59% |
| Child Advocacy Organizations | 33 | EPSDT | 59% |
| Health Care Coverage Advocacy Groups | 32 | Respite | 57% |
| Parent Mental Health Group | 30 | Health & Wellness Promotion/Prevention | 55% |
| Regional Genetics Collaboratives | 28 | Immigrant Families/Families of Diverse Cultures | 55% |
| Vocational Rehabilitation Agencies | 28 | | |

Impact on Families

Using a call-back protocol developed by John Snow, Inc., a public health consulting firm, F2Fs gathered feedback from families on the impact of their services last year:

- 92% of families reported the assistance they received was useful, very useful, or extremely useful in helping them partner in decision-making;
- 93% of families reported the assistance they received was useful, very useful, or extremely useful in helping them find and/or learn about community services; and
- 93% reported the assistance they received was useful, very useful, or extremely useful in helping them feel more confident and were better able to navigate needed services.

Impact on Programs & Policies

Last year 16% families reported they participated in committees, task forces, advisory boards, and at other levels of program and/or policy. Of those families, 88% reported that the assistance and/or training they received was useful, very useful, or extremely useful in helping them represent CYSHCN and their families.

F2Fs self-reported their impact in specific policy areas in their communities.

| Policy Area | % Rating: Significant to Moderate Impact |
|--|--|
| Supporting transitions | 98.% |
| Ensuring that consumers partner in their individual care | 96% |
| Promoting community based services easy for families to access | 96% |
| Infusing cultural and linguistic competence | 96% |
| Promoting Medical Homes | 92% |
| Implementing the ACA | 90% |
| Ensuring that consumers partner at program and policy levels | 90% |
| Contributing to core public health program functions (sharing family needs, educating the public, collaborating, evaluating) | 90% |
| Contributing to the development of integrated systems of care | 86% |
| Promoting continuous screening | 84% |
| Workforce development (including families) | 76% |

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 from <http://www.childhealthdata.org>
2 National Survey of Children's Health. NSCH 2011/12. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved from www.childhealthdata.org
3 Patient-Centered Outcomes Research Institute (2014). Research Prioritization Topic Briefs, Topics 7-13. PCORI Scientific Program Area: Addressing Health Disparities. Retrieved from <http://www.pcori.org/sites/default/files/PCORI-Addressing-Disparities-Topic-Brief-7-to-13-011314.pdf>
4 Lucille Packard Foundation for Children's Health. A Review of the Literature Pertaining to Family-Centered Care for Children with Special Health Care Needs (2014). Retrieved from <http://cschn.wpengine.netdna-cdn.com/wp-content/uploads/2014/10/Review-of-the-Literature-Pertaining-to-Family-Centered-Care-for-CSHCN.pdf>
5 Evidence for Family-Centered Care for Children With Special Health Care Needs: A Systematic Review. Kuhlthau, Karen A. et al. Academic Pediatrics, Volume 11, Issue 2, 136 - 143.e8. Retrieved from [http://www.academicpediatrics.org/article/S1876-2859\(10\)00359-1/pdf](http://www.academicpediatrics.org/article/S1876-2859(10)00359-1/pdf)