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

2014 Activities & Accomplishments of Family-to-Family Health Information Centers

CONTENTS

State-Specific F2F HIC information:

Information on each F2F HIC demonstrating their work for families

F2F State by State Charts:

Family Voices, Inc.
3701 San Mateo Blvd. NE, Suite 103, Albuquerque, NM 87110
Phone (505) 872-4774 or (888) 835-5669 • Fax (505) 872-4780
www.fv-ncfpp.org • www.familyvoices.org

This report was developed with funding from the Health Resources and Services Administration(HRSA)/Maternal and Child Health Bureau (MCHB) /Division of Services for Children with Special Health Needs (DSCSHN), through cooperative agreement #U40MC00149
June 12, 2014

OUR MESSAGE

Family-to-Family Health Information Centers: A Critical Resource

One in five families in the U.S. has at least one child with special health care needs (CSHCN)—needs that require health and related services of a type or amount beyond that required by children generally. For many families the impact of their child's special health care needs can be significant - increased out-of-pocket costs, challenges in navigating multiple systems, additional effort needed to provide and coordinate care, reduced work hours or giving up work altogether, as well as the emotional strain from such responsibilities.

Like their peers, children with special needs deserve every opportunity to enjoy a happy and healthy childhood at home and in their communities. Families equipped with reliable, accurate information about ways to support their children's health, education and social development can help them grow into productive adults as defined by their personal, family and community cultural beliefs and values.

Family-to-Family Health Information Centers (F2F HICs) help families of children and youth with special health care needs deal with the challenges of caring for a child with special health care needs. **These centers are successful, efficient and cost effective because they are staffed by parents who themselves have learned how to find and obtain financing; how to navigate community services; and how best to communicate and partner with providers.** Their family experience gives them empathy, and ensures that they are a trusted source of help. Formal family leadership training allows them to help other families solve problems.

Family-to-Family Health Information Centers provide information to help families:

- Understand chronic problems that require ongoing care and have long-term consequences.
- Coordinate care from a variety of medical specialists and ancillary medical services/therapies.
- Learn care-giving skills, such as daily living adaptations and monitoring medical progress.
- Identify and apply for financing programs offered by a myriad of federal, state and private programs including understanding changes due to the Affordable Care Act (ACA).
- Gain advocacy and communication skills, including skills to partner with their child's provider.
- Cope with the emotional demands of caring for a CSHCN.

The effectiveness of Family–to-Family Health Information Centers in every state is enhanced by the Family Voices national network of support and mentorship coordinated by the Family Voices National Center for Family/Professional Partnerships (NCFPP). Family Voices NCFPP helps F2F HICs to actively share tools, strategies and approaches for helping individual families and for improving programs and policies from state to state across the country, and provides training, technical assistance and resources to enhance this peer support

This booklet provides background information on CSHCN, Family Voices and the NCFPP, and highlights the work of each of the F2F HICs, from which vulnerable families receive the critical support they need. Thank you for taking the time to learn about these important activities!

Cristine E Marchand

Cristine Marchand
Executive Director, Family Voices

Nora Wells

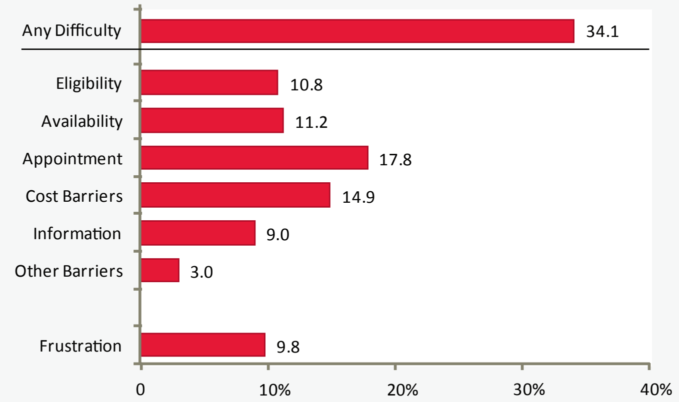
Nora Wells and Bev Baker
Co-Directors, Family Voices
National Center for Family Professional Partnerships

ABOUT CSHCN

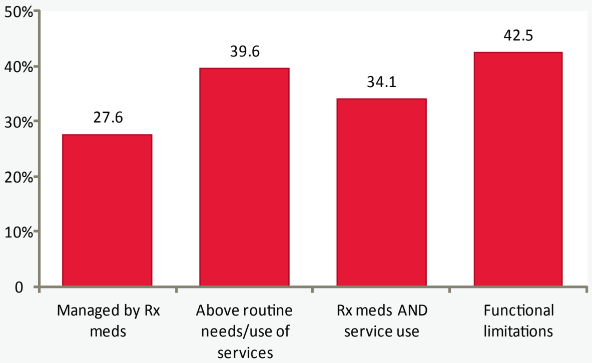
The Maternal and Child Health Bureau (MCHB) defines **children with special health care needs (CSHCN)** as those children who have or are at risk for chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.

- It is estimated that there are from 11.2 million (15.1%)[1] to 14.6 million (19.8%)[2] children with special health care needs under the age of 18 in the United States.
- More than 1 in 5 households with children in the United States have at least one child with special health care needs. This translates into almost 9 million households nationally. [1]
- About 60% of CSHCN experience more complex service needs that go beyond a primary need for prescription medications to manage their health condition. [1] Families of these more complex children are the group most frequently contacting F2F HICs for assistance.
- CSHCN account for 40% or more of medical expenditures for children overall.[1]

Prevalence of Specific Difficulties and Parental Frustration in Accessing Community-Based Services



% of CSHCN whose Insurance is Inadequate by Type of Special Health Need



CSHCN have complicated needs that are usually not isolated to a single doctor's office. CSHCN and their families often require services from multiple providers as well as schools and other community based organizations. CSHCN with more complex needs are those with functional limitations that make them unable to do the things most children the same age can do. They are more likely to have insurance that doesn't cover needed services, and/or unreasonable out of pocket expenses and/or problems seeing needed health providers.[1]

> *"Brooke has Cohen syndrome which is a genetic disorder that affects her developmentally and physically. Children with this disorder have moderate to severe intellectual disability and progressive vision issues. Brooke also has the other symptoms that can come with this disorder such as low muscle tone, neutropenia, and difficulties with eating. We have found it very difficult to provide the therapy our daughter needs. I try to find work that allows me to still care for our daughter. She is currently approved for long term care and we are praying that this program will help us be able to provide the therapies she needs."*
>
> \- a mother in Arizona

---

[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 09/18/2012 from 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 05/01/2014 from www.childhealthdata.org.

ABOUT F2F HICs

Family-to-Family Health Information Centers (F2F HICs) are family-staffed organizations that assist families of children and youth with special health care needs (CSHCN) and the professionals who serve them.

Each Family-to-Family Health Information Center is unique, reflecting the needs and character of the community and state that it serves. Organizational structure, locations, partnerships, and specific initiatives may vary. However, all F2F HICs provide:

1. Assistance to families and professionals in navigating health care systems;
2. Information, education, training, support and referral services;
3. Outreach to underserved / underrepresented populations;
4. Guidance on health programs and policy;
5. Collaboration with other F2F HICs, family groups, and professionals in efforts to improve services;
6. Evaluation and outcome assessment; and
7. Peer support based on common experiences and trusted information.

The success of F2F HICs and their critical value to families is highlighted in the following excerpt from a study conducted by the Research Triangle Institute:*

> *"Through their work to promote family-centered, culturally competent, and linguistically appropriate care and medical homes for CSHCN, Family-to-Family Health Information Centers are contributing to improvements in the quality of health care. They are also playing an important role in reshaping local and state policies and practices regarding care for CSHCN. By helping families to provide a consumer perspective on program and policy issues, Family-to-Family Health Information Centers enable states to develop more effective ways to assist families with CSHCN."*

The F2F HIC 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 and Resources Service Administration, Maternal and Child Health Bureau, Division of Children with Special Health Care Needs. Each F2F is awarded $95,700 annually.

---

*Angela M. Greene, M.S. et al., *Activities and Accomplishments of the Family to Family Health Care Information and Education Center Grantees.* Research Triangle Institute International, 2006.

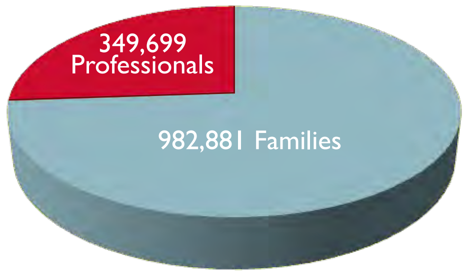
F2F HIC DATA: PEOPLE SERVED

Data on the following pages summarizes the activities and accomplishments of F2F HICs from June, 2012 - May, 2013.

Total Served

Over 1.3 million individuals were provided information, assisted, or trained by the 51 F2F HICs across the country (each state plus the District of Columbia). This total represents 74% families and 26% professionals.

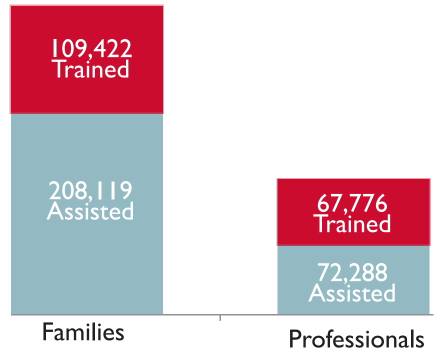
Families and professionals are served through many ways: by phone, email, and in-person; at conferences and community fairs; listservs and newsletters; and through support groups and social media.



> *"The F2F program taped a viewing of the Access for All television series about our collaboration with Title V to re-design the CSHCN program in order to deliver more family-friendly services. This television show reaches approximately 30,000 individuals during its airtime run."*
>
> \- West Virginia F2F Director

One-to-One Assistance and Training

F2Fs provide free one-to-one consultation by phone, email, or in-person. For many families who are overwhelmed or feel over loaded with information, this direct assistance from knowledgeable and sympathetic peer parents is extremely helpful. Professionals often call the F2F requesting assistance or resources for a specific family. In total, F2Fs responded to over 280 thousand families and professionals seeking help.



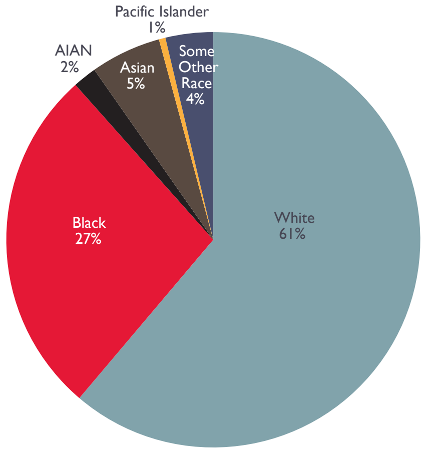
F2F programs provide training on a number of different topics, such as state health care financing programs, the Affordable Care Act, advocacy, and family/professional partnerships. Over 177 thousand families and professionals participated in trainings offered by F2Fs across the country. Trainings are done in-person, via webinar, and online.

> *"D has helped us break down what we thought were dead ends. D has been a listening ear; she has gotten services for our child, and basically been a Godsend to us."*
>
> \- Anonymous Respondent to Virginia F2F survey

Serving Diverse Populations

F2Fs outreach to and serve families with CSHCN in their communities. The chart shows average percentages of families served by race when the family self-identifies. About 10% of families served choose to self-identify.

Of those families who did self-identify 25% indicated they were Hispanic.



F2F HIC DATA: INFORMATION FOCUS & RESULTS

F2F HICs provide information most frequently in these focused areas:

Public Health Care Financing - accessing ACA, Medicaid, SCHIP, Title V, SSI, other public health programs

Family Support - seeking, obtaining, and/or providing family support, such as family-to-family, peer-to-peer, or sibling support

Communicating with providers - improving the quality of the family - provider relationship.

Care Coordination - understanding roles of multiple providers & facilitating communication

Advancing Knowledge - providing information or identifying opportunities to develop family leadership skills

Disability Awareness - discussing abilities disabilities, discrimination, attitudinal barriers, civil rights

School-based financing - working with schools regarding financing health-related services

Cultural Competence - understanding or promoting the family perspective of all cultural/ linguistic populations

Schools - resolving school issues other than financing

Systems Involvement - providing information and mentoring on involvement at a systems level

The ultimate goal of F2F HICs is to improve the access, equity, quality, integration, and accountability of health care for families of CSHCN. This is achieved by helping families to have the confidence to partner in decision-making and navigate services.

Data show that F2F HICs have been successful in impacting families in these areas. **91% of families report that the assistance and training they received from the F2F has made them better able to partner in decision-making, better able to navigate services, and more confident about getting the health care services their child needs.**

Juanita Dominguez is a Spanish-speaking mom to three daughters, ranging in age from 3 to 17. Erika, her middle child, has spina bifida with secondary hydrocephalus and requires a wheelchair. As Erika grew, she became too heavy for her mother to carry and it was increasingly difficult to assist her getting in and out of their family van. Juanita needed resources to have a ramp installed and was referred to Family Voices Colorado.

Ileana Perez, a bilingual FV Colorado Family Navigator, connected the Dominguez family to Variety Colorado, a children's charity and successfully helped Juanita apply for the funding of a wheelchair ramp for their van.

Juanita shared that her experience with Ileana and Family Voices was "*Very fast, very friendly. There were no obstacles in getting the help we needed. I am so grateful*."

ABOUT: FAMILY VOICES

Family Voices was incorporated in 1992 to give families of children with special health care needs a strong, united voice in discussions around health care reform. Built on a legacy of family leadership that helped to develop Medicaid Home and Community Based Waivers, influence hospital visiting policies, organize peer support, and impact special education and early intervention legislation as well as many other programs and policies, Family Voices continues to be a powerful force in keeping families at the center of children's health care.

Family Voices Mission

Family Voices aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities. Through our national grassroots network, we provide families tools to make informed decisions, advocate for improved public and private policies, build partnerships among professionals and families, and serve as a trusted resource on health care.

At the core of Family Voices are grassroots families supported by State Affiliated Organizations (SAOs) and Family-to-Family Health Information Centers (F2Fs). This network and our partnerships with provider and policy groups allows us to bring a vibrant family perspective to multiple arenas important to improving quality health care for children.

Family Voices and the F2Fs

Family Voices created the concepts and model to establish family-run F2Fs and oversaw successful demonstration projects that were funded initially by the Robert Wood Johnson Foundation, the federal Maternal and Child Health Bureau (MCHB), and the Center for Medicare and Medicaid Services (CMS). These original projects documented the enormous value of this family-to-family assistance.

A 2006 photo of Polly Arango, a founder of Family Voices, and her extended family. Polly is in the 2nd to last row, just to the left of center. Her son, Nick is in the front row on the left.

> *"We all come from families. Families are big, small, extended, nuclear, multi-generational, with one parent, two parents, and grandparents. We live under one roof or many. A family can be as temporary as a few weeks, or as permanent as forever. We become part of a family by birth, adoption, marriage, or from a desire for mutual support. As family members, we nurture, protect, and influence each other. Families have strengths that flow from individual members and from the family as a whole. Each family is a culture unto itself, with unique values and its own way of realizing dreams. Together, our families are the source of our rich cultural heritage and spiritual diversity. Our families create neighborhoods, communities, states, and nations."*
>
> - Developed and adopted by the New Mexico Legislative Young Children's Continuum and New Mexico Coalition for Children, June 1990

ABOUT FAMILY VOICES NCFPP

Now in its 9th year, Family Voices National Center for Family/Professional Partnerships (NCFPP) project provides vital national leadership to both families and professionals around establishing effective family/professional partnerships at all levels of children's health care, a core element in achieving family-centered care.

The NCFPP serves as the technical support provider for a network of F2Fs/SAOs, developing highly successful structures of support through information sharing, resource development, training, capacity building and leadership development. Regular communication takes place among members of this network through listservs, conference calls, webinars, social media, mentoring and an interactive website. This extensive system of peer support has allowed fledging family leaders to learn from more experienced leaders and has spread promising practices from state to state. Multiple topics are addressed during one-to-one technical assistance (TA) interactions. The most frequently requested topics in FY2013 were: family/professional partnerships, F2F HIC data tracking/reporting, and family leadership development.

With the new cooperative agreement awarded for FY2014, the NCFPP recognizes and addresses the complex current health care environment that family leaders and their partners face within their states and at the federal level. The goals of the NCFPP currently focus on promoting proactive partnering among families, service providers and policy makers in order to improve the quality of care for children and their families by:

- Increasing the capacity of families, and others to partner around full implementation of the Affordable Care Act,
- Strengthening the primary care workforce through family/professional learning opportunities, and
- Improving access to quality care and innovation in the areas of family-centered care, cultural and linguistic competence and shared decision making.

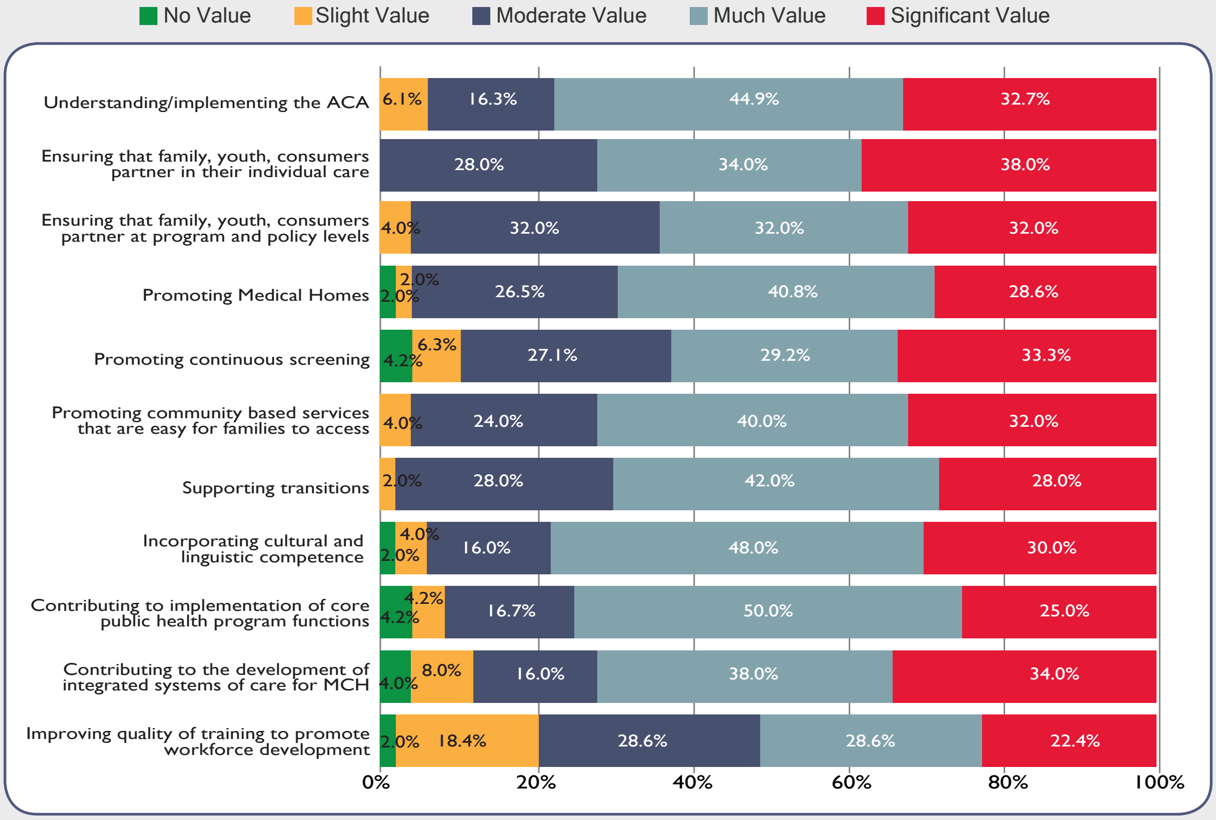
The NCFPP accomplishes these goals through technical assistance, training, and collaboration with F2Fs/SAOs and partners. Examples of this work include:

- Development of online train-the trainer course on Culturally-Competent Family/Professional Partnership
- Webinar series on ABC's of Quality Improvement for family/professional teams (joint effort with NICHQ)
- Documentation of family-identified best practices in reaching culturally-diversed and underserved families
- Work with the AAP Medical Home Implementation National Center on testing the Family-Centered Care Assessment in pediatric practices
- Input of family perspectives to restructure the National Survey of Children with Special Health Care Needs/National Survey of Children's Health
- Participation in the Genetic Alliance demonstration awards project aimed at improving access to genetics services and support
- Collaboration with the Centers for Disease Control and Prevention to educate families and providers on flu prevention and treatment
- Work with the National Center for Children's Vision & Eye Health on the design and dissemination of educational materials regarding children's vision health
- A national meeting of family leaders focused on leadership development

NCFPP DATA: IMPACT

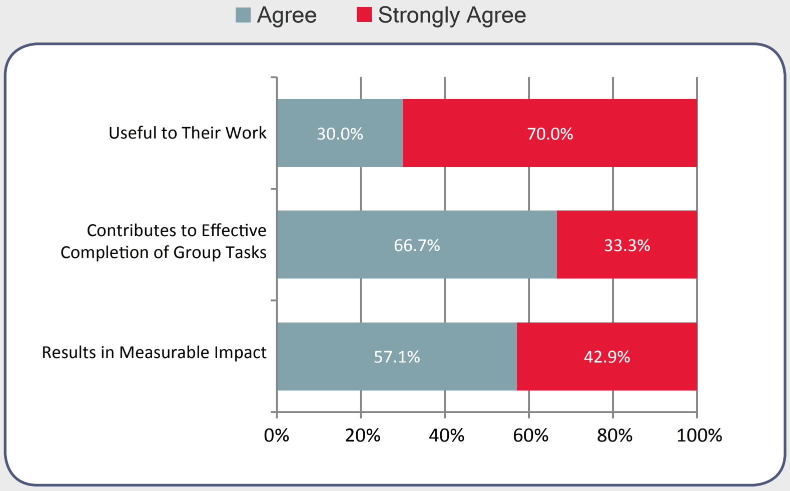
Data summarizes the activities and accomplishments of the NCFPP from June, 2012 - May, 2013.

Impact on Work of F2Fs/SAOs



> *"The NCFPP has provided a wealth of information to our activities over the past year, especially about the ACA. Information has been used to enhance the state perspective and provide families with much needed clarity and direction. There has also been great information with respect to Medical Home and working with tribal health in our state that has lent a clearer direction for supporting both families and professionals in our state."*
>
> \- anonymous F2F/SAO staff

Impact on Work of Professional Partners



> *"The relationship with NCFPP has been instrumental in cultivating projects and activities of mutual interest that further the patient-centered piece of the medical home work that we undertake as a national center. Additionally, the NCFPP representative to our national center's advisory group brings a wealth of knowledge, expertise and experience that we would not otherwise have. This is a tremendous asset to the work of our national center."*
>
> \- anonymous professional partner

F2F: Family Voices of Alabama

Family Voices of Alabama (FV of AL) had its beginnings in 1992 as a grassroots volunteer organization committed to speaking up about the needs of CSHCN in health care reform. As the F2F in AL, we provide information, training, technical assistance and peer support to families of CSHCN as well as those who serve them. We mentor families via one-to-one contact; nurture collaboration between families and professionals and assist families to be better able to participate in systems building activities in their communities and states. Throughout all of our activities, we integrate the philosophy of Family Centered Care, Family Professional Partnership, and Cultural Competence.

HIGHLIGHT: *Partners in Care Summit*

The *Partners in Care Summit* (PIC) is a two day conference designed to bring together families of CSHCN, youth, and professionals serving CSHCN. The first day is reserved for families and youth, and focuses on leadership development as well as practical information requested by families. There is time for networking and resource sharing. The second day is attended by families, youth and professionals, all learning together.

Session topics have included family engagement, medical home development, and transition to adult life for CSHCN, with an emphasis on health care transitions. There have also been sessions on timely topics of interest, such as the Affordable Care Act and changes to the Medicaid program in Alabama.

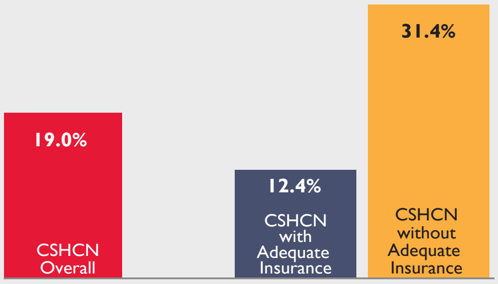
For the past two years, our F2F has partnered with Children's Rehabilitation Service (state CSHCN Program) and their D70 project (State Implementation Grants for Systems of Services for CSHCN). The additional funding that these partners have provided has allowed the F2F to support more families to participate in the Summit, and to bring in more national speakers. Attendance has grown from 100 in the first years to 150 years in the last two years.

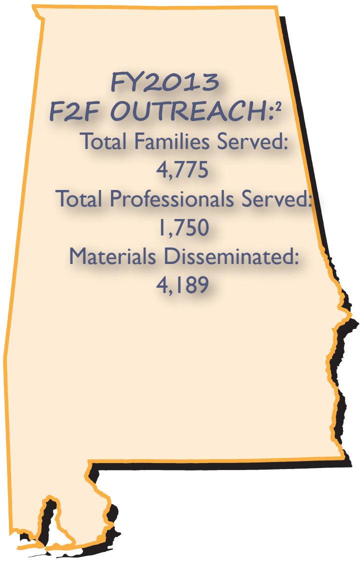
FEEDBACK: Professionals and families have consistently given the summit outstanding evaluations. The evaluation asks if participants felt they have learned new skills or strategies that will help them promote better partnerships between families and professionals to make good health care decisions. 93% report that they agree or strongly agree that they did learn at least one new skill or strategy. Also, of those participants who indicated an increase in knowledge and ability/skills, almost all indicated a 1-level increase, a statistically significantly finding.

CSHCN in AL[1]

- 200,367 children (17.8%)
- 57,685 children have inadequate insurance
- 45,083 children have conditions that consistently affect their activities
- 67,428 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:





FY2013 F2F OUTREACH:[2]

Total Families Served: 4,775

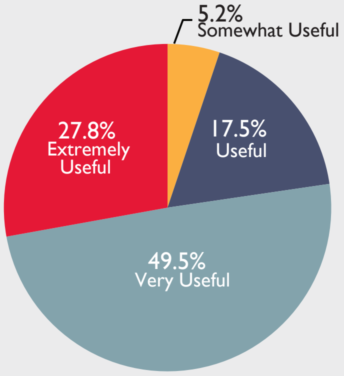
Total Professionals Served: 1,750

Materials Disseminated: 4,189

IMPACT:

Family/Provider Communications

Families rate the usefulness of the assistance/information/resources received from the AL F2F in helping them partner with (communicate with, talk with, work with) professionals to make decisions about their child's health care.[2]



CONTACT:

Family Voices of Alabama
1050 Government Street, Mobile, AL 36604-2404
Phone: 877-771-FVOA (877-771-3862)
Contact: Susan Colburn, susan.colburn@rehab.alabama.gov

---

[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 04/03/2014 from www.childhealthdata.org.

[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

F2F: Stone Soup Group

The F2F is a critical project of Stone Soup Group (SSG), a statewide nonprofit organization created in 1992 by parents of children and youth with disabilities, health care providers, and social workers who shared a common vision for interconnected, collaborative, family-driven assistance for other families of children and youth with special needs. Our name is a nod to the children's fable, in which a village of people contributes to feed a hungry stranger and one another. This spirit of collaboration and input of varied experience and knowledge is the philosophy behind the work we do at SSG. Our services are available statewide to help families with medical, disability, mental health, and special education issues and most are at no cost to families.

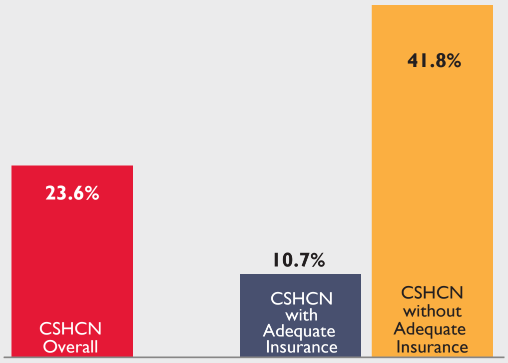
HIGHLIGHT: Teen Friendship and Dating

SSG has worked in collaboration with the University of Alaska Anchorage, Center for Human Development and others to teach teens and young adults with intellectual and related developmental disabilities about building and maintaining healthy relationships. Facilitated by staff, group sessions focus on teaching participants new skills such as personal boundaries, gender differences, the dating process, etc. This is followed by a chaperoned community activity where participants work on applying these new skills. To date, a total of 25 participants have "graduated" and the response from families has been overwhelmingly positive. Parents are relieved to have a structured, safe environment for their child to explore these important health issues and participants are proud of their accomplishments.

CSHCN in AK[1]

- 19,916 children (10.9%)
- 7,109 children have inadequate insurance
- 5,067 children have conditions that consistently affect their activities
- 7,198 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:

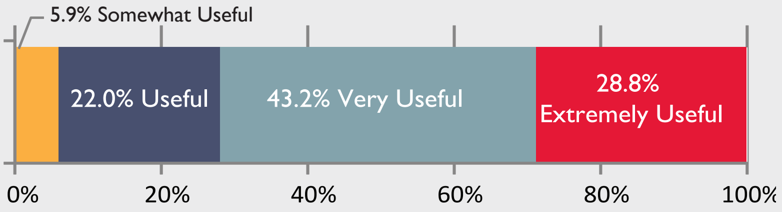


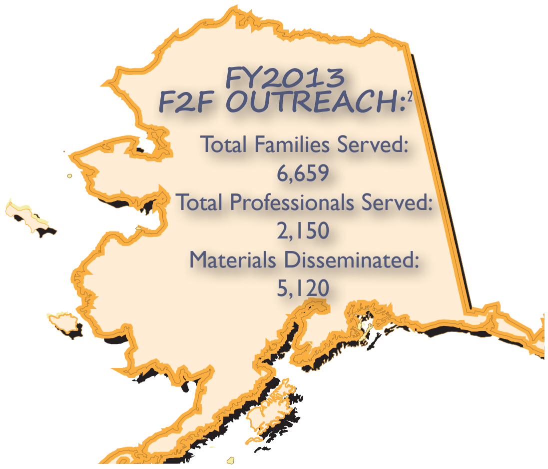
IMPACT on a Family:

After our first group graduated, a mom approached our booth while at an event. She was ecstatic about the program and wanted to know if her daughter could attend again. She said the program was exactly what she was looking for and told the following story: Her daughter is a very beautiful girl and at first sight it is not obvious that she has a disability. Because of this, she has received a lot of unwanted attention that she did not know how to handle. This was evident when a boy in the program began to repeatedly call her. Staff worked with the girl to build her confidence and with the boy to help him understand the negative aspects of his behavior. Both participants learned from the experience. According to the mom, *"peer to peer interaction, where they can learn these skills and practice this communication in a safe way, is what makes this program so unique and special!"*

IMPACT: Family/Provider Communications

Families rate the usefulness of the assistance/information/resources received from the AK F2F in helping them partner with (communicate with, talk with, work with) professionals to make decisions about their child's health care.[2]





FY2013 F2F OUTREACH:[2]

Total Families Served: 6,659

Total Professionals Served: 2,150

Materials Disseminated: 5,120

CONTACT: Stone Soup Group • 307 E. Northern Lights Blvd., #100 • Anchorage, AK 99503 • Phone: 877-786-7327 (AK only) or (907) 561-3701 • Website: http://www.stonesoupgroup.org • Contact: Amy Westfall, amyw@stonesoupgroup.org

---

[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 04/03/2014 from www.childhealthdata.org.

[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

F2F: Raising Special Kids

The Arizona Family-to-Family Health Information Center, a project of Raising Special Kids, is a parent-run center that provides free, confidential technical assistance to families raising CSHCN, professionals, and others. Through this project and others, we partner with health care providers, state agencies, programs for medical residents and student nurses, and other community organizations. Our goals are to promote understanding of the value of family-centered, culturally competent care so these principles are put into practice.

CSHCN in AZ[1]

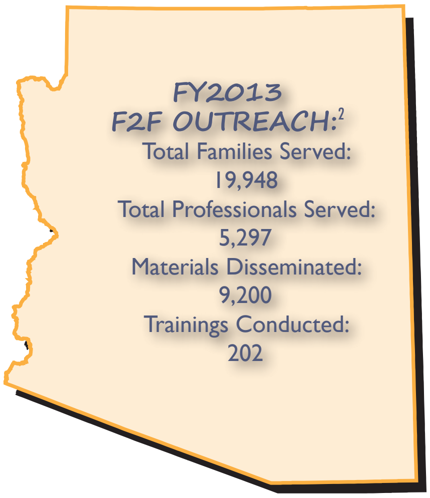
- 241,067 children (13.9%)
- 84,777 children have inadequate insurance
- 70,074 children have conditions that consistently affect their activities
- 88,998 children do not receive family-centered care

HIGHLIGHT: *Partners in Preparedness*

Raising Special Kids has been participating in a statewide Emergency Preparedness workgroup called *Partners in Preparedness*, addressing access and functional needs, since 2012. Raising Special Kids' role is to provide the perspective of families with children who have disabilities and complex medical needs. There are currently 21 community partners in the workgroup. We participated in the planning committee for the *2013 Statewide Partners in Preparedness Conference* which 124 people attended, including emergency management personnel, public health staff, seven Native American tribes, and individuals and parents of children with disabilities. As a result of our work, the AZ Department of Emergency Management is forming a subcommittee to address the specific needs of children who are medically fragile. Though the *Partners in Preparedness* workgroup we are participating in the Arizona Department of Emergency Management Arizona Disability Assessment Program.

IMPACT on a Family:

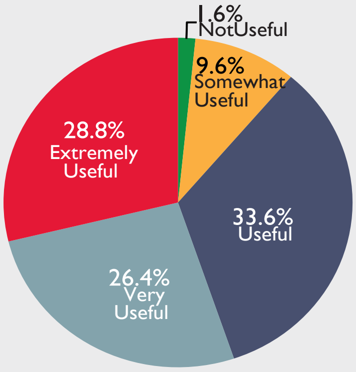
The health needs of Adilynn, adopted daughter of Laurie and her husband, have required multiple medical procedures and over a dozen specialists. *"We have been hospitalized a total of four times and with every stay we would leave with more doctors, tests, and stress to come,"* Laurie said. *"We were bombarded with paperwork, insurance issues, and the feeling that we were drowning and couldn't catch up."* Following Adilynn's surgery, Laurie received a call from Raising Special Kids. *"They helped me cope with her new feeding tube and the best help of all was that I got pointed in the right direction on how to get Long Term Care set up!"* Through Raising Special Kids, Laurie was connected with another mom who also has a child with complex medical needs. *"I could talk to someone who understands and someone who is a few steps ahead of where we were at the time. I now know just how important Raising Special Kids is to those who have kids with special needs."*



FY2013
F2F OUTREACH:[2]
Total Families Served:
19,948
Total Professionals Served:
5,297
Materials Disseminated:
9,200
Trainings Conducted:
202

IMPACT: Family Confidence

Families rate the usefulness of the support/information/resources they received from the AZ F2F in helping them feel more confident about getting their child the health care and services that s/he needs.[2]



CONTACT:

Raising Special Kids
5025 E. Washington St. #204, Phoenix, AZ 85034
Phone: (602) 242-4366 • Toll Free: (800) 237-3007 • Fax: (602) 242-4306
Website: http://www.raisingspecialkids.org/
Contact: Vickie French, vickief@raisingspecialkids.org

---

[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 04/03/2014 from www.childhealthdata.org.

[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

F2F: Arkansas Disability Coalition

The Arkansas Disability Coalition (ADC) is a statewide organization that assists families and individuals with all types of disabilities, providing health-related support, information, resources and training. We work to ensure that all Arkansas families of children or youth with any kind of disability or special health care need are empowered with the knowledge and assistance they require to make informed decisions that support their child or youth's health and development, through advocating the value and power of partnerships between families, health care professionals, lawmakers and the community-at-large.

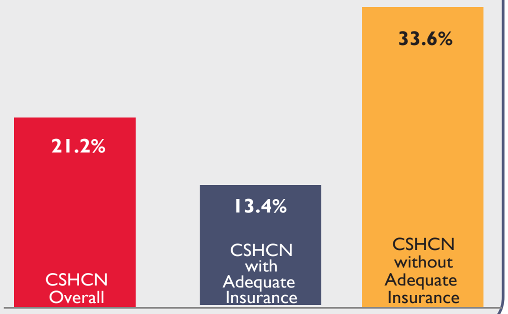
HIGHLIGHT: Minority Outreach

In this project designed to help Hispanic families of CSHCN in the Little Rock School District (LRSD), the AR F2F provided cultural competency training, resource information, and referral services around health to extend the family supports that two of the LRSD elementary schools could offer. In the eight months this project has been active we have provided direct assistance to 67 families. As a result of our work: the school district has a better understanding of the Hispanic community in central Arkansas; the relationship between the schools and Hispanic families has improved; and Hispanic families are now more aware of available health resources and in a better position to act as self-advocates. We will now use this experience to inform a pilot project to develop a statewide minority outreach plan.

CSHCN in AR[1]

- 139,580 children (19.8%)
- 48,743 children have inadequate insurance
- 44,523 children have conditions that consistently affect their activities
- 52,323 children do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:

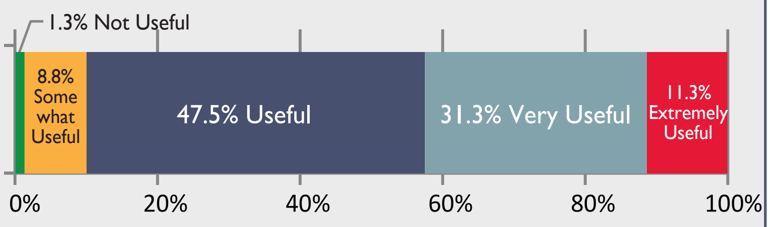


IMPACT on a Family:

The AR F2F recently worked with a mom of an 8-year-old child who had suffered with chest pains for months. Fearing the high cost of medical services, his parents had not taken their child to see a doctor. We connected the family with AR Children's Hospital and the child received a complete check-up. The mother noted in our follow-up call that she was very thankful for the F2F's involvement as she would never have taken the child to a hospital for fear of the bills associated with hospitals. She was not aware that Children's Hospital had so many services that were available to her for free. Her son is now in a 1-year care plan through AR Children's Hospital and she is very grateful. Her son now has much less chest pain and their family is better equipped to deal with the challenges that he faces.

IMPACT: Service Navigation

Families rate the usefulness of the support/information/resources they received from the AR F2F in helping them find and/or learn about community services (primary health care, intervention programs, translation services, etc.)[2]




FY2013 F2F OUTREACH:[2]

Total Families Served: 5,487

Total Professionals Served: 241

Materials Disseminated: 2,213

CONTACT:

Arkansas Disability Coalition
1501 N. University Avenue, Suite 268, Little Rock, AR 72207
Phone: 501-614-7020 • 800-223-1330 • Fax: 501-614-9082
Website: http://www.adcpti.org/
Contact: Bryan Cozart, bryan.cozart@adcpti.org

---

[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 04/03/2014 from www.childhealthdata.org.

[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

F2F: Family Voices of California

Family Voices of California (FVCA) is a statewide collaborative of locally-based parent run centers working to ensure quality health care for children and youth with special health care needs. FVCA provides information and a forum for parent centers and families to advocate for improved public and private policies, builds partnerships between professionals and families, and serves as a vital resource on health care.

CSHCN in CA[1]

- 997,157 children (10.6%)
- 353,181 children have inadequate insurance
- 289,340 children have conditions that consistently affect their activities
- 379,891 do not receive family-centered care

HIGHLIGHT: *Project Leadership* and *Health Summit*

FVCA works to increase the number of family members with CSHCN who are prepared and supported to become advocates for health care policy and systems improvements through its *Project Leadership* training. Recent graduates of this program participated in the *2014 FVCA Health Summit*. This Summit provided information and education to 133 participants (64 parents or adult family members, 11 youth and 58 professionals) about key components, benefits and concerns related to the California Children's Services (CCS) Title V program; how to access behavioral services through schools; Medi-Cal and private insurance; oversight and monitoring of Medi-Cal Managed Care after the transition of Healthy Families to Medi-Cal. 98% of Summit participants agreed or strongly agreed that they learned new information about policy issues that affect families of CSHCN.

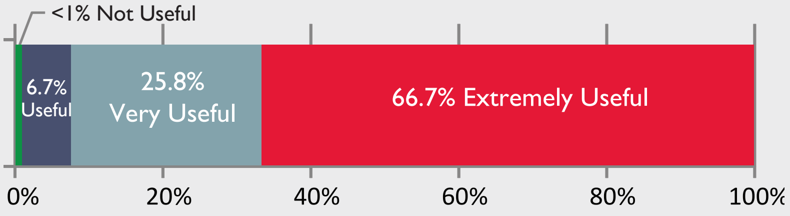
IMPACT on a Family:

Two parents from one family shared their thoughts and experiences after they graduated from the *FVCA Project Leadership* training program and attended the *Health Summit and Legislative Day*. Emelyn, the mom wrote *"Project Leadership training has allowed me to further build my confidence as an advocate. This training has given me the tools, information, and necessary leadership skills to further my advocacy voice for Mia, my daughter, and other families. I am very interested in expanding this training for other families to find their voices in advocating for their children's needs, most especially reaching out and training for the Latino/Hispanic community."*

The father, Daniel, said *"Progressively I have taken on the role of advocate for the needs and resources for our daughter, Mia. I have had no mentor or guide. None of my other friends or family members, who are also dads, could relate to what I was going through as a father, not even my own father. So I tried my best, despite not having someone to mimic my behavior after or show me where, when and how to hone and harness my energy and to what degree to do it. That's where Project Leadership comes in. I am beyond thankful and blessed to have been part of a workshop that has guided me and empowered me and has shown me where, when and how to harness my despair into a catalyst of advocacy for my daughter."*

IMPACT: Service Navigation

Families rate the usefulness of the support information/resources they received from the CA F2F in helping them find and/or learn about community services (primary health care, intervention programs, translation services, etc.)[2]



FY2013 F2F OUTREACH:[2]

Total Families Served: 99,444
Total Professionals Served: 46,140
Materials Disseminated: 12,594
Web Visits: 519,154

CONTACT:

Family Voices of California, Support for Families of Children with Disabilities
1663 Mission St. 7th Floor, San Francisco, CA 94103
Phone: (415) 282-7494 • Fax: (415) 282-1226
Website: http://www.familyvoicesofca.org/
Contact: Pip Marks, pmarks@familyvoicesofca.org

---

[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 04/03/2014 from www.childhealthdata.org.
[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

F2F: Family Voices Colorado

Family Voices Colorado is a collaborative of Family-Driven Organizations and Family Navigators that work with families, health care providers, other professionals and volunteers across our state to improve access to and quality of health care for young people with special needs. We help with application and enrollment for Medicaid and CHIP; understanding health insurance options through the new marketplace, Connect for Health Colorado; undertaking an appeal processes for public or private insurance; developing a culturally competent, medical home approach to care in the primary care office; or navigating complex service systems (such as disability, SSI, education, mental health).

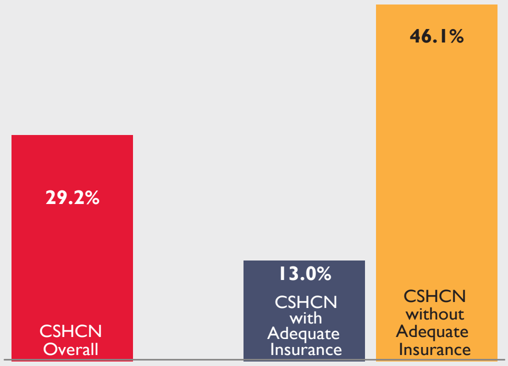
HIGHLIGHT: Collaboration of Colorado's Family Driven Organizations

Collaborating with other Individual Family Navigators/ Family-Driven Organizations has helped us to streamline outreach, assistance, service delivery and advocacy for the families we serve. Due to a very fragmented system in Colorado, this type of collaborative approach provides families with coordinated help. To date, our 10 different Family Navigators/Family-Driven Organizations have assisted over 5,000 parents and professionals on a variety of topics related to their CSHCN. In addition, every Family Navigator/ Family-Driven Organization works on specific projects to support the collaborative, such as the redesign of the Colorado Resource Directory providing access to over 2,750 resources.

CSHCN in CO[1]

- 167,524 children (13.7%)
- 70,432 children have inadequate insurance
- 43,543 children have conditions that consistently affect their activities
- 55,051 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:



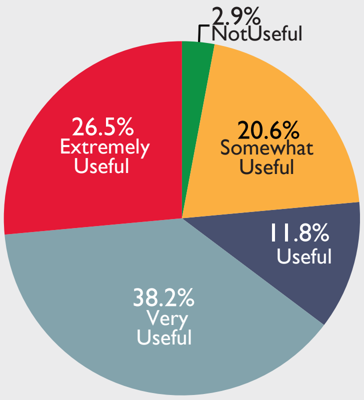
IMPACT on a Family:

Family Voices Colorado assisted a family who was being pressured to bring their daughter home from a residential treatment center. Emma had intense mental health needs as well as developmental disabilities. Family Voices helped the family work with the appropriate institutional representatives within the Medicaid Managed Care Ombudsman Program, Department of Health Care Policy and Financing, Behavioral Health Institute, and the residential treatment center to complete appropriate evaluations. They continued to help the family through a negotiation process of securing documentation from Emma's care providers and psychiatrist to convince the funding agencies of the medical necessity of continuing her placement, without having to reevaluate the situation on a monthly basis. Emma's Mom has taken the lessons she learned from working with Family Voices to become an advocate for other families facing similar situations.

IMPACT:

Service Navigation

Families rate the usefulness of the support/information/resources they received from the CO F2F in helping them find and/or learn about community services (primary health care, intervention programs, translation services, etc.)[2]



FY2013 F2F OUTREACH:[2]

Total Families Served: 10,656

Total Professionals Served: 3,733

Materials Disseminated: 8,705

Trainings: 56

CONTACT:

Family Voices Colorado
13199 East Montview Blvd Suite 200, Aurora, CO 80045
Phone: Phone: (303) 733-3000 • Toll-Free: (800) 881-8272
Website: http://www.familyvoicesco.org
Contact: Dina Castro, dina@familyvoicesco.org

[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 04/03/2014 from www.childhealthdata.org.

[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

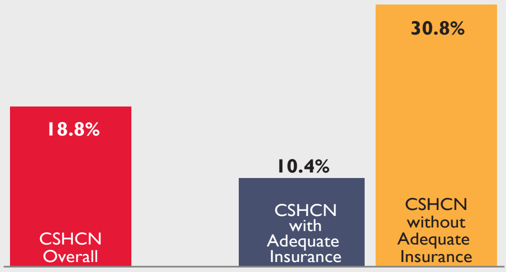
F2F: PATH Parent to Parent/Family Voices of CT

PATH is a network of families providing informational and emotional support to others who have a child with developmental or health related needs. PATH reaches out to help strengthen families coping with similar situations across the state of Connecticut, and works with the organizations that serve these families to reduce isolation, empower families as advocates for their children and reaffirm their values as parents and caregivers.

CSHCN in CT[1]

- 139,453 children (17.3%)
- 52,051 children have inadequate insurance
- 40,019 children have conditions that consistently affect their activities
- 44,632 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:



HIGHLIGHT: State Implementation Grant for Autism & other Developmental Disabilities

PATH/Family Voices of CT (FVCT) works with multiple partners in a Collaborative to Improve Autism Services with a goal of enhancing Connecticut's existing infrastructure supporting children and youth with autism spectrum disorder (ASD) and other developmental disabilities. Project activities include providing one-to-one parent-to-parent support and training to families/caregivers of children and youth with autism and training to professionals and clinicians responsible for screening families of diverse populations when English is not their primary language and when they have different cultural views on child development. Under this project to date, PATH/FVCT has provided support and training to 97 parents and professionals, including CT's Medical Initiative Programs, Birth to Three Provider programs, insurance companies and parent support groups. As part of this training, PATH/FVCT developed a video to educate the public on the top 10 things a child with ASD wants you to know. This training and the video have been very well received and we continue to get requests for this resource from across the state.

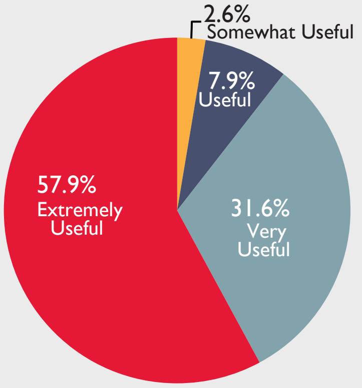
IMPACT on a Family:

"Our nine year old daughter Jana has autism. Jana knows only a few words and she needs help with almost everything, including eating, bathing, and dressing. Jana does not read and she cannot count to more than 5. When Jana was first diagnosed with autism, we knew nothing about it. We were new to the United States and everything, including Jana's condition, was new to us. We were referred to PATH/FVCT by Northwest Medical Home and have learned much since then. PATH/FVCT has been a great source of information about autism and they have helped us find ways to help Jana learn. We are seeing Jana make advances every day now. Without Kevin and PATH/FVCT, these things would not be happening. Thank you."

- Paul and Sissy Wang

IMPACT: Family/Provider Communications

Families rate the usefulness of the support/information/resources they received from the CT F2F in helping them partner with (communicate with, talk with, work with) professionals to make decisions about their child's health care.[2]



FY2013 F2F OUTREACH:[2]

Total Families Served: 23,861
Total Professionals Served: 9,903
Web Visits: 52,823
Materials Disseminated: 3,447

CONTACT:

PATH/FVCT
P.O. Box 117, Northford, CT 06472
Phone: 1-800-399-PATH (CT only) or 1-203-234-9554
Website: http://www.pathct.org/
Contact: Nanfi Lubogo, nlubogo@pathct.org
Carmina Cirioli, accirioli@att.net

---

[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 04/03/2014 from www.childhealthdata.org.
[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

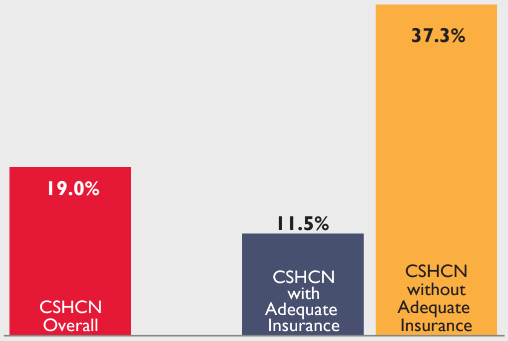
F2F: Delaware Family Voices

Delaware Family Voices (DE FV) is a non-profit run by families of CSHCN, whose mission is to achieve family-centered care and help families be full partners at all levels of decision making. This mission is achieved by: assisting families as they navigate health systems, insurance plans and Medicaid; educating families and health care providers about access to services and resources; promoting family-centered care and medical homes for CSHCN; working with families, health care providers, agencies, advocacy and support groups; linking families to providers, managed care programs and public programs; and promoting discussion among groups that serve children.

CSHCN in DE[1]

- 36,143 children (17.5%)
- 8,916 children have inadequate insurance
- 7,112 children have conditions that consistently affect their activities
- 12,724 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:



HIGHLIGHT: Managed Care Organization Monthly Calls

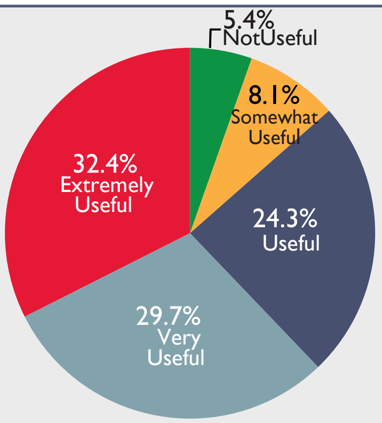
DE FV facilitates monthly calls with Medicaid, Managed Care Organizations, home health agencies, providers, and families of CSHCN to help professionals identify critical issues for families and to provide families with a non-adversarial forum to provide feedback on their experiences. On the calls, a family has up to 10 minutes of uninterrupted time to ask a question or discuss an issue, followed by a problem-solving time in which anyone can participate. Over the years we have seen specific policy changes because of these calls. Many organizations require at least one staff member to participate in this each month as they learn so much about services systems and how policies affect families. An example of an impact is that Medicaid is now considering covering hippotherapy after families and an occupational therapist described the benefits on a recent call. Families have found they are listened to and appreciate the efforts of participants to address their issue. Everyone who participates indicates that they learn something new with each call.

IMPACT on a Family:

After a mom had received assistance from DE FV around finding mental health services for her daughter with intellectual disabilities, she told the DE FV staff: *"You are truly a very special person to me and Breanna. I was thinking about what you said to me about being strong. I was a nervous but your counsel gave me courage. Thank you for your support."*

IMPACT: Family/Provider Communications

Families rate the usefulness of the support/information/resources they received from the DE F2F in helping them partner with (communicate with, talk with, work with) professionals to make decisions about their child's health care.[2]



FY2013 F2F OUTREACH:[2]

Total Families Served:
1,752

Total Professionals Served:
1,140

Materials Disseminated:
1,766

CONTACT:

Delaware Family Voices, Inc. • 222 Philadelphia Pike #11, Wilmington, DE 19809
Phone: (302) 669-3030 • Toll-Free: (877) 235-3588 • Fax: (302) 478-3350
Website: http://www.defv.org
Contact: Ann Phillips, annp@defv.org

---

[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 04/03/2014 from www.childhealthdata.org.
[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

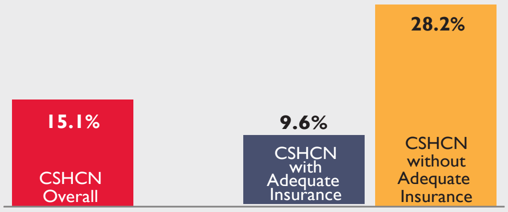
F2F: Advocates for Justice and Education

Since 1996, Advocates for Justice and Education, Inc. (AJE) has endeavored to empower youth and parents to be effective advocates to ensure that children with disabilities receive appropriate services to meet their needs. The F2F at AJE, in partnership with Mary's Center for Maternal and Child Care, provides training and workshops to families of CSHCN, trains parents and caregivers to be Family Navigators to provide emotional support to other families, produces resources and publications on best practices and programs affecting CSHCN, educates professionals working with CSHCN, and partners with stakeholders in the medical and health care fields.

CSHCN in DC[1]

- 18,819 children (16.6%)
- 5,628 children have inadequate insurance
- 4,043 children have conditions that consistently affect their activities
- 7,533 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:



HIGHLIGHT: *Leadership Institute for Spanish-Speaking Families*

Recently AJE collaborated with Mary's Center and other agencies serving CSHCN to host a *Parent-to-Parent Leadership Institute for Spanish-speaking Families* at the Mary's Center Medical Home location. Forty-eight parents and caregivers of CSHCN attended the two-day training to become Certified Family Navigators. The *Parent-to-Parent Leadership Institute* offers a comprehensive training that focuses on health care and educational advocacy, the laws that supporting health care, education and related services, and most importantly empowering families and developing their leadership skills. Some of the topics of this years' two-day training included: Youth Mental Health Advocacy, Nutrition and Child Development, Multi-systemic Therapy, Transfer of Educational Rights, Understanding the Special Education Process, D.C. Health Benefits Exchange, Overview of Autism Spectrum Disorders, and Working Effectively with Doctors.

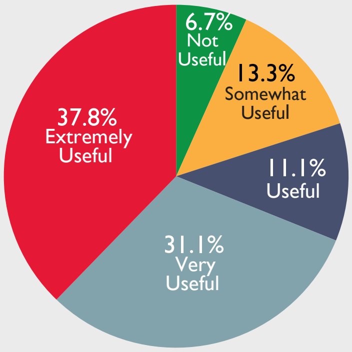
IMPACT on a Family:

A parent sought assistance from AJE with obtaining educational, medical, and community-based supports after her daughter had recently been diagnosed with epilepsy. AJE helped the parent to obtain Supplemental Security Income and to access a local support group for teens with epilepsy. We're pleased with not only the outcomes the family achieved, but also with the growth and leadership of the youth. The youth was able to effectively communicate with her teachers, school administrators, and medical providers about the accommodations she desired during her Individualized Educational Planning (IEP) meeting, resulting in a modified Individualized Health Plan (IHP). Following the IEP meeting, the youth informed AJE that she felt empowered and prepared to advocate for herself when needed.

IMPACT:

Family/Provider Communications

Families rate the usefulness of the support/information/resources they received from the DC F2F in helping them partner with (communicate with, talk with, work with) professionals to make decisions about their child's health care.[2]



FY2013 F2F OUTREACH:[2]

Total Families Served:
5,013

Total Professionals Served:
786

Web Visits:
13,086

Materials Disseminated:
1,400

Trainings:
150

CONTACT:

Advocates for Justice and Education, 1012 Pennsylvania Avenue, SE , Washington, DC 20003
Phone: (202) 265-1432 • Fax: (202) 678-8062 • Website: http://www.aje-dc.org/
Contact: Weade Wallace, weade.wallace@aje-dc.org

---

[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 04/03/2014 from www.childhealthdata.org.

[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2014.

F2F: Family Network on Disabilities

Founded in 1985 by a group of parents, the Family Network on Disabilities in Florida is a grassroots organization advocating for persons with disabilities and their families. What started as a group of parents meeting for support and to share information on their children with disabilities has now grown to a full network of families and individuals across the state of Florida. Family Support, Training, Assistance, and Resources (Family STAR) is the F2F project and has the goal to assist families of CSHCN to make informed decisions about health care for their children.

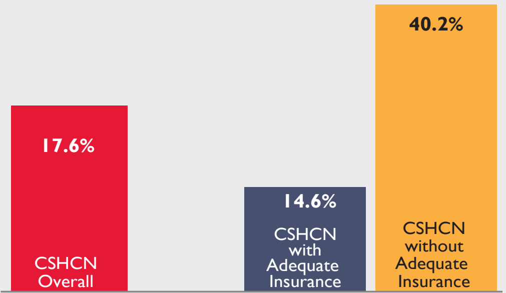
HIGHLIGHT: *Healthcare Toolkit*

The *Healthcare Toolkit* helps families of children and young adults with special health care needs to be prepared for a medical visit. This *Toolkit* provides a family-friendly way for families to keep their children's and young adult's health information at their fingertips and improves communication between families and providers. Having records and transcripts in one place may help cut down on health cost, for example, when doctors do not have to duplicate tests. The 102 families, youth, and professionals who have used the *Healthcare Toolkit* have provided very helpful feedback on how to improve this resource and we have implemented the changes and suggestions made by all participants. This has been a wonderful opportunity for collaboration with families, youth, and health care professionals.

CSHCN in FL[1]

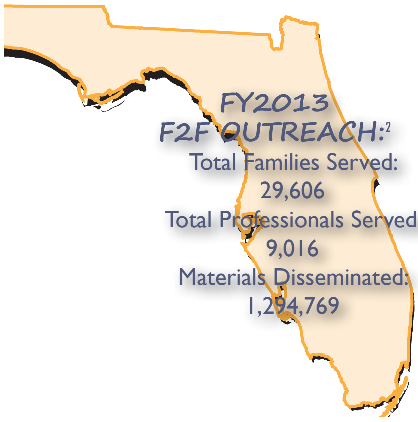
- 606,215 children (15.0%)
- 198,648 children have inadequate insurance
- 177,321 children have conditions that consistently affect their activities
- 255,698 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:



IMPACT on a Family:

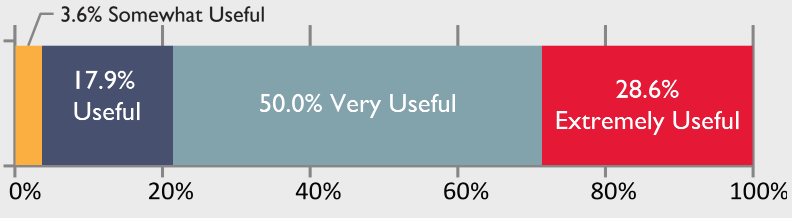
We have worked with families throughout Florida helping them get a better understanding of the Affordable Care Act, including the positive changes in the Act and how the health care exchange works. We have worked closely with a single mother who, because of our assistance, was able to get the health care coverage she needed for her children enabling them to continue their health care services without interruption. She quotes: *"Thanks to Family STAR of FND, my family has the health care we need. Family STAR has been a blessing to my entire family."*



FY2013
F2F OUTREACH:[2]
Total Families Served:
29,606
Total Professionals Served:
9,016
Materials Disseminated:
1,294,769

IMPACT: Family Confidence

Families rate the usefulness of the support/information/resources they received from the FL F2F in helping them feel more confident about getting their child the health care and services that s/he needs.[2]



CONTACT:
Family Network on Disabilities
2196 Main Street, Suite K, Dunedin, FL 34698
Phone: (727) 523-1130 / • Toll-Free: (800) 825-5736
Website: http://www.fndfl.org/
Contact: Marilyn Ruiz, marilyn@fndfl.org

---

[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 04/03/2014 from www.childhealthdata.org.
[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2014.

F2F: Parent to Parent of Georgia

Since our beginning in 1980, Parent to Parent (P2P) of Georgia has been the go-to resource for support, information, education, and leadership development for Georgians with disabilities or special health care needs, ages birth to 26, and their families. The F2F project at P2P provides families of CSHCN and the professionals that serve them, with one-on-one assistance and face-to-face and online training specifically around health. We help families navigate through Georgia's health care system; connect families to resources within their communities; and provide training to help families and youth participate in planning and decision-making on health related issues.

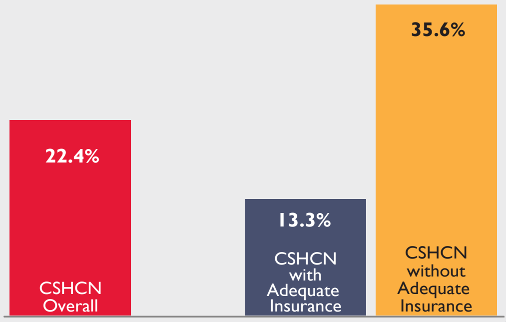
HIGHLIGHT: Round Table Discussions on Transition Planning

We are collaborating with Children's Medical Services (CMS, Georgia's MCHB Division that serves CSHCN) to convene discussion groups of parents and professionals across the state around transition planning for Georgia. To date we have conducted six round table discussions to learn what families need for transition services and support; what families have experienced in this area; what services are working well and what are not; and what is their biggest fear about their child's transition. When all eight round table discussions are complete, results will be used to develop a Georgia State Transition Plan. We are thrilled that CMS began this important process with families and has selected a family-driven organization to facilitate this work! This represents a very significant shift in approach and we are anxious to see the results!

CSHCN in GA[1]

- 411,526 children (16.0%)
- 118,817 children have inadequate insurance
- 96,450 children have conditions that consistently affect their activities
- 139,533 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:

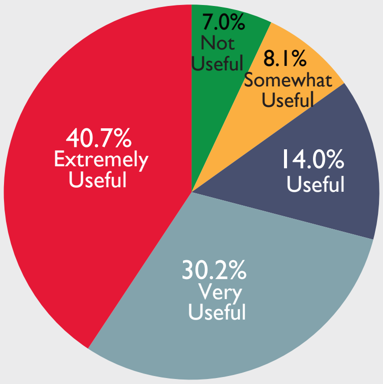


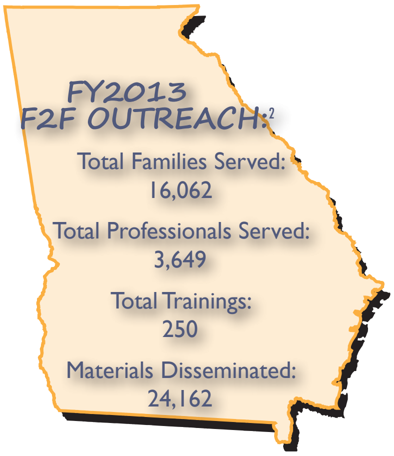
IMPACT on a Family:

A single parent who speaks Spanish and has four children with special health care needs was recently provided extensive support by our Spanish-speaking coordinator. We helped the parent understand SSI, Medicaid and the guardianship process, and now her children are receiving SSI and Medicaid services and she is successfully navigating the system to procure guardianship for her now 17 year old. The parent also attends our health related trainings in Spanish so she can be up to date on any changes in the health care system. We have connected her to Hispanic resources within her community so she now has a source of ongoing local support close to home. And finally we have matched her to a trained supporting parent so she can talk specifically about some of the health issues her children are experiencing.

IMPACT: Family/Provider Communications

Families rate the usefulness of the support/information/resources they received from the GA F2F in helping them partner with (communicate with, talk with, work with) professionals to make decisions about their child's health care.[2]





FY2013 F2F OUTREACH:[2]

Total Families Served: 16,062

Total Professionals Served: 3,649

Total Trainings: 250

Materials Disseminated: 24,162

CONTACT:

Parent to Parent of Georgia • 3070 Presidential Parkway, Suite 2130, Atlanta, GA 30340
Phone: (770) 451-5484 • Toll-Free: (800) 229-2038 • Fax: (770) 458-4091
Website: http://p2pga.org
Contact: Sitara Nayak, sitara@p2pga.org

---

[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 04/03/2014 from www.childhealthdata.org.
[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

F2F: Hilopaʻa Family-to-Family Health Information Center

In 2007, to meet the needs of Hawaii families of children with special health care needs, the Hawaiʻi Pediatric Association Research and Education Foundation (HPAREF) and Family Voices of Hawaiʻi, partnered together to form the Hilopaʻa Family-to-Family Health Information Center. The name Hilopaʻa, was given by Kupuna Kahauanu Lake to exemplify the driving force behind the center, to "braid firmly" the service system for our children and youth. Our F2F HIC is staffed by parents and friends of CSHCN and we provide free, confidential assistance, information and referral, and training to families raising children and youth with special health needs, self-advocates and the professionals who serve them.

HIGHLIGHT: *Hiʻilei Hawaiʻi*

As a result of the significant change in early intervention eligibility criteria, the Hilopaʻa F2F HIC is a proud partner on a new project with the Hawaiʻi Title V Program - providing family support and developmental screening for children birth to age three, who are not eligible for early intervention services. This "follow along" program seeks to mentor families on childhood development and assist families to engage with their medical homes regarding developmental concerns and resources. The Ages and Stages Questionnaire (ASQ) and the Modified Checklist for Autism in Toddlers Revised (M-CHAT-R) are distributed to families who chose to voluntarily participate in this program to help families understand child development and look for signs that may need further attention. We have received 42 referrals to date from every island in the state. A specific role for the F2F will be to measure child development progression, future eligibility for early intervention and special education, and the family's ability to track their son's or daughter's developmental milestones. The overall program will also measure the rate of families who choose to be followed through Hiʻilei Hawaiʻi program and those who opt not to, once they are denied services through early intervention.

IMPACT on a Family:

The Hilopaʻa F2F HIC assisted a family in obtaining retroactive Medicaid eligibility in excess of 4 months for a child with an extensive stay in a hospital's intensive care unit. The family was contemplating filing for bankruptcy as they were unable to see how they would be able to pay their child's extensive and ongoing hospital bills The Medicaid coverage eliminated the considerable out-of-pocket expenses the family was facing and they were relieved that Medicaid would be able to cover future hospital expenses. In addition, the family now has more options through the Medicaid Long Term Care Services and Supports when the child is able to be discharged, as the family's private insurance would only provide a nominal amount of in-home care.

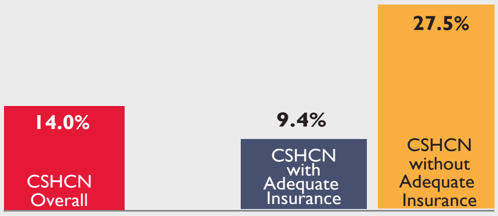
CONTACT:

Hilopa'a Family-to-Family Health Information Center
1319 Punahou Street Room 742, Honolulu, HI 96826
Phone: (808) 791-3467 • Fax: (808) 531-3595
Website: http://www.hilopaa.org/
Contact: Leolinda Parlin, leo@hilopaa.org

CSHCN in HI[1]

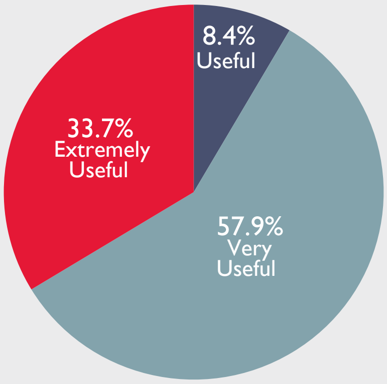
- ➢35,022 children (12.3%)
- ➢8,774 children have inadequate insurance
- ➢8,275 children have conditions that consistently affect their activities
- ➢11,262 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:



IMPACT: Family/Provider Communications

Families rate the usefulness of the support/ information/resources they received from the HI F2F in helping them partner with (communicate with, talk with, work with) professionals to make decisions about their child's health care.[2]



FY2013
F2F OUTREACH:[2]

Total Families Served: 3,298
Total Professionals Served: 1,527
Materials Disseminated: 13,158
Web Visits: 8580

---

[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 04/03/2014 from www.childhealthdata.org.
[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

F2F: Idaho Parents Unlimited, Inc.

Founded in 1985, Idaho Parents Unlimited, Inc. (IPUL) is a statewide organization which houses the Idaho Family-to-Family Health Information Center (F2F), along with Idaho Family Voices, the Idaho Parent Training and Information Center, the Creative Access Art Center and VSA Idaho, the State Organization on Arts and Disability. The F2F project works to help sustain the health and well-being of Idaho's families, their children and youth with special health care needs. The program values family-centered care and honors the strengths, cultures, traditions and expertise in the family/professional partnership.

CSHCN in ID[1]

- 53,280 children (12.7%)
- 18,693 children have inadequate insurance
- 15,396 children have conditions that consistently affect their activities
- 19,965 do not receive family-centered care

HIGHLIGHT: Pediatric Patient-Centered Medical Home Demonstration

IPUL partners with the Idaho Department of Health and Welfare, Division of Medicaid, in the Children's Healthcare Improvement Collaborative to provide support and information to families who serve as parent partners in three medical home pediatric practice sites throughout the state. Utilizing resources from Family Voices National and other states, we created a medical home workshop which includes an overview of what comprehensive, coordinated, family-centered care looks like for CSHCN, as well as Idaho-specific information.

The parent partners, care coordinators, medical home coordinators, and project staff have leaned heavily on IPUL to provide this training and resources both internally within the project and to parents of children with special health care needs. This model of parent/professional collaboration is working very well. We have offered approximately 20 training workshops over the past two years, and have trained both parents and providers within the practice clinics. Both groups report an increase in knowledge, access to services, and improved parent/professional collaboration. The partnership has now evolved and IPUL is a partner resource in the newly developed Idaho Health & Wellness Collaborative for Children (IHAWCC), which has been established as Idaho's first Pediatric Improvement Partnership. The Improvement Partnership is a collaboration of public and private partners that uses measurement-based efforts and a systems approach to improve the quality of children's health care.

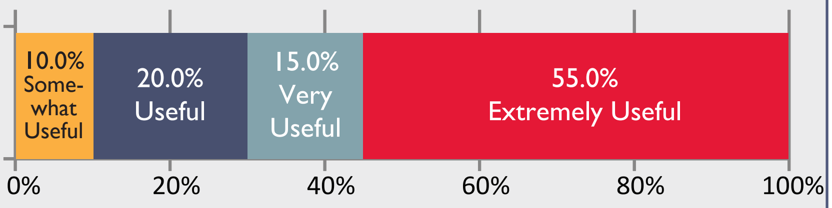
IMPACT on a Family:

"I have an 11-year-old son diagnosed with Asperger's Disorder, ADHD, and learning disabilities. I have recently been trying to get my son enrolled in children's services through Health and Welfare. Trying to navigate systems is like trying to find your way through a labyrinth. I came across the IPUL webpage and an online form, I described my frustrations, expecting that someone would contact me within the week. IPUL called me the next day with information on the appeal process for SSI. They contacted the Care Coordinator at my child's doctor's office. By the end of that day, my son had an appointment the next day. Without IPUL I still wouldn't know what to do. I was extremely impressed by how quickly they provided help. IPUL has continued to stay in contact with me, which I appreciate. The relationship IPUL has with the Care Coordinators at various medical specialty offices is crucial to helping children with special health care needs receive all the services they need."

- Heather I. (parent)

IMPACT: Family/Provider Communications

Families rate the usefulness of the support/information/resources they received from the ID F2F in helping them partner with (communicate with, talk with, work with) professionals to make decisions about their child's health care.[2]



FY2013 F2F OUTREACH:[2]

Total Families Served: 6,030

Total Professionals Served: 2,214

Web Visits: 265,880

Materials Disseminated: 1,424

CONTACT:

Idaho Parents Unlimited, Inc. • 500 South 8th Street P. O. Box 50126 • Boise, ID 83702
Phone: (208) 342-5884 • Toll free: (800) 242-IPUL (4785) • Fax: (208) 342-1408 • Website: http://www.ipulidaho.org
Contact: Angela Lindig, angela@ipulidaho.org

[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 04/03/2014 from www.childhealthdata.org.

[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

F2F: Family Voices of Illinois

Family Voices of Illinois, the Arc of Illinois Family-to-Family Health Information Center, offers free services for families of children and youth with special needs. We provide information directly to families and professionals seeking help via toll-free multi-lingual information line, email and in person. We offer in-depth training and technical assistance on health issues for CSHCN; leadership development for parents and organizations; and linkages to local, regional, statewide and national partners.

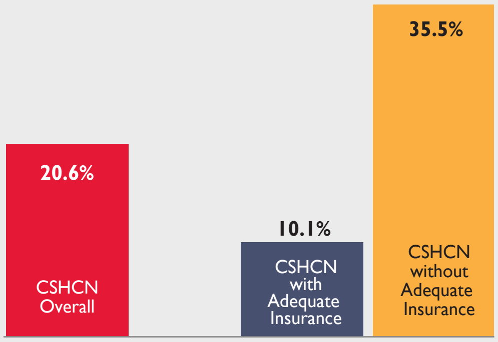
HIGHLIGHT: *Update on Health Care Reform* Annual Conference

Each fall, Family Voices of Illinois holds an annual *Update on Health Care Reform for CSHCN* seminar featuring presentations by state agency representatives, advocates and family leaders. In this year's seminar 104 individuals participated in workshops on Medicaid Reform, the Affordable Care Act for Special Populations, Private Health Insurance Marketplace, and Disability Advocacy. Scholarships and stipends were available for families and CEUs and CPDUs were provided for professionals. Feedback: *"This seminar provided clarification on ACA implementation in Illinois especially route of access." "This seminar will help me to navigate my child's insurance coverage needs as well as understand more about their Medicaid coverage. I feel much more confident now. I know where to go AND folks to call if I have questions."*

CSHCN in IL[1]

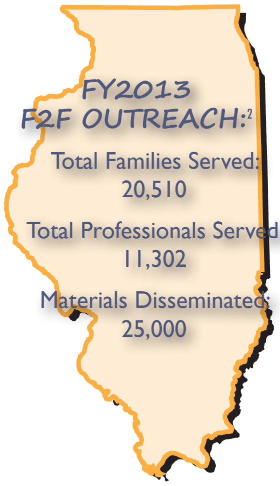
- 452,574 children (14.3%)
- 157,296 children have inadequate insurance
- 122,054 children have conditions that consistently affect their activities
- 145,706 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:



IMPACT on a Family:

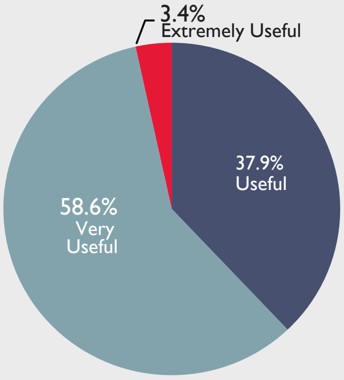
We recently assisted a mother and two children, all of whom have a serious genetic disease. They were referred by a pediatric tertiary care center. We helped them to understand the insurance options newly available under the ACA and to learn the difference between Other Health Impaired IEPs and 504 plans and to decide which option is most appropriate for them. We referred them to our state's Title V CSHCN program for care coordination assistance, informed them about pre-registering with the first responders in their community, and how to obtain a Persons With Disability parking placard, as well as a reserved street parking space. We explored possible Medicaid eligibility options for the children and explained SSDI eligibility for the mother. The mother shared her appreciation: *"Thank you for all your valuable information and resources. It is good to know there are people out there looking to help each other out. I will keep you posted on our status."*



FY2013
F2F OUTREACH:[2]
Total Families Served:
20,510
Total Professionals Served:
11,302
Materials Disseminated:
25,000

IMPACT: Family Confidence

Families rate the usefulness of the support/information/resources they received from the IL F2F in helping them feel more confident about getting their child the health care and services that s/he needs.[2]



CONTACT:

Family-to-Family Health Information Center
20901 LaGrange Rd., Suite #209, Frankfort, IL. 60423
Phone: 866-931-1110 English • 800-588-7002 Spanish
Toll Free: 866-931-1110 • Fax: 815-464-5292
Website: http://www.familyvoicesillinois.org/
Contact: Faye Manaster, familytofamily@thearcofil.org

---

[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 04/03/2014 from www.childhealthdata.org.
[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

F2F: Family Voices Indiana

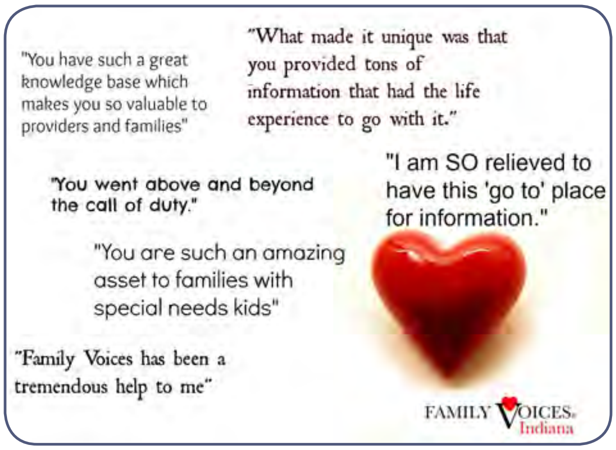
Families at all stages of the journey of raising children with disabilities and special health care needs encounter a complex maze of systems and services. Systems are undergoing frequent changes, and new policies and programs, new procedures for enrollment and re-determination, changes in eligibility requirements and program coverage are providing even more challenges to families seeking care for their children. Developing and supporting family leaders as partners at all levels allows systems to better understand family needs and helps families to better navigate and influence the process. It is the mission of FV Indiana to fill the information needs of families while developing family leaders to be sure that a strong family voice is available to help systems to meet needs.

CSHCN in IN[1]

- ➢268,717 children (17.0%)
- ➢90,466 children have inadequate insurance
- ➢74,372 children have conditions that consistently affect their activities
- ➢79,784 do not receive family-centered care

HIGHLIGHT: Guide to the ACA

Our guide to the ACA focuses on important topics for families of CSHCN to consider when evaluating health insurance policies, including information about the new Marketplace. The guide's information is accessible in various formats: online information; monthly blog articles; in-person trainings; online videos; and a "webquest" document with ACA information linked to relevant resources and applications. All of this material is available via a newly developed portal on our website dedicated to health care reform. We have logged approximately 300 hits on our health care reform portal and over 750 hits on the ACA blog series; that information is also disseminated via social media and by partner agencies. In addition, the online video has been viewed over 50 times in a very short period of time.



"You have such a great knowledge base which makes you so valuable to providers and families"

"What made it unique was that you provided tons of information that had the life experience to go with it."

"You went above and beyond the call of duty."

"I am SO relieved to have this 'go to' place for information."

"You are such an amazing asset to families with special needs kids"

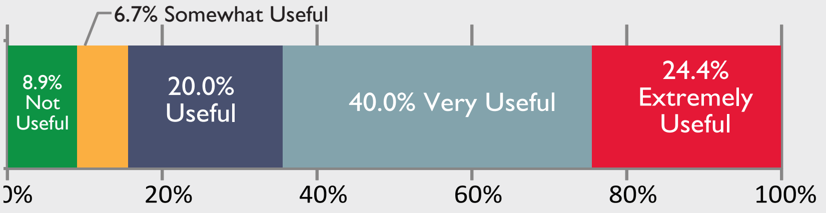
"Family Voices has been a tremendous help to me"

IMPACT on a Family:

We were contacted by the grandmother of child with significant health care needs who had been referred by the National Center for Family/Professional Partnerships. She was seeking assistance in finding resources to better support her granddaughter's needs. Our specialist explained various programs that might be appropriate and the grandmother decided to pursue our Medicaid waiver program. The form is often confusing for families and our specialist assisted the grandmother in understanding the program and in completing the necessary paperwork. *"I am willing to do the 'leg work' but am not always clear as to what 'leg work' I should be doing. This is where Family Voices Indiana has been a tremendous help. I truly am overjoyed with the help provided by Family Voices Indiana."* - Nancy L.

IMPACT: Family Confidence

Families rate the usefulness of the support/information/resources they received from the IN F2F in helping them feel more confident about getting their child the health care and services that s/he needs.[2]



FY2013 F2F OUTREACH:[2]

Total Families Served: 19,880

Total Professionals Served: 1,865

Web Visits: 26,914

Materials Disseminated: 12,793

Trainings: 130

CONTACT:

Family Voices Indiana. • 445 N Pennsylvania St Ste 941, Indianapolis, IN 46204
Phone: (317) 944-8982 • Website: http://fvindiana.org
Contact: Rylin Rodgers, info@fvindiana.org

---

[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 04/03/2014 from www.childhealthdata.org.

[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

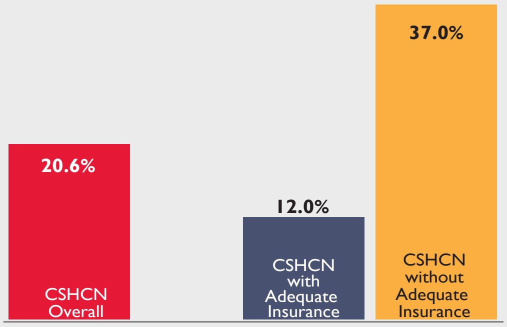
F2F: ASK Resource Center

Parents of children with special needs formed Access for Special Kids Resource Center (ASK) in 1992. The F2F project at ASK, Family-to-Family Iowa, is a statewide network of organizations and trained family members who provide various forms of natural supports to families of children with special needs (developmental, behavioral, emotional, and/or physical). Guided by a Family Advisory Council of organizations from across Iowa, we work together to help families navigate the health supports and services available for their CSHCN; help families by connecting them with other parents with similar experiences and help families develop self-advocacy skills through trainings and resources.

CSHCN in IA[1]

- ➢105,815 children (15.0%)
- ➢31,825 children have inadequate insurance
- ➢25,693 children have conditions that consistently affect their activities
- ➢33,421 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:

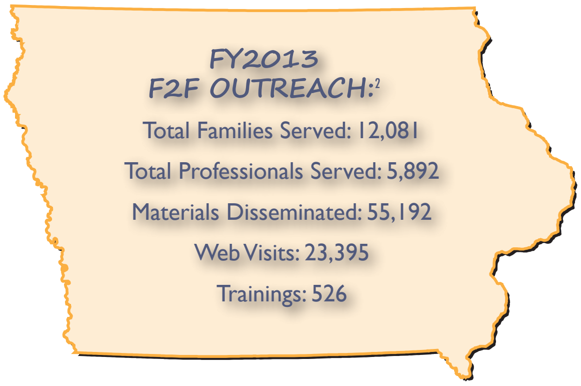


HIGHLIGHT: *Together We Can Conference*

Our Family-to-Family Iowa project is made up of over thirty organizations that not only support families, but work together to improve one another's outreach and support strategies. Due to budget cuts, families and family organizations lost the opportunity to participate in a statewide family conference where they had networked and supported one another for a number of years. The only conferences left targeted professionals. We blended funding from several sources to meet the need for a conference for families that would share critical information and resources, and provide opportunities for networking. The 2013 conference had 182 participants, representing families from all metropolitan areas of Iowa and many rural regions. Evaluations indicated an average growth of knowledge of 2.5 points on a 5 point Likert scale for each session (15 sessions) and all Keynotes (3 Keynotes). 98% of surveyed participants rated the timeliness, high quality, and usefulness of conference materials as a 4 or 5 on a 5 point scale (5 being the highest).

FEEDBACK: Many of the family participants in the conference indicated they would use the resources to help other families once back home, and many reported later in the year that they had done so via: creating job opportunities, starting new support groups in local areas, and connecting to solve issues across the state via social media.

- *"What a great conference. Do it again it! Families need you!"*
- *"I got so much out of this conference. So many great people that really cared about families and support us"*
- *"This was really excellent and I am so glad I got to attend. Well organized and very useful information!"*



FY2013
F2F OUTREACH:[2]
Total Families Served: 12,081
Total Professionals Served: 5,892
Materials Disseminated: 55,192
Web Visits: 23,395
Trainings: 526

CONTACT:

Family-to-Family IOWA c/o ASK Resource Center
5665 Greendale Road, Suite D, Johnston, Iowa 50131
Phone: (515) 243-1713 • Toll Free: (800) 450-8667 • Fax: 515-243-1902
Website: http://www.askresource.org/
Contact: Karen Thompson, Project Director, karen@askresource.org
Paula Connolly, Project Coordinator, paula@askresource.org

---

[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 04/03/2014 from www.childhealthdata.org.
[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

F2F: Families Together, Inc.

For more than 30 years, Families Together, Inc., has encouraged, educated and empowered Kansas families, which include children with disabilities. The F2F at Families Together, Inc. was established to provide guidance and support around health issues for families of children and youth with special health care needs. We help families navigate the health care systems and work with their child's medical home. We help families become better advocates for their children. We provide this help through one-to-one interactions with families and professionals and through a variety of trainings and other educational opportunities offered across the state

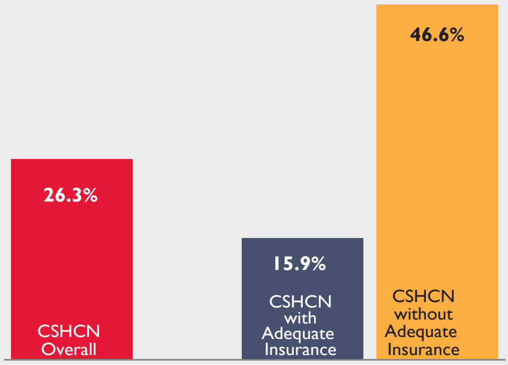
HIGHLIGHT: *Health Summits / Team Empowerment Conferences (TEC)*

Every fall we hold an annual *Health Summit/TEC* to provide news and current resources on health issues for CSHCN. Families of CSHCN, youth with SHCN, professionals, and vendors participate in the summit. Topics addressed are timely, and this year included: Health Homes in KanCare, Affordable Care Act, Mental Health and Health Care, Sexuality, and Stress Management. Our keynote speaker was an individual with a disability who shared her experience growing up and overcoming challenges in her life. We provided scholarships for families to attend. Forty-one individuals participated in the event. Feedback demonstrates the importance of this event for families: *"The keynote speaker gives me hope that my child can take on the world if she wants." "The Sexuality workshop answered so many questions." "Thank you so much for the opportunity to participate in this Summit. It was so helpful to me and my child."*

CSHCN in KS[1]

- ➢120,822 children (17.3%)
- ➢37,465 children have inadequate insurance
- ➢28,930 children have conditions that consistently affect their activities
- ➢35,755 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:



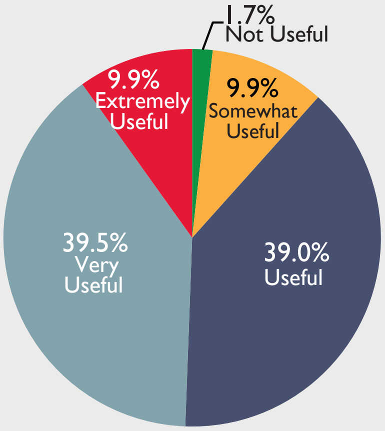
IMPACT on a Family:

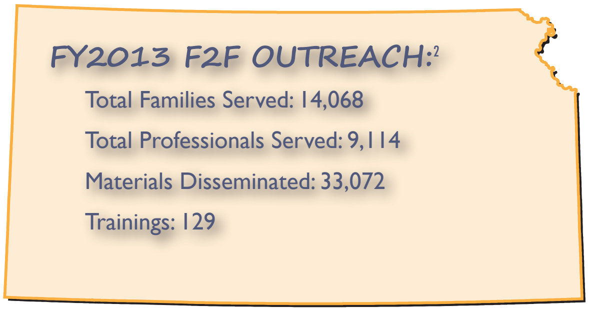
"My son, Karim, is 10 years old and has Down Syndrome. Going to the Health Team Empowerment conferences and other meetings, has changed our life. I was a mom that did everything for Karim. At nine years old I was still feeding and dressing him. Everything Karim wanted he got - all he had to do was point. I was treating him like a baby. My son was not happy and my family and I didn't realize we were harming him. With the support and information provided by the Family-to-Family Health Information Center at Family Together, Inc., we learned to help Karim become more independent. Karim is a different child now - he plays with the other children, gets dressed, cleans up after himself and of course he gets in trouble like any other 10 years old. Thank you." - Karim's mom

IMPACT:

Family Confidence

Families rate the usefulness of the support/information/ resources they received from the KS F2F in helping them feel more confident about getting their child the health care and services that s/he needs.[2]





FY2013 F2F OUTREACH:[2]

Total Families Served: 14,068
Total Professionals Served: 9,114
Materials Disseminated: 33,072
Trainings: 129

CONTACT:

Families Together, Inc.
3033 West 2nd Street, Room 122 • Wichita, KS 67203
Phone: (316) 945-7747 • Toll Free: (888) 815-6364
Website: http://familiestogetherinc.org
Contact: Tami Schwindt-Allen, tami@familiestogetherinc.org

---

[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 04/03/2014 from www.childhealthdata.org.
[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

F2F: Kentucky Family-to-Family Health Information Center

The KY F2F at the Commission for Children with Special Health Care Needs is a network of trained Support Parents who have expertise with health care delivery systems that prepares them to provide key support to families of individuals with special needs. The F2F helps families make more informed choices by providing information, resources and training.

CSHCN in KY[1]

- ➢197,916 children (19.5%)
- ➢55,061 children have inadequate insurance
- ➢58,511 children have conditions that consistently affect their activities
- ➢63,376 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:

HIGHLIGHT: Affordable Care Act - Enrollment Assistance

KY F2F has been very involved with the Affordable Care Act in Kentucky. We recruited 10 Support Parents/Mentors who were interested in becoming Kynectors. They received training and worked directly with families across the state to assist them in enrolling and answering their questions. There were many barriers that made families hesitant to enroll. Some families were confused from the stories they had heard. Many families were not familiar with how to use the technology to enroll. Others didn't realize that the ACA was for children and adults. Some feared government involvement. Our Kynectors helped families understand the program and when they ran into specific issues we were able to talk with the Office of Health Benefit Exchange and seek solutions. Many families, who had not understood the process until they connected with us, expressed their gratitude.

IMPACT on a Family:

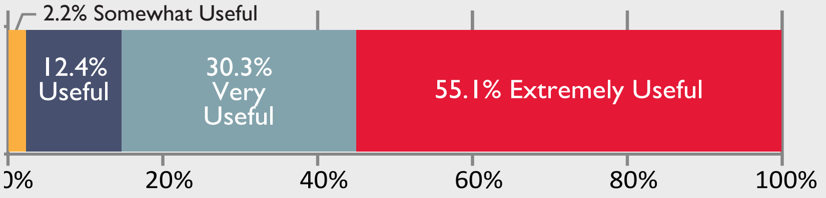
"I came to the Kentucky Family-to-Family Health Information Center at the Commission for Children with Special Health Care Needs through a social group for teens and young adults with disabilities. One of my peers in the group was the daughter of the Co-Director of Family-to-Family. She invited me to be a Mentor/Support Person.

As a Mentor/Support Person for Kentucky's Family-to-Family, I help individuals with special needs and their parents with difficult situations. I speak with them, sharing all I've learned at Kentucky Family-to-Family and what I know from my life experiences. Being a young woman with Cerebral Palsy, I can relate to the kids as someone who understands the barriers they face, and when I do, it isn't pandering, because I've gone through a lot of the same things they are experiencing. Parents can see what I have accomplished and feel hope that their children can achieve a great deal, despite their disabilities. I recently talked with a family whose daughter was having the same surgery I had several years ago—so I could speak as to how her daughter feels and share with them how it still helps me now. I also trained to be a Kynector and helped families navigate their way through what seemed like an overwhelming process in signing up for the Affordable Care Act.

What being a Mentor/Support Person has done for me is push me to be an even better person. I feel blessed in terms of my disability: I am thankful that I have come so far. I am thankful that parents can look to me as a positive example and kids can see me as a peer, a mentor, and a friend. Working as a Mentor/Support Person I am able to give back and the immense joy I feel because of that is indescribable."

IMPACT: Family/Provider Communications

Families rate the usefulness of the support/information/resources they received from the KY F2F in helping them partner with (communicate with, talk with, work with) professionals to make decisions about their child's health care.[2]



FY2013 F2F OUTREACH:[2]
Total Families Served: 3,026
Total Professionals Served: 622
Materials Disseminated: 15,770
Trainings:273

CONTACT:

KY Family-to-Family Health Information Center
310 Whittington Parkway Suite 200, Louisville, KY 40222
Phone: (502) 429-4430 • Toll-Free: (800) 232-1160 •
Fax: (502) 429-7161
Contact:
Debbie Gilbert, DebbieA.Gilbert@ky.gov (Eastern KY)
Sondra Gilbert, Sondra.Gilbert@ky.gov (Western KY)

---

[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 04/03/2014 from www.childhealthdata.org.

[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

LOUISIANA

F2F: Bayou Land Families Helping Families

Bayou Land Families Helping Families (BLFHF) is a non-profit family resource center that provides information and referral, education and training and peer to peer support to individuals with disabilities or special needs and their families. As the F2F, we partner with Families Helping Families Resource Centers across the state, all of whom are led by parents of CSHCN to assist families dealing with their child's health care challenges and to help them navigate the health care financing maze.

HIGHLIGHT: Bridging the Gap: Transitioning from Adolescence to Adulthood

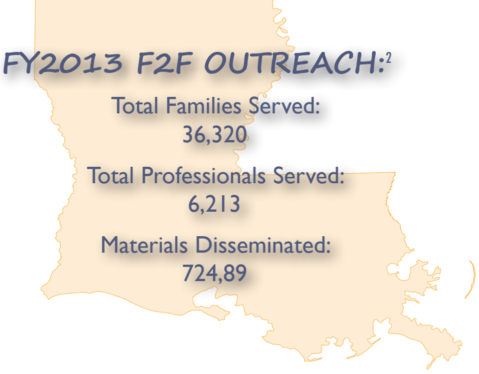
Adolescents transitioning into adulthood have previously relied on parental support and need further education on self-advocacy. To address these needs we have developed a Leadership Academy to prepare adolescents with a disability to transition to adult care services in such areas as:

- Health Care: Information on what adolescents will need to transition from pediatric care to adult health care and what options are available to them
- Education: The importance of having a transition plan in an IEP and information on transitioning to post-secondary education
- Employment: Information and resources on employment opportunities and independent living
- Advocacy: Education on self-advocacy

Our first Leadership Academy is scheduled for May 29, 2014 and families and professionals who have received information about the Leadership Academy anticipate that the information gained will be very useful.

IMPACT on a Family:

A family that came to us for help was on the verge of placing their young son in an institution because of extremely challenging behaviors and concern for the safety of their other child. They had been unsuccessful in connecting to services on their own and their requests for help from their Medicaid Waiver support coordinators had gone unanswered. We were able to connect the family directly with developmental disability services to use for emergency respite when their support coordination services failed to assist them. This mom told us that although she had made multiple calls, we had done more for their family in one day then any support coordinator or other service provider had been able to accomplish.



FY2013 F2F OUTREACH:[2]

Total Families Served:
36,320

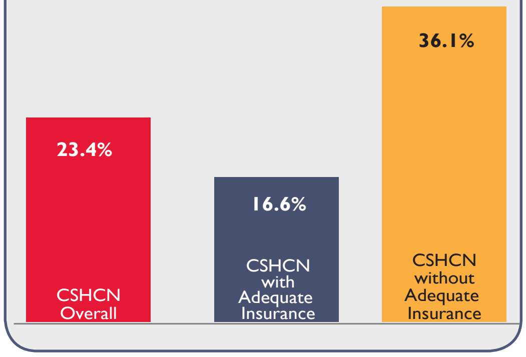
Total Professionals Served:
6,213

Materials Disseminated:
724,89

CSHCN in LA[1]

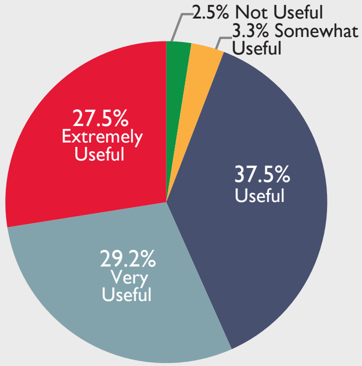
- ➢207,840 children (18.6%)
- ➢63,816 children have inadequate insurance
- ➢62,937 children have conditions that consistently affect their activities
- ➢80,160 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:



IMPACT: Family/Provider Communications

Families rate the usefulness of the support/ information/resources they received from the LA F2F in helping them partner with (communicate with, talk with, work with) professionals to make decisions about their child's health care.[2]



CONTACT:

Bayou Land Families Helping Families, Inc.
286 Hwy. 3185, Thibodaux, LA 70301
Phone: (985) 447-4461•1-800-331-5570
Fax: (985) 447-7988
Website: http://www.blfhf.org
Contact: Julie Folse,
F2fhic@gmail.com

---

[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 04/03/2014 from www.childhealthdata.org.
[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

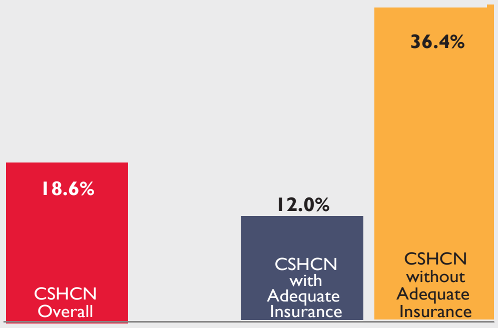
F2F: Maine Parent Federation

The Maine Parent Federation (MPF), in existence since 1984, administers the F2F Center in Maine through Project REACH (**RE**sponsive **A**dvocacy for **C**hildren's **H**ealth). The goal of the program is to assure that Maine's families of children with special health care needs partner in decision-making at all levels and are satisfied with the services they receive. Families receive a wide variety of information, education, referral, training, advocacy and a range of family supports. The program builds upon the partnership between MPF and Maine's Maternal and Child Health Title V CSHCN Program.

CSHCN in ME[1]

- 53,122 children (19.4%)
- 13,620 children have inadequate insurance
- 14,086 children have conditions that consistently affect their activities
- 14,469 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:



HIGHLIGHT: *Family Support Navigator Program*

This past year, we have instituted the *Navigator Program*, which trains support parents to better help families of CSHCN. Navigators work with the family to develop a family support plan which identifies the family's need and strategies to meet those needs. A plan of empowerment is developed, identifying training or activities to help the family gain the skills and knowledge they need to be able to navigate the system without support if the situation should arise again. We have trained 18 Navigators within the program. Early evaluation results are very positive. 100% of the families who have received Navigator services report that their Navigator understood their needs and that they could not have gotten the supports they needed without the help of the Navigator. We received initial funding for this program from the state Children's Behavioral Health program and have been able to expand with blended funding from several grants.

IMPACT on a Family:

A family with a young adult incarcerated in a youth detention facility connected with a Navigator. The Navigator went to the home to meet with the parents and found that the family had many questions about how to help their child and that the father himself had mental health issues and was unable to leave the house. The Navigator helped the family develop a plan and become involved in their child's program. The family members are on their way to becoming stronger, more informed, and more involved.

FY2013 F2F OUTREACH:[2]

Total Families Served: 15,948

Total Professionals Served: 4,273

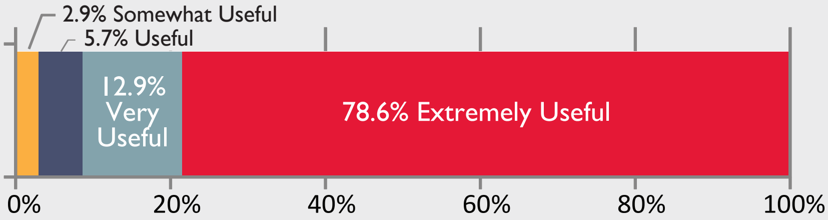
Materials Disseminated: 40,200

Trainings: 88

IMPACT:

Service Navigation

Families rate the usefulness of the support/information/resources they received from the ME F2F in helping them find and/or learn about community services (primary health care, intervention programs, translation services, etc.)[2]



CONTACT:

Maine Parent Federation, Inc.
PO Box 2067, Augusta, ME 04338
Phone: (800) 870-7746 • Email: parentconnect@mpf.org
Website: http://www.mpf.org
Contact: Robin Levesque, rlevesque@mpf.org

---

[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 04/03/2014 from www.childhealthdata.org.

[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

F2F: The Parents' Place of Maryland

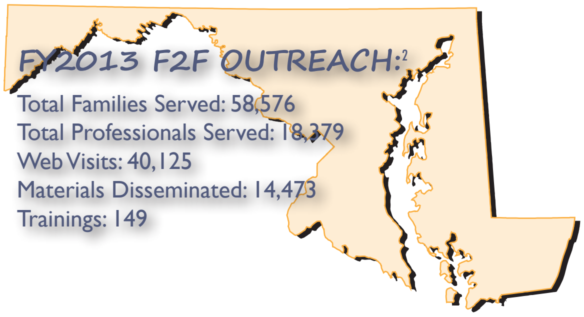
Founded in 1991, The Parents' Place was created by parents of children and youth with disabilities to help other parents and families facing similar challenges. The purpose of our F2F is to ensure that children and youth with special health care needs have the knowledge and assistance they need to make informed decisions that support their child's health. We provide peer support to families, and information and education to families, professionals and the community at large.

HIGHLIGHT: *Maryland Community of Care Consortium for Children and Youth with Special Health Care Needs*

The *Maryland Community of Care Consortium for Children and Youth with Special Health Care Needs (COC)* is a working group of over 150 diverse stakeholders, including families, providers, advocates, consumers, administrators, and professionals from the public and private service systems. The COC meets quarterly and offers a forum for information exchange, problem solving, consensus building, and collaborative action. Using the national agenda for CSHCN and core outcomes as a starting point, the COC works to improve systems of care for Maryland CSHCN and their families. Organizations and individuals across the state have formed new partnerships that positively impact and effectively address gaps and barriers in services, such as bringing mobile rehabilitation services to rural areas. In addition, this statewide initiative has spawned regional COC consortia that are working at the local level to further improve services for CSHCN and their families.

IMPACT on a Family:

We recently assisted the family of a child with autism and other disabilities that had encountered multiple barriers to receiving services for their child. Mom enrolled in our Health LEADers training program and became an active member of the COC. We helped her understand the newly expanded Maryland Habilitative Services Mandate that now requires coverage for autism treatment. After being refused services by their insurance company, mom was able to successfully advocate for her child based on her knowledge of the new law and secure the necessary treatment. She had this to say: "*Because of the information and opportunities shared through the Health LEADers and COC programs, I was able to gain the confidence and knowledge to advocate not only for my child, but others as well. I recently provided testimony at the state and national level regarding issues related to children with autism and other developmental disabilities.*"



FY2013 F2F OUTREACH:[2]

Total Families Served: 58,576
Total Professionals Served: 18,379
Web Visits: 40,125
Materials Disseminated: 14,473
Trainings: 149

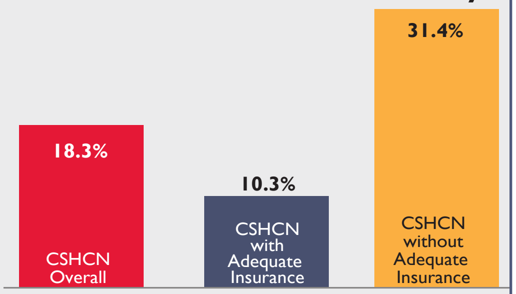
CONTACT:

Parents' Place of Maryland
801 Cromwell Park Drive, Suite 103
Glen Burnie, MD 21061
Phone: (410) 768-9100
FAX: (410) 768-0830
Website: http://www.ppmd.org
Contact: Josie Thomas, Executive Director
Pattie Archuleta, Family-to-Family Coordinator

CSHCN in MD[1]

- ➢211,442 children (15.7%)
- ➢69,425 children have inadequate insurance
- ➢47,847 children have conditions that consistently affect their activities
- ➢67,001 do not receive family-centered care

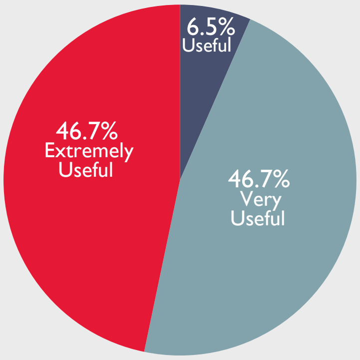
CSHCN Whose Conditions Cause Financial Problems for the Family:



IMPACT:

Family Confidence

Families rate the usefulness of the support/information/resources they received from the MD F2F in helping them feel more confident about getting their child the health care and services that s/he needs.[2]



---

[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 04/03/2014 from www.childhealthdata.org.

[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

F2F: Massachusetts Family Voices at the Federation for Children with Special Needs

Massachusetts Family Voices at the Federation for Children with Special Needs provides free, confidential, individualized assistance to families raising children and youth with special health care needs and promotes parent/professional partnerships with health professionals, school personnel, and others. Activities include: providing a forum for families to connect & share information & resources about health issues; advocating for improved systems of health care for children & youth with special health care needs; and developing opportunities and mentoring families to partner with health care professionals.

HIGHLIGHT: Listserv

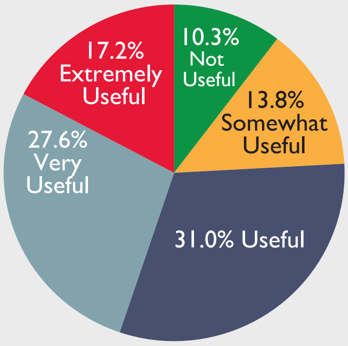
We have created a very active statewide listserv where families of CSHCN and their professional partners share information, resources, ask questions and learn from each other's collective experience. Currently over 600 parents/professional participate. Each posting on the list is moderated by staff with the intention of keeping a friendly, positive, and informative tone. At times we ask that some responses be done offline (directly to person posting) to assure confidentiality. Posts are approved by a moderator at least once a day. We also post a "question of the week" to facilitate discussion of a current topic. Community events are also frequently shared. The outcomes have been overwhelming. A recent month had over 250 postings about a wide range of topics such as: a referral to a provider equipped to meet specific needs, tips on how to book appointments to avoid long waits with a specific provider, advice on choosing health coverage when an employer changes plans, questions on how to coordinate Medicaid benefits and private insurance, a conference on Respite care. The listserv helps families and professionals learn more about what is available for a specific child as well as sharing information broadly with others. Families regularly thank us for this resource.

IMPACT on a Family:

A parent called us requesting assistance for their son with social/emotional issues. We were able to help them navigate the Masshealth system and get access to Behavioral Health services. They now have a home-based therapist. As a result the son is learning coping strategies, the family has learned different communication strategies, and the stress level has decreased for all. The parent has since joined our listserv to connect with other families and share resources.

IMPACT: Family/Provider Communications

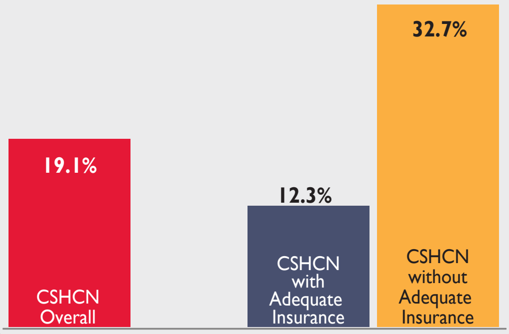
Families rate the usefulness of the support/information/resources they received from the MA F2F in helping them partner with (communicate with, talk with, work with) professionals to make decisions about their child's health care.[2]

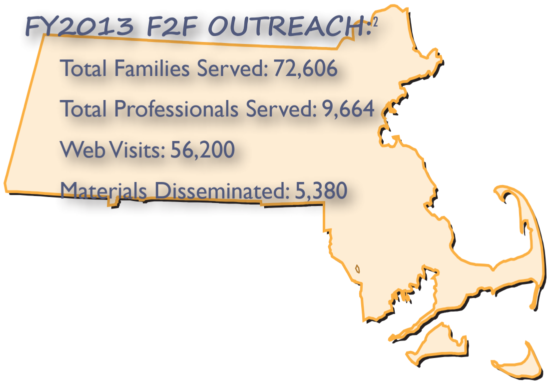


CSHCN in MA[1]

- ➢261,475 children (18.3%)
- ➢85,476 children have inadequate insurance
- ➢64,675 children have conditions that consistently affect their activities
- ➢73,281 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:





FY2013 F2F OUTREACH:[2]

Total Families Served: 72,606
Total Professionals Served: 9,664
Web Visits: 56,200
Materials Disseminated: 5,380

CONTACT:

Mass Family Voices
at Federation for Children with Special Needs
The Schrafft Building • 529 Main Street, Suite 1102
Boston, MA 02129
Phone: (617) 236-7210 • Toll-Free: (800) 331-0688
Fax: (617) 572-2094
Website: http://fcsn.org/mfv/
Contact: Cathy Hickey, chickey@fcsn.org

---

[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 04/03/2014 from www.childhealthdata.org.

[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

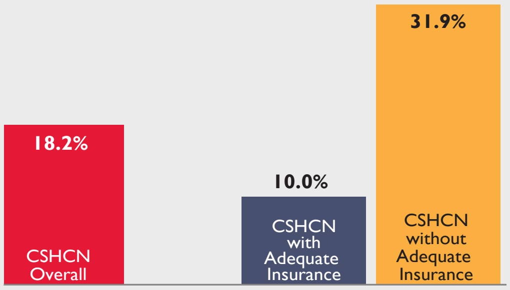
F2F: MI Family-to-Family Health Information Center at the Michigan Public Health Institute (MPHI)

MPHI was awarded the F2F grant one year ago. Our work this year has centered around building infrastructure for the work of this grant, including hosting an open forum to create interest in the MI F2F HIC and to engage community partners; forming an advisory board made up of parents and community partners; development of a website; and ground work on a resource repository that will be used by families as well as community partners.

CSHCN in MI[1]

- 430,222 children (18.4%)
- 140,760 children have inadequate insurance
- 105,514 children have conditions that consistently affect their activities
- 141,967 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:



HIGHLIGHT: *Care Coordination: Empowering Families*

In partnership with the Region 4 Midwest Genetics Collaborative, we provided the training, *Care Coordination: Empowering Families.* The goal was to provide a learning opportunity for parents of CSHCN to gain the skills, knowledge, and resources they need to coordinate care for their child with complex needs in partnership with a culturally competent medical home. Participants learn the concept of the medical home, advocacy skills, techniques to organize information and find reliable resources, tips to navigate health care and insurance systems including information on the ACA, skills to increase communication and coordination between multiple providers, transition planning, and the importance of peer support and coping with stress. Eighteen parents attended this one day training held in Detroit, Michigan. In an evaluation 100% of the participants stated they were likely to include new individuals on their child's care team, that they see the role they play in their child's health care changing as a result of the training, and agreed that they had skills and knowledge surrounding medical home, care coordination, transition, advocacy, and communication skills after the training.

IMPACT on a Family:

Rico L. shared this information about his experience with the Care Coordination: Empowering Families training he attended in Detroit. *"The training you gave was on point and very helpful. As a result of this training, I feel much more confident and prepared to deal with medical obstacles. My daughter now has a patient care coordinator who is able to schedule appointments in one day, back to back, instead of our having to come to the hospital multiple times. I hope you do more such trainings to help parents who need this foundational information to cope with their child's medical challenges."*

CONTACT:

Michigan Public Health Institute
2364 Woodlake Drive Suite 180
Okemos, MI 48864
Phone: (517) 324-8366
Fax: (517) 347-6189
Website: www.f2fmichigan.org
Contact: Kristen Hawkins,
khawkins@mphi.org

---

[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 04/03/2014 from www.childhealthdata.org.

[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

F2F: PACER Center

Founded in 1977, PACER Center was created by parents of children and youth with disabilities to help other parents and families facing similar challenges. The F2F at PACER provides a central source for families of CSHCN to obtain support, advocacy, and information about the health care system. We promote family-centered care and family and professional collaboration at all levels of health care and have a strong commitment to promote and support the needs of families from racially, culturally, and linguistically diverse communities.

HIGHLIGHT: Workshop: *Stay on the Right Track: Help Your Child Eat Well, Stay Fit, and Lead a Healthier Lifestyle*

This collaborative workshop offers information that parents of children with disabilities and special health care needs can use to help the whole family live a healthier lifestyle. Information on nutrition, exercise, well child visits, and community recreation resources is presented by a nutritionist, exercise physiologist, pediatrician, and F2F staff. Our most recent workshop was attended by 98 families. As a result of the workshop, one parent approached her local recreation center to explore the possibility of developing a class specifically for CSHCN. Ten children between the ages of 6 and 12 now participate in the weekly class. They play soccer, floor hockey, ride bikes, dance and participate in obstacle courses. Meanwhile the parents get to know each other in the bleachers and exchange experiences and resources. Feedback: *"This type of networking for both the parents and the kids doesn't happen often when your child has a disability or special health care need. By having the workshop, PACER's F2F was the spark to make this community recreation class happen."*

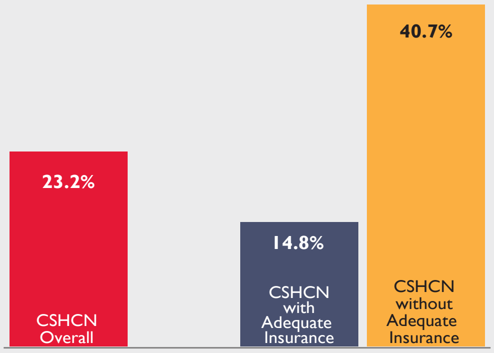
IMPACT on a Family:

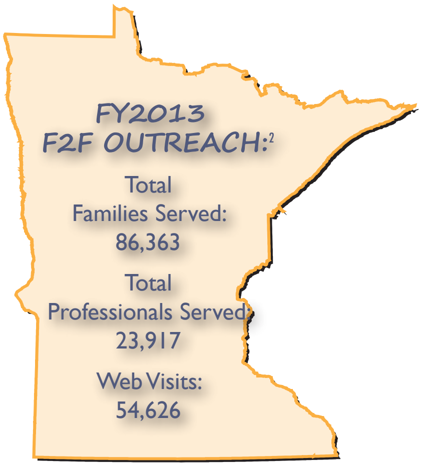
We were recently contacted by a family that adopted a child with significant special health care needs from our state foster care system. When the adoption was finalized, the child's in-home nursing hours were drastically reduced from 24 hours to 12 hours per day. We helped the family appeal the reduction of hours and reinstate the amount to the original 24 hour in home nursing care. Quote from family: *"Thank you so much for your help navigating our daughters appeal process! I am so thankful for your insight, encouragement and listening ear and for making phone calls when I was overwhelmed! We are so blessed by your help, care and concern."*

CSHCN in MN[1]

- 179,162 children (14.3%)
- 56,689 children have inadequate insurance
- 33,718 children have conditions that consistently affect their activities
- 50,879 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:





FY2013 F2F OUTREACH:[2]

Total Families Served: 86,363

Total Professionals Served: 23,917

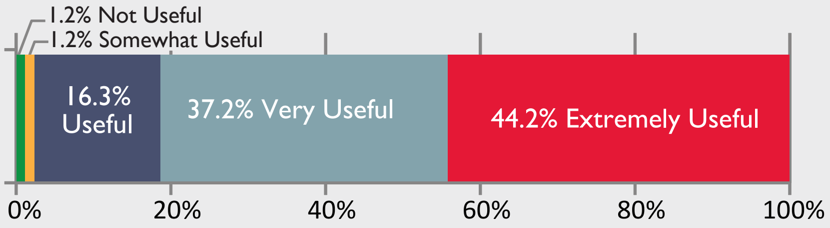
Web Visits: 54,626

CONTACT:

PACER Center
8161 Normandale Blvd,
Bloomington, MN 55437
Phone: (952) 838-9000
Toll-Free: (888) 248-0822
Fax: (952) 838-0199
Website: http://www.pacer.org/
Contact:
Wendy Ringer, wendy.ringer@pacer.org

IMPACT: Service Navigation

Families rate the usefulness of the support/information/resources they received from the MN F2F in helping them find and/or learn about community services (primary health care, intervention programs, translation services, etc.)[2]



---

[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 04/03/2014 from www.childhealthdata.org.

[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

F2F: Family Voices of Mississippi

The MS F2F is a collaboration of The University of Southern Mississippi Institute for Disability Studies and the Title V Children's Medical Program (CMP) of the Mississippi State Department of Health and LIFE of Mississippi, Inc. Located in the Jackson office of the Institute for Disability Studies, the F2F is managed by the parent of a CSHCN. Through project activities, the F2F Center works to enable families to be knowledgeable, comfortable and competent in addressing the Title V system with regard to their child's unique health care needs as well as in advocating for ongoing and continuous quality improvement.

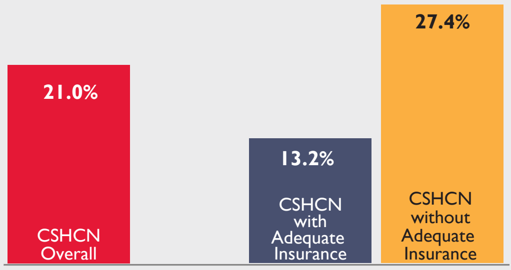
HIGHLIGHT: Empowering Families with Resource to Navigate the Health Care System

The Mississippi F2F in partnership with CMP assists families in navigating complex system of health care and education. CMP coordinates pediatric multi-specialty services through the University of Mississippi Medical Center (Mississippi's Children Hospital), and other specialty programs statewide. By placing a parent liaison within a CMP facility, the MS F2F provides families with best practice tools that empower them to make decisions that will impact their children with special health care needs. The F2F also assists professionals serving CSHCN around the state by sharing community resources.

CSHCN in MS[1]

- 124,905 children (16.4%)
- 41,255 children have inadequate insurance
- 34,948 children have conditions that consistently affect their activities
- 53,437 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:

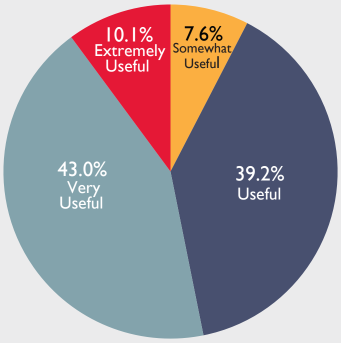


IMPACT on a Family:

The MS F2F Parent Liaison recently assisted a mother and her child with a physical impairment and developmental delay. The child's wheelchair had malfunctioned at school, and the child had remained at home for more than a week missing important days at school. The Parent Liaison helped the mother transport the wheelchair to a local vendor for services since the mother did not have an accessible vehicle or the $85 vendor service fee. While in route to and from the vendor, the Parent Liaison was able to help the mother understand the importance of keeping her child's CMP clinic appointment, which would allow the child to be seen by the multi-specialty professionals, and also get wheelchair services through an onsite durable medical equipment vendor. The Parent Liaison was able to share information about medical home, decision making, accessing community-based services, partnering, communicating with providers and the Affordable Care Act as well as advocating for services for the family. The 23-year-old mother of three children, expecting her fourth child, was thrilled to have someone who really understood her challenges.

IMPACT: Family/Provider Communications

Families rate the usefulness of the support/information/resources they received from the MS F2F in helping them partner with (communicate with, talk with, work with) professionals to make decisions about their child's health care.[2]



FY2013 F2F OUTREACH:[2]

Total Families Served: 2,890

Total Professionals Served: 2,328

Trainings: 131

CONTACT:

Family Voices of Mississippi, 118 College Drive, Hattiesburg, MS 39406-0001
Phone: (601) 432-6261
Website: http://www.usm.edu/disability-studies/family-2-family-overview

---

[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 04/03/2014 from www.childhealthdata.org.

[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

F2F: Missouri Family-to-Family, UMKC-Institute for Human Development

The Missouri Family-to-Family serves individuals with disabilities and/or special health care needs, their families, and professionals who support them. We offer free, individualized, and family-centered support provided by family information specialists and trained family mentors. Our resources are available, in print or virtually, in English, Spanish and other languages and alternative formats.

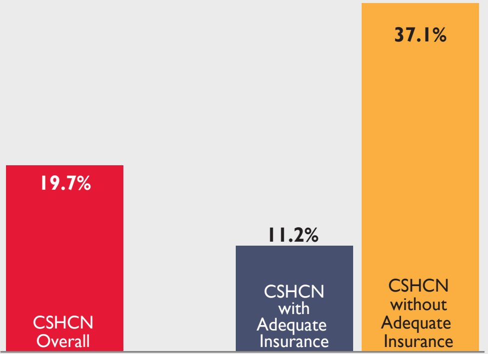
HIGHLIGHT: *Charting the Life Course: Tools for a Good Life*

Charting the Life Course is a Framework that we have developed to help CSHCN at any age or stage of life and their families to think about what they need to know, identify how to find or develop supports, and discover what it takes to live a good life. We have developed tools based on this Framework, including a Life Course Booklet with questions to guide families in thinking about quality life for their CSHCN. Additionally, the Life Course Folder provides families with resources and information on services and eligibility criteria. The Trajectory Worksheet helps people create a vision for a good life for their CSHCN and encourages them to explore a variety of supports to obtain that vision, including community resources, technology, friends and family, as well as traditional resources for which they may be eligible.

CSHCN in MO[1]

- 252,734 children (17.7%)
- 79,149 children have inadequate insurance
- 69,763 children have conditions that consistently affect their activities
- 83,670 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:



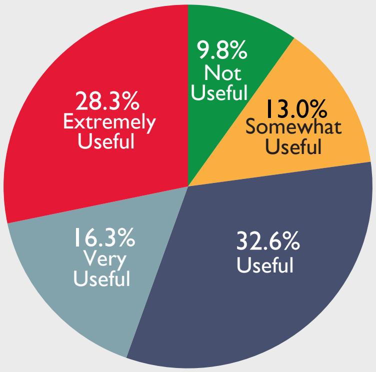
IMPACT on a Family:

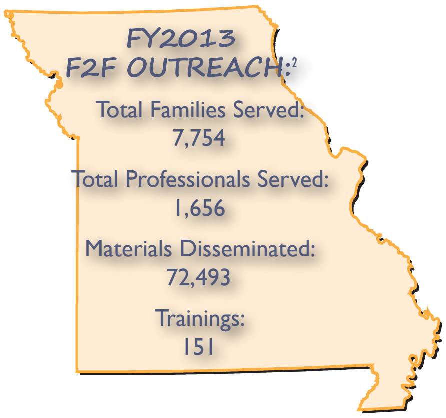
Missouri Family-to-Family conducted a workshop to help families learn about Charting the Life Course, and how to use the Trajectory Worksheet in planning for their family member with a special health care needs. A mother of an 8 year old reported back to us that she went home that night and applied what she had learned to her family's unique situation. One of her biggest takeaways from the workshop was that she and her family were not just planning for services, but were actually planning for LIFE! The mother shared her appreciation: *"The Trajectory Worksheet really helped us as a family think positively about the future and think about life experiences and supports that will help not only my son with special needs, but our entire family as we move forward with a vision for a good life. Thank you!"*

IMPACT:

Service Navigation

Families rate the usefulness of the support/information/resources they received from the MO F2F in helping them find and/or learn about community services (primary health care, intervention programs, translation services, etc.)[2]





FY2013 F2F OUTREACH:[2]

Total Families Served: 7,754

Total Professionals Served: 1,656

Materials Disseminated: 72,493

Trainings: 151

CONTACT:

Missouri Family-to-Family, UMKC-Institute for Human Development
215 W. Pershing, Kansas City, MO 64108
Phone: (816)235.1763 (Kansas City) • Toll-Free: (800) 444.0821
Fax: (888) 503.3107(fax)
Website: http://www.mofamilytofamily.org
Contact: Michelle Reynolds, reynoldsmc@umkc.edu

---

[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 04/03/2014 from www.childhealthdata.org.

[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

F2F: Parents, Let's Unite for Kids (PLUK)

PLUK, a private, nonprofit organization formed in 1984 by parents of children with special needs in the state of Montana. PLUK provides information, support, training and assistance to children at home, school and as adults, and houses the Montana F2F.

HIGHLIGHT: *Family Advocates in Medical Settings*

Using the Rhode Island Pediatric Practice Enhancement Project as a model, the Montana F2F began to collaborate with the Mountain States Regional Genetics Collaborative (MSRGC) in March of 2013 to provide care coordination to families of CSHCN in two pediatric practices. This project facilitates pediatric medical home implementation by providing practices a low-cost, high value method of ensuring family-centered, community-based, culturally effective, coordinated, comprehensive, accessible and continuous care. It places and supports trained *Family Advocates* in these pediatric clinical settings to link families with community resources, assist physicians and families in accessing specialty services, and identify systems barriers to coordinated care. *Family Advocates* within these medical home practices:

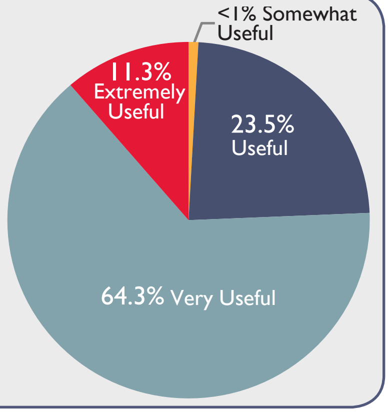
- Answer families' questions about systems of care and community resources
- Give families a consistent source of information so care for a patient does not stop between visits.
- Bridge the gap between the medical practice and other areas of family concern such as education, social services, family issues, etc.
- Demonstrate a commitment to family-centered care, and give a medical practice the ability to address the family as a whole, rather than just the initial purpose of the appointment
- Help families understand and carry out medical recommendations
- Allow for a Systems-of-Care approach to coordinating a family's non-medical special health-care needs
- Show families a commitment to helping their family and child have healthy outcomes

Plans are in place to expand the project to two more locations with four more *Family Advocates*. Agreements have been completed with another private pediatric practice and with a hospital primary care system. The lessons learned from the clinical experience of the first cohort of *Family Advocates* will be shared through trainings within the state. The goals for year two will be to actualize the model and develop a comprehensive data collection and evaluation plan to support sustainability.

IMPACT:

Service Navigation

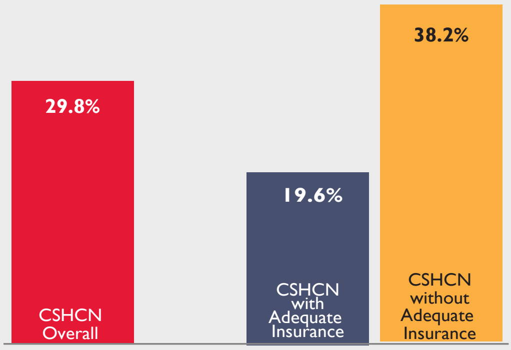
Families rate the usefulness of the support/information/resources they received from the MT F2F in helping them find and/or learn about community services (primary health care, intervention programs, translation services, etc.)[2]



CSHCN in MT[1]

- 30,571 children (14.0%)
- 10,284 children have inadequate insurance
- 9,152 children have conditions that consistently affect their activities
- 10,508 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:



IMPACT on a Family:

A Family Advocate recently helped a family whose children did not yet have insurance. The Family Advocate discovered that the family had low literacy skills and was not able to complete paperwork needed to apply for insurance. The Family Advocate helped the family to complete the paperwork and the family was able to get signed up for health insurance.

FY2013 F2F OUTREACH:[2]

Total Families Served: 12,301
Total Professionals Served: 3,153
Web Visits: 32,780
Materials Disseminated: 20,000
Trainings: 83

CONTACT:

Parents, Let's Unite for Kids
516 North 32nd Street, Billings, MT 59101
Phone: (406) 255-0540 • Toll-Free: (800) 222-7585
Fax: (406) 255-0523
Website: http://www.pluk.org/
Contact: Roger Holt, rholt@pluk.org

---

[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 04/03/2014 from www.childhealthdata.org.
[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

F2F: PTI Nebraska

PTI Nebraska, the Family-to-Family Health Information center, is a statewide resource for families of children with disabilities and special health care needs. We provide one-to-one assistance to parents and professionals on services and disability specific information; conduct relevant, no-cost workshops statewide; disseminate printed and electronic resources; and encourage and support parents in leadership roles.

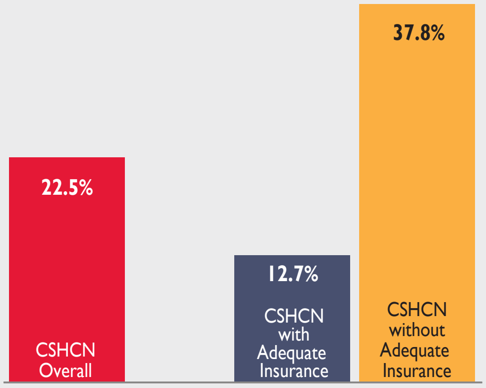
HIGHLIGHT: PTI Webinars

The F2F through PTI Nebraska offers webinars twice a month to families and professionals across the state on topics of interest. Many topics are chosen based on input suggested on the webinar evaluations. The webinars are presented twice during the day, during lunch hour and in the evening. This provides families options to participate at times that are convenient. Webinars are enhanced with a teleconference connection. Initially, we were concerned that not all families would know how to connect to a webinar. However, the teleconference support provided through a voice link assists with the computer connection as well as providing an easy way to voice questions in a manner that everyone understands. The webinars are well attended and have reached both urban and rural families better than any other method of sharing information. In the past year 126 parents and professionals have participated from all regions of the state. Topics have included the Individual Health Care Plan, Teaching Teens about Health Care, Disaster Preparedness, Transition, and Seizures and Children.

CSHCN in NE[1]

- 61,071 children (13.7%)
- 20,068 children have inadequate insurance
- 11,936 children have conditions that consistently affect their activities
- 19,225 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:



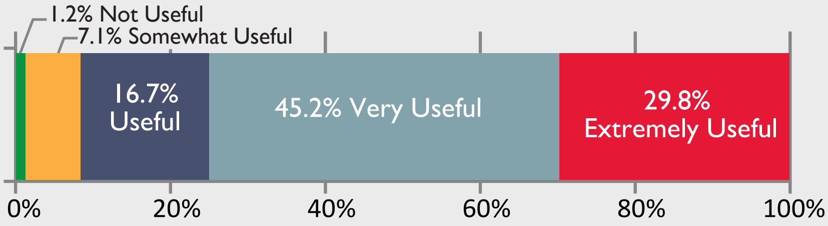
IMPACT on a Family:

A family sought the support of the F2F at PTI Nebraska several times over many months while trying to get ACA insurance coverage for their children. Both parents are insured through the Veterans Administration, but their coverage as veterans didn't cover their 2 children. They ran into problems on the ACA enrollment website when seeking coverage for their children. The ACA website kept sending the family to Nebraska Medicaid. Knowing they were over income for Medicaid in Nebraska because Nebraska has not expanded Medicaid, the family filed the application anyway. The ACA website stated that the children would be eligible for Medicaid. After many attempts of re-entering enrollment information, they were told that because the parents had coverage, there would be no tax credit for the children's coverage. Because the youngest child has autism, the site kept sending the family to Nebraska Medicaid for which the child wasn't eligible. We helped by providing information on the ACA 800 number, the Medicaid application process, issues with denial that were part of the ACA enrollment process, and talked through the parents' resulting frustration. Finally on the last day for sign up, the family was able to get through the enrollment process, choose a plan for the children and pay the initial premium.

IMPACT:

Family Confidence

Families rate the usefulness of the support/information/resources they received from the NE F2F in helping them feel more confident about getting their child the health care and services that s/he needs.[2]



FY2013 F2F OUTREACH:[2]

Total Families Served: 2,122
Total Professionals Served: 424
Web Visits: 7,554
Materials Disseminated: 1,089,902

CONTACT:

PTI Nebraska
564 Leavenworth St, Suite 202
Omaha, NE 68105
Phone: (402) 346-0525
Toll-Free (800) 284-8520
Fax: (402) 934-1479
Website: http://pti-nebraska.org/
Contact: Nina Baker, nbaker@pti-nebraska.org

---

[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 04/03/2014 from www.childhealthdata.org.
[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

F2F: Family TIES of Nevada

Family TIES of Nevada is a statewide nonprofit organization established in 2001 and directed by people with disabilities or family members of CSHCN. Families TIES has been the home of the NV F2F since 2005. The F2F offers no-cost family-centered services that include training, information and assistance, community outreach, emotional support and advocacy to families of CSHCN. We are committed to ensuring that all families of CSHCN participate in making informed choices about health care in order to promote good treatment decisions, cost-effectiveness, and improved health outcomes for such children.

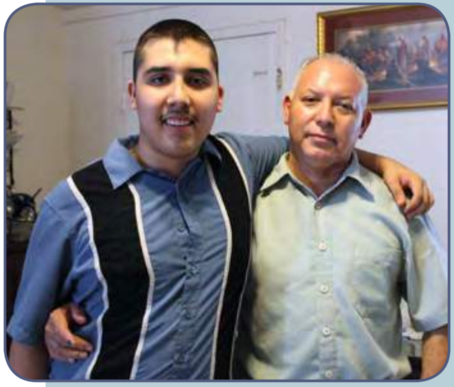
CSHCN in NV[1]

- 82,108 children (12.0%)
- 28,055 children have inadequate insurance
- 23,550 children have conditions that consistently affect their activities
- 33,400 do not receive family-centered care

HIGHLIGHT: Collaboration to Support Young Children

Working with partners in the S. Nevada Immunization and Health Coalition (SNIHC), the need for an immunization clinic and back to school fair customized especially for the unique needs of CSHCN emerged as a priority after recognizing how overwhelming our large back-to-school events can be for children with special needs. Family TIES and Nevada Early Intervention Services-South (NEIS) teamed up to create a new community event (Family TIES Health Day) to ensure CSHCN have access to immunizations and a healthy start to the school year. The event drew 20 vendors and more than 100 families who made connections to health resources including pediatricians, immunizations, vision screening, WIC programs, and disability resources. Families expressed appreciation for the opportunity to get the resources needed for the school year while avoiding long lines, overstimulation and 'meltdowns' experienced during previous back-to-school events. This collaboration introduced new SNIHC partners who are focused on serving CSHCN. Family TIES and NEIS were recognized by SNIHC with the Silver Syringe Award for Collaboration of the Year 2013.

IMPACT on a Family:

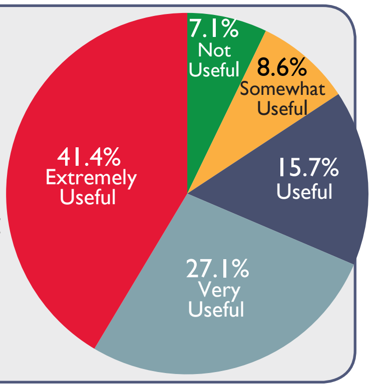


We assisted a father and two children, ages 12 and 18, both with autism. We helped the parent get the support and information he was seeking primarily related to transition services for his older son. By connecting him to the appropriate state and community agencies that provide services to individuals with developmental disabilities, the youth received life and social skills and safety training in the home setting under the supported living arrangement program; vocational rehabilitation services for job training skill development; and legal resources on guardianship. We also connected the father to two parent matches with Hispanic parents of children with autism who are trained parent mentors. The father shared his appreciation: *"When I contacted Family TIES it changed my life. I received a lot of support and information which helped get my children the services they need. Connecting me with another family that has a child with autism was a great relief."*

IMPACT:

Family/Provider Communications

Families rate the usefulness of the support/information/resources they received from the NV F2F in helping them partner with (communicate with, talk with, work with) professionals to make decisions about their child's health care.[2]



FY2013 F2F OUTREACH:[2]

Total Families Served:
4,008

Total Professionals Served:
2,717

Web Visits:
69,933

Materials Disseminated:
8,189

Trainings:
112

CONTACT: Family TIES of Nevada

Reno Office
3100 Mill Street, Suite 117
Reno, NV 89502
Phone: (775) 823-9500

Las Vegas Office
6130 Elton Avenue, Suite 100
Las Vegas, NV 89107
Phone: (702) 740-4200

Contact:
Melanie Kauffman, GPC
mkauffman@familytiesnv.org
CSHCN Helpline: (866) 326-8437

---

[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 04/03/2014 from www.childhealthdata.org.
[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

F2F: NH Family Voices

As the F2F, NH Family Voices provides free technical assistance and emotional support to families of CSHCN and the professionals who serve them. Our resources include a lending library, publications, support groups, online training center, and links to other resources.

CSHCN in NH[1]

- 54,569 children (19.0%)
- 15,265 children have inadequate insurance
- 11,706 children have conditions that consistently affect their activities
- 16,056 do not receive family-centered care

HIGHLIGHT: Schools & Medicaid

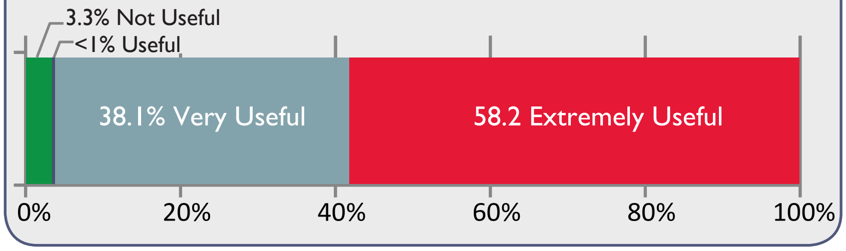
In the process of making a rule change, NH Department of Health and Human Services (DHHS) created a tenuous situation for families who were allowing their child's school to bill their Medicaid for medically necessary services under the Medicaid to Schools provision. The newly implemented rule allowed the denial of "Duplicative Services," leaving it unclear if families would be able to access services such as PT/OT/Speech, nursing, etc. outside of the school through their Medicaid coverage. When the rule committee declined to acknowledge the confusion, families began to consider refusing school access to their Medicaid, thus leaving a potential hole of thousands of dollars within NH School budgets.

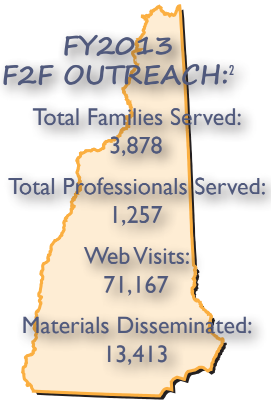
A committee consisting of NH Family Voices and other partners (The Parent Training and Information Center, NH Association of Special Ed Administrators, Disabilities Rights Center, Developmental Disabilities Council, MSBT—a private company providing Medicaid Billing for schools, and the NH School Administrators Association) worked to educate legislators of this issue, resulting in new legislation. The bill faced challenges around family privacy but with effective teamwork, groups came to an agreement allowing families access to the needed services without giving up their privacy. Work from all parties resulted in an amendment clarifying that only a list of "related services" would be shared by school systems with DHHS and that such services were not considered "duplicative" if they were deemed "medically necessary" by a physician.

The bill successfully passed the house and will now go back to the Senate. We are expecting it to pass and be signed by our Governor, a win for families and for the system.

IMPACT:
Service Navigation

Families rate the usefulness of the support/information/resources they received from the NH F2F in helping them find and/or learn about community services (primary health care, intervention programs, translation services, etc.)[2]





FY2013 F2F OUTREACH:[2]

Total Families Served:
3,878

Total Professionals Served:
1,257

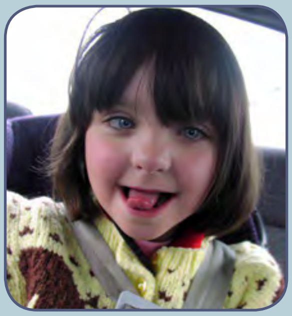
Web Visits:
71,167

Materials Disseminated:
13,413

CONTACT:

NH Family Voices
129 Pleasant St., Concord, NH 03301
Phone: (603) 271-4525
Toll Free: (800) 852-3345 X 4525
Website: http://www.nhfv.org
Contact
Terry Ohlson-Martin / Martha-Jean Madison
nhfamilyvoices@nhfv.org

IMPACT on a Family:



"I had newly arrived in NH fearing that my daughter might not live since doctors had been unable to treat her seizure disorder. She was a year old and could barely swallow. She couldn't sit, talk or stay awake for long. I found NH Family Voices and you helped me to find a home to rent, the best doctors, and a swallow consult. My daughter is now doing wonderfully after a long road! I was penniless, homeless, and hungry but determined to get my daughter the help she needed even when it seemed impossible to find. I was so desperate! You were my compass and I'll never be able to thank you enough"

---

[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 04/03/2014 from www.childhealthdata.org.

[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

F2F: Statewide Parent Advocacy Network of NJ (SPAN)

Family Voices-NJ @ SPAN's F2F provides information and support that families of CSHCN need to effectively partner in decision-making at all levels to achieve the MCHB six core outcomes for their children. We work towards better health care systems in NJ and tackle critical issues such as health promotion and prevention, managed care and other insurance, SSI, early intervention, screening, medical home, transition, and health disparities. In addition to family-to-family support, families can access recorded workshops, a website, and a wealth of materials, in English and Spanish.

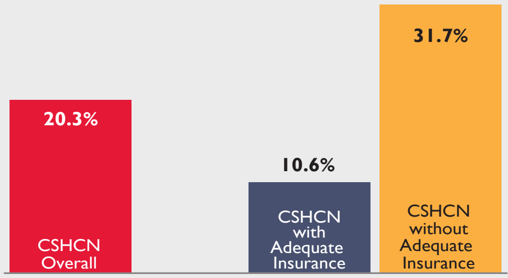
HIGHLIGHT: Family-Led Screening Training and Family Support

Through our Statewide Community of Care Consortium for Children with Special Healthcare Needs, SPAN facilitates an Early and Continuous Screening Workgroup that is focused on enhancing early screening using validated tools and connecting families to immediate support. Last year, SPAN trained 195 staff of 15 Federally Qualified Health Centers as well as pediatric and family residents at RWJ Medical School. Outcomes included statistically significant increases in awareness about the importance of developmental screening and community resources, staff understanding of the benefits of using AAP screening guidelines and recommended tools, and intention to use what was learned. SPAN also provided diverse Family Resource Specialists at over 18 community-based "quick peek screenings" hosted by Children's Specialized Hospital, helping underserved (immigrant, low literacy, limited English proficient) families to access immediate parent-to-parent support, make follow-up evaluation appointments, and get connected to community-based resources.

CSHCN in NJ[1]

- 294,346 children (14.4%)
- 115,361 children have inadequate insurance
- 71,458 children have conditions that consistently affect their activities
- 101,738 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:

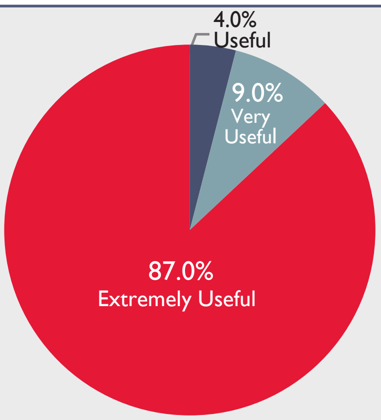


IMPACT on a Family:

Samuel Estrada was diagnosed at an early age and received early intervention (EI) services because of early developmental screening. His Spanish-speaking family was part of a parent support group led by two doctors who are part of SPAN's network. As he transitioned from EI, he still showed some delays and "jargon language." When the school district denied him special education services, his doctors connected his family to SPAN's F2F. We helped the family request an independent evaluation, but the district refused and filed due process against the family. With our support at the mediation meeting, and help from his medical home, the evaluations were completed and he received appropriate preschool special education services. Today, Samuel is thriving, and his "jargon language" is gone. At our last meeting with the family, he recited the Pledge of Allegiance to our Family Resource Specialist clearly and with pride as he laid his hand on his chest!

IMPACT: Family/Provider Communications

Families rate the usefulness of the support/information/resources they received from the NJ F2F in helping them partner with (communicate with, talk with, work with) professionals to make decisions about their child's health care.[2]



FY2013 F2F OUTREACH:[2]

Total Families Served: 197,715

Total Professionals Served: 70,685

Web Visits: 97,661

Materials Disseminated: 348,170

Trainings: 340

CONTACT:

SPAN of NJ
35 Halsey St., Fourth Floor, Newark, NJ 07102
Phone: (973) 642-8100 • Toll-free: (800)-654-SPAN
Fax: (973) 642-8080
Website: http://www.spanadvocacy.org
Contact: Mercedes Rosa, mercedesrosa@spannj.org

---

[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 04/03/2014 from www.childhealthdata.org.

[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

F2F: Parents Reaching Out

Parents Reaching Out supports all families throughout New Mexico, including those who have children with disabilities or may be at risk. The F2F staff work closely with families and professionals giving them knowledge and tools to make informed decisions around health care. We provide training opportunities, resources and information at no cost. As a statewide organization we value our community partners. Together we are able to build strong support for families and communities.

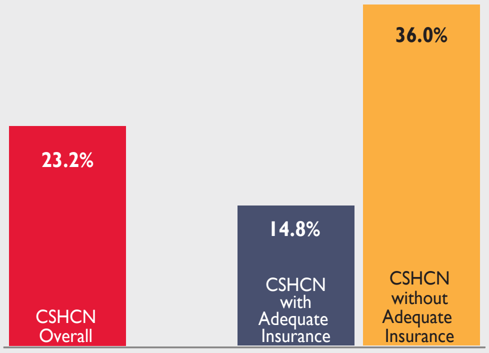
HIGHLIGHT: Blue Cross/Blue Shield Partnership

We participate on a variety of committees and have developed numerous partnerships across the state. We are particularly proud of a collaboration with Blue Cross and Blue Shield of NM to educate families on Centennial Care, Affordable Care Act, and Medical Homes. In 2013 we hosted mini conferences in Gallup and Albuquerque. In collaboration with our partners, we provided high quality training, materials, and resources to the many families who participated. Following these conferences, focus groups met to discuss the usefulness of the conference, follow-up issues, and impact on participants. As a result of the conference, 100% of family participants felt that they could make more informed decisions about their family's health care. Due to the success of the conferences, we have received additional funding to hold mini conferences in Taos and Roswell in 2014.

CSHCN in NM[1]

- 70,725 children (13.8%)
- 22,587 children have inadequate insurance
- 18,713 children have conditions that consistently affect their activities
- 27,403 do not receive family-centered care

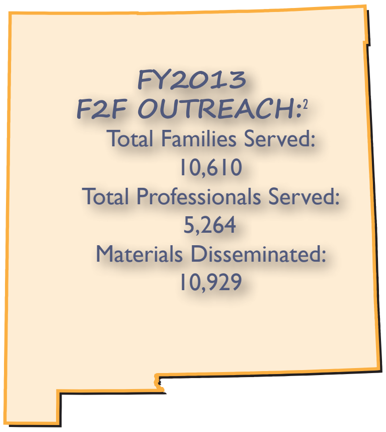
CSHCN Whose Conditions Cause Financial Problems for the Family:



IMPACT on a Family:

"When you find out your child has a diagnosis, there is no guide book that tells you all the things you should know about health care, early intervention, or educational systems. Parents Reaching Out outlined a path of supports and services available in New Mexico and walked me through navigating that path. It has been extremely helpful getting connected to these resources. There is still so much to learn but Parents Reaching Out has gotten me off to a good start and I know they are available to support me if I have questions along the way."

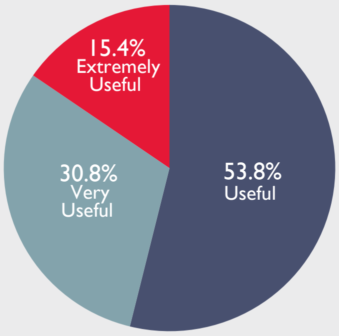
-Gabriel C.



FY2013
F2F OUTREACH:[2]
Total Families Served:
10,610
Total Professionals Served:
5,264
Materials Disseminated:
10,929

IMPACT:
Service Navigation

Families rate the usefulness of the support/information/resources they received from the NM F2F in helping them find and/or learn about community services (primary health care, intervention programs, translation services, etc.)[2]



CONTACT:

Parents Reaching Out - PRO
1920 B Columbia Drive SE, Albuquerque, NM 87106
Phone: (505) 247-0192 • Toll-Free: (800) 524-5176 • Fax: (505) 247-1345
Website: http://parentsreachingout.org
Contact: Mayline Jaramillo, mjaramillo@parentsreachingout.org

---

[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 04/03/2014 from www.childhealthdata.org.

[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

F2F: Parent to Parent of NYS

Parent to Parent of NYS, which began in 1994, is a statewide not for profit organization established to support and connect families of individuals with special needs. The 13 offices, located throughout NYS, are staffed by Regional Coordinators, who are parents or close relatives of individuals with special needs. The F2F offers families: information on health topics, connections with Health Care Resource Parents, referrals to community resources, and trainings on health care financial issues, collaborating with professionals and other health care topics.

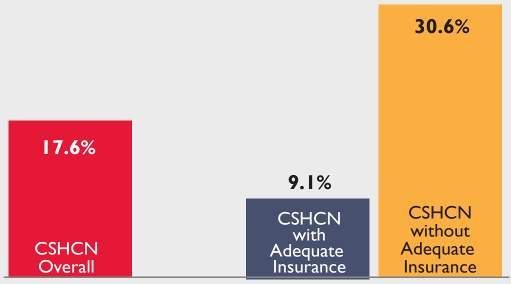
HIGHLIGHT: *Entitlements/Benefits Workshop*

This workshop includes information on Medicaid, CHIP, the ACA, Social Security, SNAP, WIC, and utilities assistance. Working primarily through two special needs schools, one for students in Pre-K through sixth grade and the other for students aged 14 -21, a total of 52 families and professionals were provided with information regarding these resources over the last year. The presentation has been very well received and additional sites are requesting this workshop. Most recently, F2F HIC staff has been co-presenting with staff from a comprehensive clinical services agency for individuals with autism. F2F HIC staff present on entitlements, benefits, and the ACA; the staff from the clinical agency provides an overview of autism insurance coverage in NYS. A professional who works with families of CSHCN commented: *"The presenter was very helpful and informative for the parents that attended this meeting. I have learned a lot and will share this information with the service coordinators at my agency."*

CSHCN in NY[1]

- 660,565 children (15.0%)
- 239,388 children have inadequate insurance
- 182,675 children have conditions that consistently affect their activities
- 279,008 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:

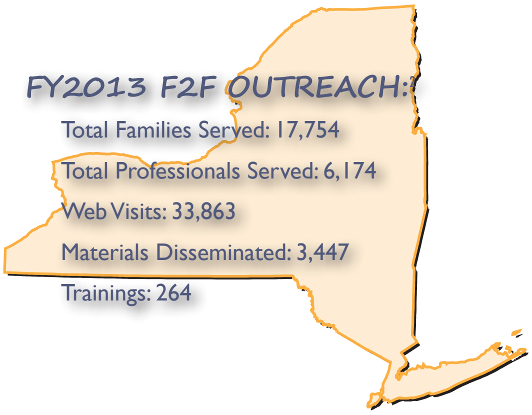


IMPACT on a Family:

Overwhelmed by the prospect of an extensive hand surgery for her six-month-old son at an out-of-state Shriner's Hospital, an Upstate NY mom was further stressed when she was unable to locate an orthopedic specialist willing to handle the necessary follow-up care in her area. The child's grandmother reached out to Parent of NYS for assistance. Our F2F HIC Coordinator contacted all three major medical centers in the mom's region to inquire about the possibility of follow-up care. The facilities asked for information on the child's Medicaid benefits, information that was difficult for the family to provide. Working as a conduit of information between the family and hospital, F2F staff was able to talk with the director of orthopedic services at one of the hospitals. An orthopedic hand specialist affiliated with that hospital agreed to provide follow-up care for this infant, regardless of insurance status. Best yet, the physician had previously worked with the surgeon at Shriner's Hospital! The family, very relieved and grateful for the assistance, shared the following: *"Yes indeed it is a good day!! My daughter was ecstatic when I gave her the news! Thanks again for all your help. Lots of kudos to your staff !!!!"*

CONTACT:

Parent to Parent of NYS
500 Balltown Road
Schenectady, NY 12304
Phone: (518) 381-4350
Toll-Free: (800) 305-8817
Fax: (518) 393-9607
Website: http://parenttoparentnys.org
Contact: Lara Turney
lturney@ptopnys.org



FY2013 F2F OUTREACH:[2]

Total Families Served: 17,754
Total Professionals Served: 6,174
Web Visits: 33,863
Materials Disseminated: 3,447
Trainings: 264

---

[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 04/03/2014 from www.childhealthdata.org.

[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

F2F: Exceptional Children's Assistance Center, Inc.

North Carolina's Family-to Family program within the Exceptional Children's Assistance Center (ECAC) provides information and support to NC families who have CSHCN and the professionals who serve them. Our goal is to help families navigate services and make informed health care decisions. We connect families for peer support as well as work with policymakers to design effective programs and to assist in identifying successful service delivery models.

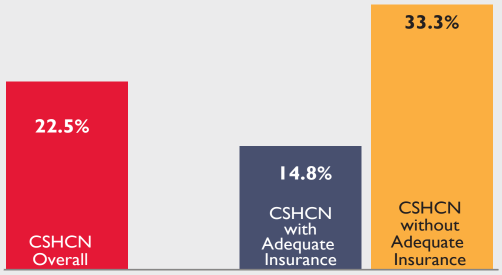
HIGHLIGHT: *Care Notebook*

The *Care Notebook* is a tool for families that gives the family a sense of mastery in overseeing their child's health care by providing a framework for stories, health data, and history of their child. Family enthusiasm, train-the-trainer activities, and the new emphasis on care coordination within the ACA and Medicaid programs have increased knowledge of the Care Notebook so that it is now being used broadly across NC. Pediatric ICU staff and administrators, Neonatal ICU staff and administrators, Katie Beckett providers, and hundreds of English and Spanish-speaking families worked on creating the most recent revision of the notebook, which is now in production. The *Care Notebook* is available in Spanish and English and can be accessed online, as a CD, and in a print version.

CSHCN in NC[1]

- 389,439 children (17.2%)
- 233,294 children have inadequate insurance
- 94,747 children have conditions that consistently affect their activities
- 127,752 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:

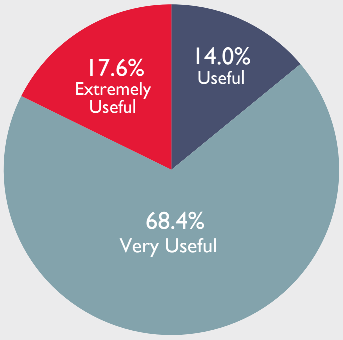


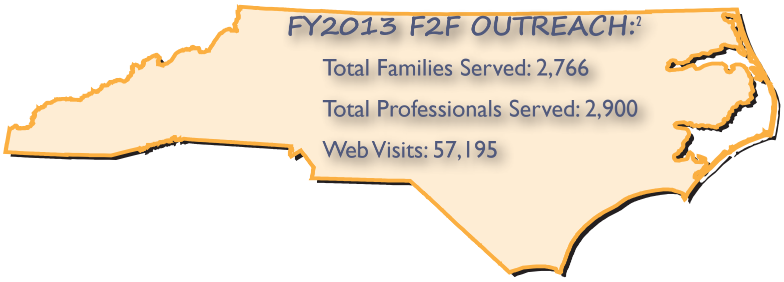
IMPACT on a Family:

Ashley contacted ECAC asking for support, education and assistance. Her daughter has a severe neurological disorder that made oral feeding very difficult. With the support of her daughter's pediatrician, the family located a feeding program that was successful in helping her daughter to finally gain weight. After her daughter graduated from the program, Ashley attempted to advocate for feeding training for the preschool staff. She met with resistance. The school recommended a plan that would have forced her daughter into a more restrictive school setting rather than providing appropriate related services and health supports in the preschool. The NC F2F was able to help Ashley understand IDEA requirements for medically fragile children like her daughter and connected her with the appropriate regional school nurse consultant who translated the child's medical needs to staff in her preschool setting. NC F2F facilitated meetings with team members to implement an appropriate program and has provided additional information and support as requested by Ashley.

IMPACT:
Service Navigation

Families rate the usefulness of the support/information/resources they received from the NC F2F in helping them find and/or learn about community services (primary health care, intervention programs, translation services, etc.)[2]





FY2013 F2F OUTREACH:[2]

Total Families Served: 2,766

Total Professionals Served: 2,900

Web Visits: 57,195

CONTACT:

Exceptional Children's Assistance Center
907 Barra Row, Suites 102/103
Davidson, NC 28036
Phone: 704-892-1321 • Parent Info Line: 800-962-6817
Fax: 704-892-5028
Website: http://www.ecac-parentcenter.org
Contact: Marlyn Wells, marlynwells@gmail.com

---

[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 04/03/2014 from www.childhealthdata.org.

[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

F2F: Family Voices of North Dakota

Family Voices of North Dakota (FVND) began assisting families of CSHCN in 1996, and since that time, has become an established resource for families and professionals seeking to improve care for CSHCN. The F2F provides assistance to families in accessing services and resources and helps them partner with providers and caregivers. We work with families, providers, public and private agencies, and advocacy or support groups to promote family-centered care and medical homes.

CSHCN in ND[1]

- 19,748 children (13.9%)
- 6,768 children have inadequate insurance
- 4,394 children have conditions that consistently affect their activities
- 6,067 do not receive family-centered care

HIGHLIGHT: *Parent Leadership Institute*

For the past 8 years, FVND has partnered with the Federation of Families for Children's Mental Health, Designer Genes, Early Intervention, North Dakota PTI, Children's Special Health Services (Title V), Pathfinder Parent Center, and the State Council on Developmental Disabilities to plan and run a *Parent Leadership Institute*. This weekend event for 25 participants provides training on understanding systems of care for CSHCN and navigating services, using the National Family Voices Leadership Guide as a resource. Participants are also provided guidance on leadership and communication styles and helped to establish goals for the coming year. While the present model has been a success, tweaks are being made to offer the course over a period of several months to promote ongoing mentorship, leadership and to extend he sections on how to impact systems.

As a result of our institute, many participants have become leaders: starting support groups; developing a state Hands and Voices chapter (advocacy for deafness community); impacting autism supports; increasing recreational opportunities for CSHCN in their communities; testifying about legislation on many issues; becoming a better advocate for their own child and mentoring other parents.

We are currently applying for other funds to increase this leadership training, provide better follow up to participants, and improve data tracking on how systems are impacted by providing this institute for families.

IMPACT on a Family:

"Carter has Sotos Syndrome, often called Cerebral Gigantism, which is a genetic condition causing physical overgrowth during the first years of life often accompanied by delayed motor, cognitive and social development. We affectionately call him our "gentle giant" because that describes his overall demeanor, although, as with other children with Sotos, he can be very aggressive. Joining the parent group run by Family Voices, 'YOU-Nique Opportunities' has opened up many opportunities for our family socially. Previously, we didn't do as much socially because we were tired of the looks and comments from people who didn't understand Carter's behavior. The YOU-Nique program has given us opportunities to participate in many great events and to meet people who do not judge or ridicule, and that has meant the absolute world to our family! With YOU-Nique Opportunities, Family Voices provides something that this community has been missing and in desperate need of for way too long. I don't know where our family would be without Family Voices!!! Thank you."

- Julie N.

FY2013 F2F OUTREACH:[2]

Total Families Served: 5,582

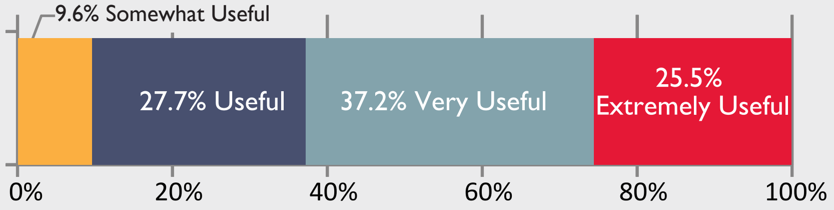
Total Professionals Served: 6,063

Materials Disseminated: 36,932

Trainings: 120

IMPACT: Family Confidence

Families rate the usefulness of the support/information/resources they received from the ND F2F in helping them feel more confident about getting their child the health care and services that s/he needs.[2]



CONTACT:

Family Voices of North Dakota • P.O. Box 163, Edgeley, ND 58433
Phone: (701) 493-2634 • Toll-Free: (888) 522-9654 • Fax: (701) 493-2635 • Website: http://fvnd.org
Contact: Donene Feist, fvnd@drtel.net

---

[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 04/03/2014 from www.childhealthdata.org.
[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

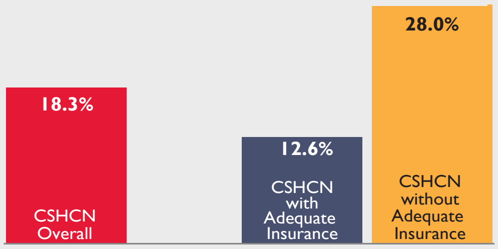
F2F: Family Voices of Ohio

Family Voices of Ohio helps families of CSHCN to learn about and access services and supports to assure optimum health care for their children. We collaborate with providers, state agencies, and other key stakeholders to raise awareness of the needs of families and to address gaps in systems and policies that adversely affect children with special health care needs. All our staff and board members are parents of children and adults who have special needs and represent a wide variety of children, health conditions, families and communities from every region in Ohio.

CSHCN in OH[1]

- ➢483,467 children (17.8%)
- ➢145,651 children have inadequate insurance
- ➢147,839 children have conditions that consistently affect their activities
- ➢139,014 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:



HIGHLIGHT: The *Ohio Respite Coalition*

The *Ohio Respite Coalition* is a statewide collaboration among family members, caregivers, advocates, respite providers, agencies, community groups, and state and local government officials who work to educate, advocate, and promote access to respite options for people who care for a loved one.

Our Health Information Specialist, Jessica, chairs the government relations committee of the *Ohio Respite Coalition*, and worked with the Ohio Department of Medicaid to implement a Respite Waiver for CSHCN who are covered by managed care. The waiver began serving families on January 1, 2014. We are currently working to increase awareness and access to respite by increasing the knowledge of the word respite and developing a standard method of training and certifying respite workers. Our vision is that all caregivers regardless of location or circumstance will have access to quality person-centered respite services and be able to use them in a timely and effective manner.

IMPACT on a Family:

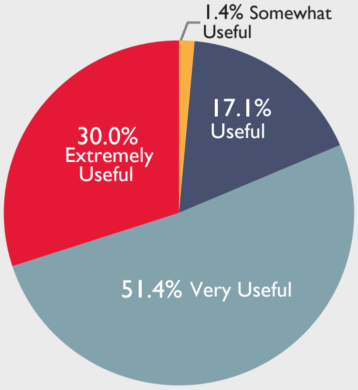
FV of OH received a phone call from a mom whose son was starting preschool and she did not have a way to get him there. We called her service coordinator in the Help Me Grow program and together we were able to arrange for this family to receive support through the County Board of Developmental Disabilities Family Support Services program. We set up transportation to preschool from United Disability Services, while we worked on adding transportation services to the IEP. Additionally, we contacted the Medicaid Care Coordinator to approve extra transportation for doctor appointments.

FY2013 F2F OUTREACH:[2]

Total Families Served:
3,470
Total Professionals Served:
1,090
Web Visits:
21,669
Materials Disseminated:
2,794

IMPACT: Family/Provider Communications

Families rate the usefulness of the support/information/resources they received from the OH F2F in helping them partner with (communicate with, talk with, work with) professionals to make decisions about their child's health care.[2]



CONTACT:

Family Voices of Ohio • 6555 Busch Blvd., Suite 112, Columbus, OH 43229
Phone: (419) 251-8190 • Toll-Free: (877) 322-2200 Ext. 8190
Website: http://www.familyvoicesohio.org
Contact: Carol Keltner, chkeltner@PremierHealth.com

---

[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 04/03/2014 from www.childhealthdata.org.
[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

F2F: Oklahoma Family Network

The Oklahoma Family Network (OFN) Family-to-Family Health Information Center informs and connects individuals with special health care needs and disabilities, their families and professionals to services and supports in their communities. OFN provides opportunities for individuals and families to strengthen their communities through leadership development and volunteering.

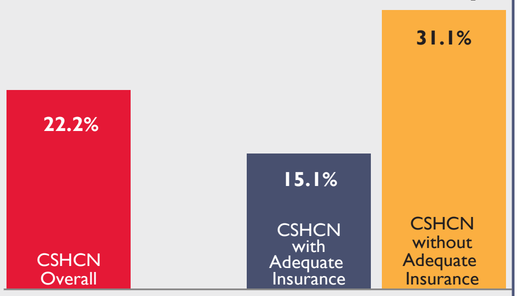
HIGHLIGHT: *2014 Annual Joining Forces - Family/Professional Partnership Conference*

We work with our partner agencies to plan and provide an annual family/professional partnership conference. This is a unique conference as it brings together many of our state agencies and family leaders. This year our theme was '*A Good Life*' and we were thrilled to have Michelle Reynolds, PhD of the Missouri Family-to-Family Network, UMKC Institute for Human Development and University Center on Excellence in Developmental Disabilities, who is a sibling of a CSHCN, as our keynote speaker. For the conference, we produced a short video which features individuals answering the question - *A Good Life Is?* The video is available on our website. The conference featured breakout sessions where we discussed and mapped out life courses. The conference was a huge success for the 141 attendees and many new partnerships were formed.

CSHCN in OK[1]

- 161,799 children (17.6%)
- 51,169 children have inadequate insurance
- 38,296 children have conditions that consistently affect their activities
- 52,325 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:



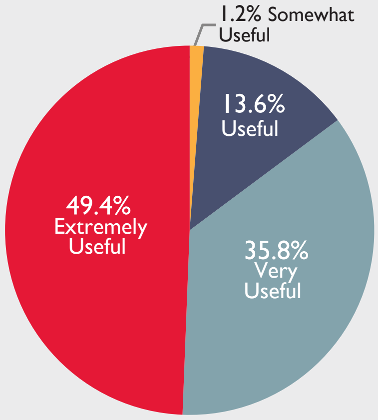
IMPACT on a Family:

"You truly never know how someone feels until you walk in their shoes. Sitting in a NICU cubicle with your undiagnosed baby is the hardest thing my husband and I have ever had to do. Day in and day out you are surrounded by medical staff, medical equipment, medical clothing, medical terminology—buzzing, beeping, alarming. You are helpless, uncertain of the future and feeling a flood of emotions all at once—fear, anger, weakness, selfishness, worthlessness, uncertainty, sadness, depression, anxiety. It's overwhelming. Then one day someone walks in—normal everyday clothing, smiling, puts their hand on your shoulder and for once asks 'What can I do for YOU?' For us that person was Ellyn of the Oklahoma Family Network. She was our weekly release—our connection to normalcy. She understood and didn't ask for an explanation, a timeline, a diagnosis. She just offered an ear at a time when we were so lost. I honestly don't know what I would have done during those long 77 days without looking forward to seeing Ellyn on Tuesday afternoons and having pie and coffee. She had walked in my shoes and knew what I needed."

IMPACT:

Family Confidence

Families rate the usefulness of the support/information/resources they received from the OK F2F in helping them feel more confident about getting their child the health care and services that s/he needs.[2]



FY2013 F2F OUTREACH:[2]

Total Families Served: 6,246
Total Professionals Served: 8,368
Materials Disseminated: 6,894
Trainings: 700

CONTACT:

Oklahoma Family Network
800 NE 15TH Street, Suite 516
Oklahoma City, OK 73104
Phone: 405-271-5072 • Toll-Free: 877-871-5072
Website: http://oklahomafamilynetwork.org
Contact: Joni Bruce
Joni-bruce@oklahomafamilynetwork.org
Heather Pike,
heather-pike@oklahomafamilynetwork.org

---

[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 04/03/2014 from www.childhealthdata.org.

[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

F2F: Oregon Family-to-Family Health Information Center

The Oregon Family-to-Family Health Information Center provides information to families who are navigating the complex world of special health care needs. We are family members ourselves, who have first-hand experience raising a child or youth with a chronic health condition, developmental delay, disability, or emotional/behavioral challenges.

CSHCN in OR[1]

- 119,187 children (13.7%)
- 42,944 children have inadequate insurance
- 34,542 children have conditions that consistently affect their activities
- 40,630 do not receive family-centered care

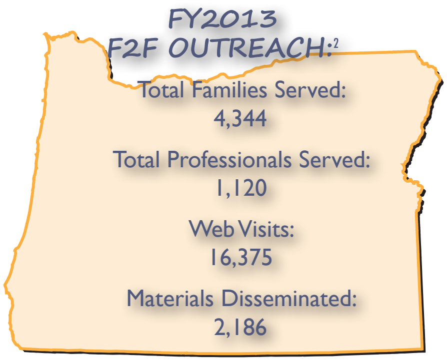
HIGHLIGHT: Regional Family Gatherings in Rural, Latino, and Slavic Communities

Since 2011, the Oregon Family-to-Family Health Information Center has conducted 31 Regional Family Gatherings throughout the state to exchange information, ideas, and support. These gatherings have taken place in rural communities and with Latino and Russian families in both metropolitan and rural Oregon.

In order to do this work, the OR F2F HIC has developed a unique "map" of the state that identifies key groups who will partner with us to offer these gatherings in locations that are familiar and welcoming to families. Our map, a 5' x 3' map of the state pinned to a wall in the office, was first populated with tags representing every known parent leader in the state. Using word of mouth, we contacted dozens of groups, like the Autism Society of Oregon and The Arc of Oregon, as well as groups that meet informally in churches and playgrounds, and everything in between. We included parent groups from the health, developmental disabilities, and mental health domains, as well as those focused on advocacy, recreation, or other topics.

Gathering the names of contact persons from agencies and organizations that touch families' lives in some way, we filled in our map and built a database. Now, for almost each of Oregon's 36 counties, we have identified a network consisting of family groups and helpful professionals such as Disabilities Coordinators at Head Start, Early Intervention Teachers, Title V Nurse Care Coordinators, Community Developmental Disabilities Case Managers, and many others. In the most rural part of Oregon, even the delivery drivers of home medical equipment have participated in our network.

Information about these organizations is provided specific to the region where the Family Gathering is taking place. We connect with an organization to host the gathering and they locate a meeting place, circulate publicity, organize registration, and let us know a focus for the meeting. Typical topics include: Resources and More, Becoming Your Child's Health Advocate, and Planning for a Healthy Transition. We bring light refreshments and plenty of resource materials. Groups are generally between 3 and 15 participants. As a result of these gatherings, families connect with one another and learn about support and health-related programs. Through the meetings we also are able to provide our state's Title V CYSHCN program with feedback about families' experiences. During the launch of our state's Health Insurance Marketplace, these Regional Family Gatherings were instrumental in providing information about the ACA and in clearing up myths and misconceptions. One family member from a frontier county remarked: *"I don't think we really knew what Obamacare was until you came out here."* She left the event with a supply of explanatory brochures about Cover Oregon and Health Care Reform to distribute to her friends.



FY2013 F2F OUTREACH:[2]

Total Families Served: 4,344

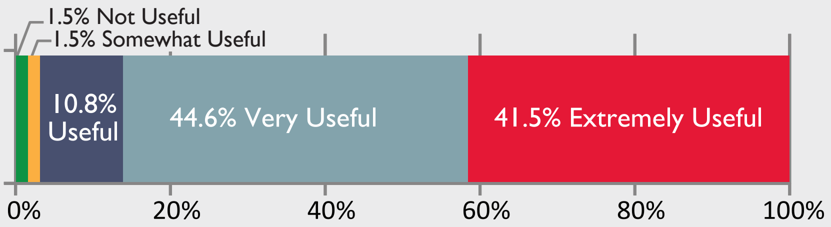
Total Professionals Served: 1,120

Web Visits: 16,375

Materials Disseminated: 2,186

IMPACT: Service Navigation

Families rate the usefulness of the support/information/resources they received from the OR F2F in helping them find and/or learn about community services (primary health care, intervention programs, translation services, etc.)[2]



CONTACT:

Oregon Family-to-Family Health Information Center • 707 SW Gaines Street CDRC, Portland, OR 97239-3011
Phone: (503) 494-0865 • Toll-Free: (855) 323-6744 • Fax: (503) 494-2755 • Website: http://www.oregonfamilytofamily.org
Contact: Tamara Bakewell, bakewell@ohsu.edu

---

[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 04/03/2014 from www.childhealthdata.org.

[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

F2F: Parent Education & Advocacy Leadership Center

The Parent Education & Advocacy Leadership Center (PEAL) was established in October 2005 as an organization of parents of children with disabilities reaching out to assist other parents of children with disabilities and special health care needs, and professionals. The PEAL F2F provides individual assistance and training on access to health care, insurance, and community support services statewide.

HIGHLIGHT: *Parent Advocate Summit*

This summer the PEAL Center hosted a weekend *Parent Advocate Summit*, reuniting trained Parent Leaders. Our goal was threefold: 1) to establish an ongoing statewide network of parent leaders/advocates, 2) to empower leaders to engage in collective advocacy, and 3) to engage parents in learning opportunities in order to help Parent Leaders develop a personal advocacy plan. The energy of the parent leaders was revitalizing as they brainstormed, networked, and galvanized their plans. Individuals identified issues of concern and laid out steps to accomplish their stated objectives. Thirty-five parent leaders attended the *Summit*, accompanied by 47 family members, totaling 82 attendees.

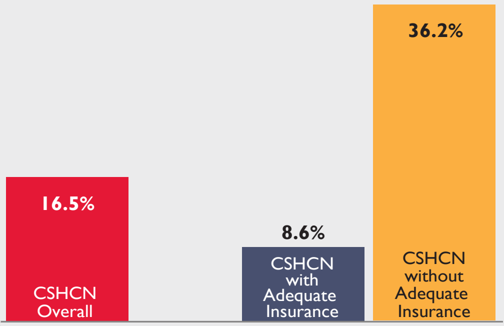
Feedback: *"It was inspiring to hear what other parent advocates were working on and beneficial to see the goals they focused on. This helped me to see what the world of the possible was for me." "We are all advocates thanks to the wonderful training we've received from PEAL."*

Video segments from the *Summit* that have been incorporated into our Online IEP Mini-Series, an E-Learning Course, can be found on our website.

CSHCN in PA[1]

- 469,906 children (17.0%)
- 119,132 children have inadequate insurance
- 116,309 children have conditions that consistently affect their activities
- 149,823 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:



IMPACT on a Family:

We assisted a single mother of a child with a rare genetic disorder that impacted his ability to participate in activities. With assistance in preparing an Individual Health Care Plan, guidance has now been provided to those working with the boy to safely incorporate him into activities with his peers. We helped the family to better communicate with their physician to provide needed supporting documentation for eligibility as well as clarification about the medical condition to people in the community who are involved with the child. We connected the family to additional resources to help with educational issues. *"Thank you for all of your help. I did not know what to do."*

FY2013 F2F OUTREACH:[2]

Total Families Served: 9,164

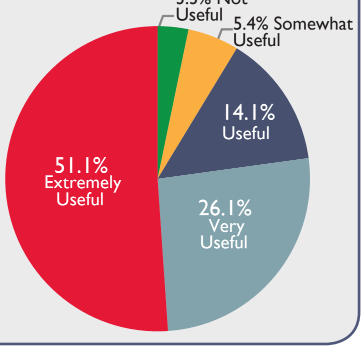
Total Professionals Served: 8,044

Web Visits: 67,161

Materials Disseminated: 59,520

IMPACT: Service Navigation

Families rate the usefulness of the support/information/resources they received from the PA F2F in helping them find and/or learn about community services (primary health care, intervention programs, translation services, etc.)[2]



CONTACT:

PEAL Center • 1119 Penn Avenue, Suite 400, Pittsburgh, PA 15222
Phone: (412) 281-4404 • Toll-Free: 866-950-1040 • Fax: (412) 281-4408
Website: http://www.pealcenter.org
Contact: Liz Healey, lhealey@pealcenter.org

---

[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 04/03/2014 from www.childhealthdata.org.

[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

F2F: RI Parent Information Network

Founded in 1991, the Rhode Island Parent Information Network (RIPIN) is a statewide nonprofit organization with a collective programmatic reach that extends to every Rhode Island community, reaching families through schools, associations, and agencies. The F2F project provides health care information, family-to-family support and leadership development for families of children with special health care needs. We work directly with organizations, institutions, and communities to address gaps and deficiencies so that individuals, parents and families are better served and viewed as equal partners.

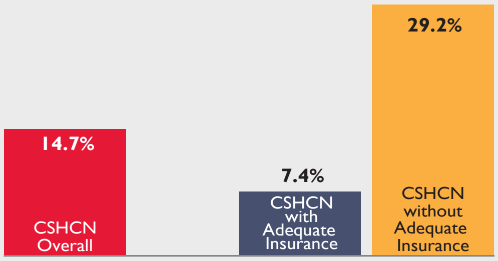
HIGHLIGHT: *Support Group Facilitator Training* with Technical Assistance Follow-up

RIPIN's *Support Group Facilitator Training* was created to educate and build skills for parents and professionals who are interested in started or revamping a support group. We begin this 4-hour training with an icebreaker activity and then delve into a discussion on what types of groups the participants are interested in. This guides the training to be specific to the participants needs. The goals of this particular training are for the upcoming facilitators to learn how to listen more effectively, be more self-confident and identify strategies to enhance support groups. The trainer continues to support and follow-up with the trainee during the start-up of the group and to mentor them on how to develop the group so it becomes self-sustainable.

CSHCN in RI[1]

- 39,170 children (17.3%)
- 11,812 children have inadequate insurance
- 10,055 children have conditions that consistently affect their activities
- 12,997 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:



IMPACT on a Family:

"My daughter Aileen was diagnosed with hydrocephalies and was unable to walk, talk or grab anything with her hands. She was legally blind. When she was six, the pediatrician and the neurologist told me that there was nothing else to do for her as she was dying slowly. At that time I had just started working for the Family Voices program as a Bi-lingual Resource Specialist. The director of the program supported me and my older daughter in this difficult time. She was there day and night, calling and visiting us. She taught me to be strong and brave and how to keep going after Aileen was gone. Two years after my baby passed away, I am still working for the Family Voices Program as a Bi-lingual Resource Specialist. I assist Spanish speaking families who are in need of resources and family support. Through a training I leaned to be a Support Group Facilitator and am now the facilitator of the Spanish support group for families who have children with special health care needs which meets monthly. Around eleven to fifteen families participate in the group. Thanks to the support I received from Family Voices, I can assist other families. My older daughter is always at the Spanish support group helping brothers and sisters who have siblings with special needs"

FY2013 F2F OUTREACH:[2]

Total Families Served:
13,046

Total Professionals Served:
6,658

Web Visits:
40,763

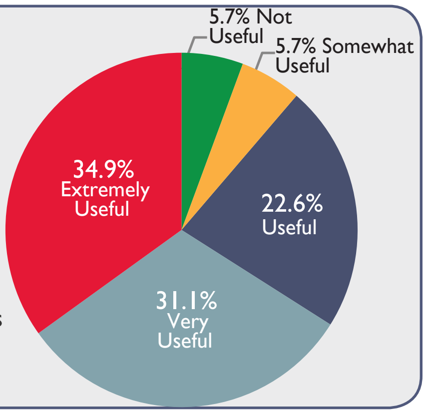
Materials Disseminated:
63,405

CONTACT:

RIPIN
210 Pontiac Avenue,
Cranston, RI 02920
Phone: (401) 270-0101
Toll-Free: (800) 464-3399
Fax: (401) 270-7049
Website: http://www.ripin.org
Contact: Tara Townsend,
townsend@ripin.org

IMPACT: Family/Provider Communications

Families rate the usefulness of the support/information/resources they received from the RI F2F in helping them partner with (communicate with, talk with, work with) professionals to make decisions about their child's health care.[2]



---

[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 04/03/2014 from www.childhealthdata.org.

[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

F2F: Family Connection SC

Family Connection SC is a statewide nonprofit organization that links families of children with special health care needs and disabilities with resources, support and education. We provide support to parents with a child or family member with any special health care need, such as an upcoming surgery, developmental delays, premature birth, physical limitations and all diagnoses including autism, asthma, ADHD and cerebral palsy. Our support for families includes a family-to-family network, statewide offices and a host of programs to educate, inspire and empower families and their children to live rich, fulfilling lives in spite of many challenges.

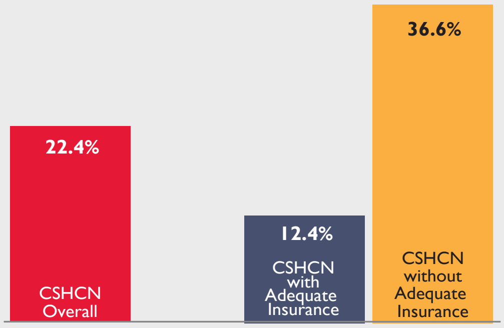
HIGHLIGHT: *Hopes and Dreams Annual Conference*

Our 2014 annual conference, *Hopes & Dreams*, was attended by more than 400 parents and professionals who care for children with special needs. This is a 2-day conference offering over 64 workshops and providing resources from 40 exhibitors. Workshops explored the issues and challenges families face in caring for children of all ages with developmental disabilities, chronic illnesses and long-term health needs. Topics ranged from Autism 101 and parent wellness to managing anxiety and feeding the picky eater. The conference featured keynote speaker Julie Petty of Fayetteville, AR. Ms. Petty, who has cerebral palsy, is a state leader in the self-advocacy movement encouraging people with disabilities to take greater control of their lives.

CSHCN in SC[1]

- 177,157 children (16.5%)
- 64,036 children have inadequate insurance
- 47,782 children have conditions that consistently affect their activities
- 61,000 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:

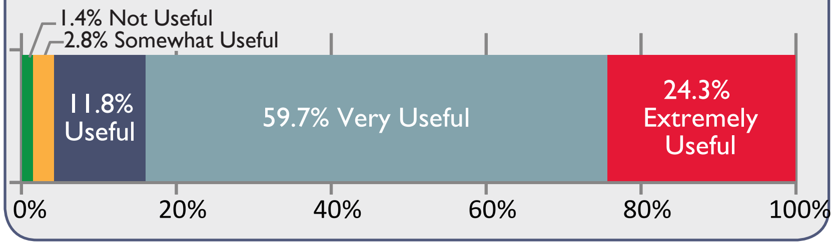


IMPACT on a Family:

> *"Not long after Millie was born she was diagnosed with mosaic Down syndrome. My husband Dan learned about a Down syndrome support group at Family Connection of SC. He felt we should go and learn more about what we were facing. It was at this meeting, surrounded by other parents on our same journey, that I first learned my daughter can be anything she wants to be. These parents shared pictures and stories of the many things their children were doing—sports, school, art, music- so many possible activities. It was a meeting of hope for me. The uncertainties of the future didn't seem so scary after talking to these families. To this day, Family Connection continues to provide the encouragement and information we need as my daughter pursues her dreams."*

IMPACT: Family Confidence

Families rate the usefulness of the support/information/resources they received from the SC F2F in helping them feel more confident about getting their child the health care and services that s/he needs.[2]



FY2013 F2F OUTREACH:[2]

Total Families Served: 13,999

Total Professionals Served: 2,820

Web Visits: 28,650

Materials Disseminated: 269,566

Trainings: 346

CONTACT:

Family Connection South Caroline • 2712 Middleburg Dr., Suite 103, Columbia, SC 29204
Tel. (800) 578-8750 • Fax: (866) 420-4082 • Website: http://www.familyconnectionsc.org
Contact: Amy Nienhuis, anienhuis@familyconnectionsc.org

---

[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 04/03/2014 from www.childhealthdata.org.

[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

F2F: South Dakota Parent Connection

South Dakota Parent Connection, Inc. (SDPC) was founded in 1985 by a group of dedicated parents and professionals to provide training and information statewide to meet the needs of parents and families caring for individuals with disabilities. The F2F project provides information and guidance around health issues to families, and the professionals who serve them, and improves access to services and resources for CSHCN.

CSHCN in SD[1]

- ➢24,415 children (12.5%)
- ➢8,003 children have inadequate insurance
- ➢7,334 children have conditions that consistently affect their activities
- ➢9,132 do not receive family-centered care

HIGHLIGHT: Workshop: Supporting Native American Families with CSHCN

Native American families, or Indian as they prefer to be called, are often outside of mainstream information systems that connect other families with CSHCN to available services and supports. In collaboration with National Family Voices, SDPC adapted a popular "*Accessing Services and Supports for CSHCN*" presentation for Native American (Indian) families to provide information on programs and resources that can support CSHCN birth to adulthood, including public/private insurance and the Marketplace. SDPC and National Family Voices presented this workshop at the National Indian Education Association Conference. SDPC also provided this workshop at the SD Indian Education Conference. These presentations were very popular and we received requests to present at two additional statewide events conferences for Indian families—the Lakota Nations Invitational Education Conference and the Oceti Sakowin Education Consortium Conference. In all, 122 family members and professionals participated in these workshops. Evaluation ratings were very positive – over 90% rated the quality of the workshop as Good, Very Good, or Excellent.

IMPACT on a Family:

Alejandra was born with hydranencephaly, a rare condition in which the brain's cerebral hemispheres are absent. When Alejandra's mother, Natasha, connected with SD Parent Connection, we sent her one of our resources - the Folder of Information of Life Experiences (FILE). *"I love the FILE! It's especially helpful when we travel to medical appointments."* SDPC introduced the family to the *Dare to Dream Conference*, which the entire family attended last year. *"We met lots of people. We see them in the community every day. SDPC helped us create a network of support and relationships for our entire family."* Natasha, an RN with Indian Health Services, refers other families of children with special needs to SDPC. She and her family hope to become involved at the state and national level advocating for other families. With help from SDPC, both Natasha and Raymon (Alejandra's father) have not only improved life for their own family, they are becoming leaders for other families.

FY2013 F2F OUTREACH:[2]

Total Families Served: 4,970

Total Professionals Served: 5,317

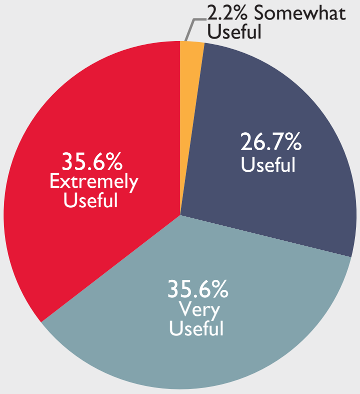
Web Visits: 11,255

Materials Disseminated: 34,047

Trainings: 105

IMPACT: Family/Provider Communications

Families rate the usefulness of the support/information/resources they received from the SD F2F in helping them partner with (communicate with, talk with, work with) professionals to make decisions about their child's health care.[2]



CONTACT:

South Dakota Parent Connection
3701 West 49th Street, Ste. 102, Sioux Falls, SD 57106
Phone: (605) 361-3171 • Toll-Free: (800) 640-4553 • Fax: (605) 361-2928
Website: http://www.sdparent.org/
Contact: Lisa Sanderson, Lsanderson@sdparent.org

---

[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 04/03/2014 from www.childhealthdata.org.

[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

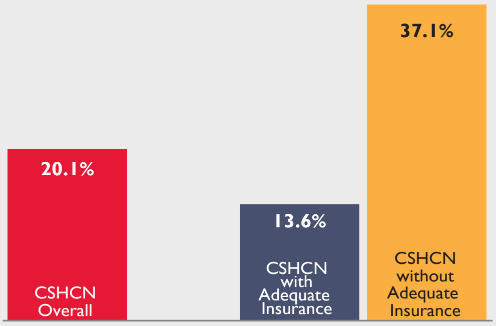
F2F: TN Disability Coalition/ Family Voices of TN

Family Voices of Tennessee (FVTN) operates the F2F as a member organization of the Tennessee Disability Coalition, an alliance of 47 organizations that promotes the full and equal participation of people with disabilities in all aspects of life. The F2F assists families as they navigate public and private health systems and insurance plans (including TennCare and commercial plans) and works with families, health care providers, public and private agencies, and advocacy or support groups to promote family-centered care and medical homes for CSHCN.

CSHCN in TN[1]

- 255,692 children (17.2%)
- 63,135 children have inadequate insurance
- 70,890 children have conditions that consistently affect their activities
- 81,696 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:

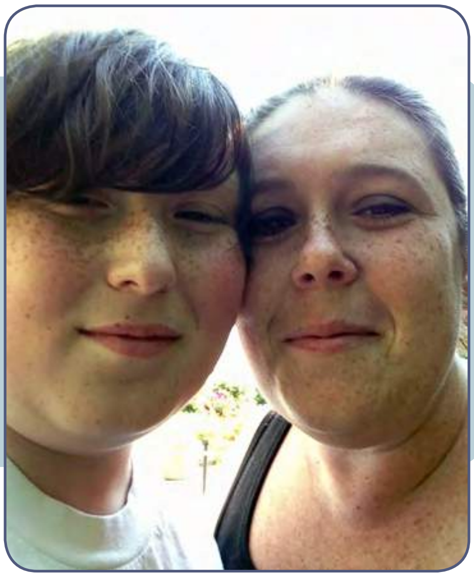


HIGHLIGHT: Family-Centered Care Workshops – Transition Booklet

Family Voices of Tennessee has trained 27 parents/family members in numerous Family Centered Care workshops across the state. These workshops teach families about what Family-Centered Care is and how to partner with their child's health care provider. Trainings are available statewide upon request. Participants leave with clear follow up activities and have scheduled calls with FVTN staff. A transition booklet called "*Dude, Where's My Transition Plan*", was developed by FVTN in collaboration with KY F2F HIC in 2012. This booklet was updated by FVTN and STEP (TN's PTI) in February 2014. Three new pages were added, including a page on allergies, internet safety and additional information regarding transportation. 500 copies have recently been printed and are being disseminated. The booklet is also available on the FVTN website.

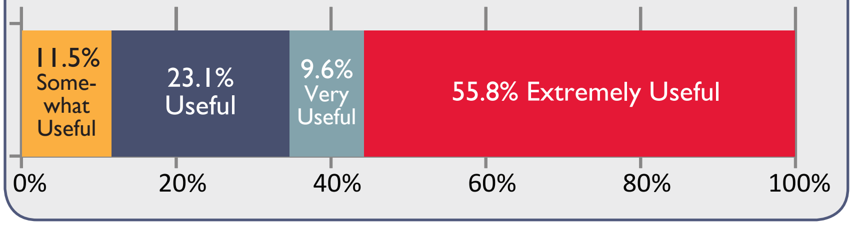
IMPACT on a Family:

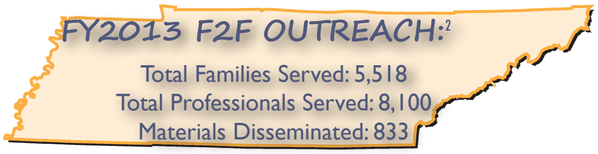
A mother who attended our first FCC workshop used the skills she learned from the workshop and the follow-up coaching calls to better engage with her son's pediatrician. With new ideas of how to partner and communicate with her son's physician she was able to have a "very successful" visit. She stated that the communication was improved and that her son received a new diagnosis from the visit. She was prepared with written notes, and questions for her physician. She felt "empowered." She stated she now attends every appointment with notes regarding her son's behaviors and questions she has to ensure good communication takes place.



IMPACT: Family/Provider Communications

Families rate the usefulness of the support/information/resources they received from the TN F2F in helping them partner with (communicate with, talk with, work with) professionals to make decisions about their child's health care.[2]





FY2013 F2F OUTREACH:[2]

Total Families Served: 5,518
Total Professionals Served: 8,100
Materials Disseminated: 833

CONTACT:

TN Disability Coalition/ Family Voices of TN, 955 Woodland Street, Nashville, TN 37206
Phone: (615) 383-9442 • Toll-Free: (888) 643-7811 • Fax: (615) 383-1176 • Website: http://www.tndisability.org/
Contact: Belinda Hotchkiss, belinda_h@tndisability.org

---

[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 04/03/2014 from www.childhealthdata.org.
[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

F2F: Texas Parent to Parent

Texas Parent to Parent (TxP2P) is committed to improving the lives of Texas children who have disabilities, chronic illness, and/or special health care needs. The F2F at TxP2P offers training, resources and support around health issues for parents, family members, professionals, and community members, to better support children with disabilities or special health care needs throughout their lives. Trainings and presentations in English and Spanish are available at no charge to professionals, parents, and parent groups across Texas.

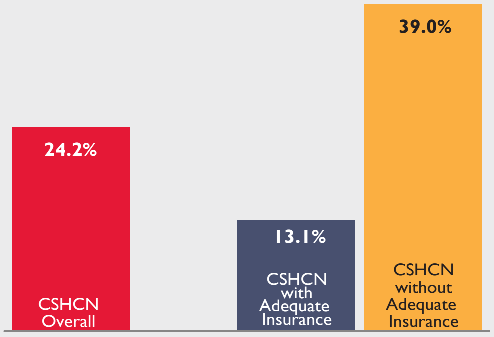
HIGHLIGHT: *Pathways to Adulthood Program*

When children with disabilities, chronic illnesses, or other special health care needs approach adulthood, parents face many issues in assisting their young adult to start their life after school. *Pathways to Adulthood* (PTA) assists families to envision a good life for their sons and daughters with disabilities after graduation, and provides support, information and tools for carrying out this vision. We offer 1:1 peer mentoring, 1:1 assistance from staff, trainings, networks of support, support groups, annual conference workshops, online resources, and a listserv on transition & Medicaid waivers. Feedback from a recent workshop participant: *"The strongest feature was the presenter's expertise, personal experience, and encouragement. Comprehensive overview such as this of all transition issues should be mandatory for all parents."*

CSHCN in TX[1]

- ➢919,876 children (13.4%)
- ➢286,736 children have inadequate insurance
- ➢247,587 children have conditions that consistently affect their activities
- ➢342,226 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:



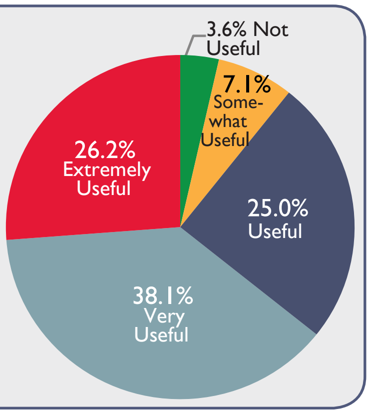
IMPACT on a Family:

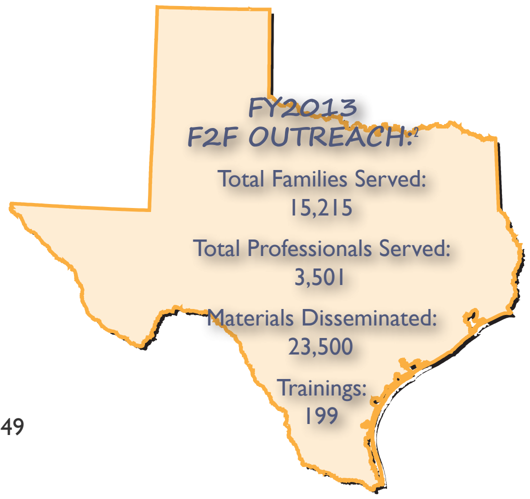
Our PTA Program has provided support for 4 families (and several more who are in the beginning phases) to create fully functioning "Networks of Support" around individuals with a disability and their family. These personal networks provide a structure of on-going support for a person with a disability during the course of that person's life and even after the parents have passed away or are no longer able to care for them. The idea of personal networks comes from a parent organization in Vancouver called PLAN (Planned Lifetime Advocacy Network). As a result of these Networks, parents feel less stressed and less anxious about the future, have been able to work with their youth's school program more effectively to prepare for transition, found jobs for their adult children, and one even was able to leave the country on vacation for the first time in 20 years. One of our families reported: *"Maverick's network has been together for over three years. The best thing that has resulted from the network is our feeling hopeful about Maverick's future. We have created a community of people who came together for one purpose (i.e. Maverick) and are, over time, becoming closer to each other, more cohesive, and more vested in Maverick's futuree."* TxP2P has created a "how-to manual" for creating Networks which is available on our website.

IMPACT:

Service Navigation

Families rate the usefulness of the support/information/resources they received from the TX F2F in helping them find and/or learn about community services (primary health care, intervention programs, translation services, etc.)[2]




FY2013 F2F OUTREACH:[2]

Total Families Served: 15,215

Total Professionals Served: 3,501

Materials Disseminated: 23,500

Trainings: 199

CONTACT:

Texas Parent to Parent • 3710 Cedar Street, Box 12 Suite 229 & 230, Austin, TX 78705-1449
Phone: (512) 458-8600 • Toll-Free: (866) 896-6001 • Fax: (512) 451-3110
Website: http://www.txp2p.org/
Contact: Laura J. Warren, Laura@txp2p.org

---

[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 04/03/2014 from www.childhealthdata.org.
[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

F2F: Utah Family Voices

The F2F at Utah Family Voices provides families with quality information and resources and expands family/professional partnerships to help families make informed decisions. We provide information, training, and guidance. We develop and implement strategies for collaboration. We conduct activities that are culturally and linguistically relevant to families and professionals around home and community based services and supports and help families assess their potential eligibility for programs and services.

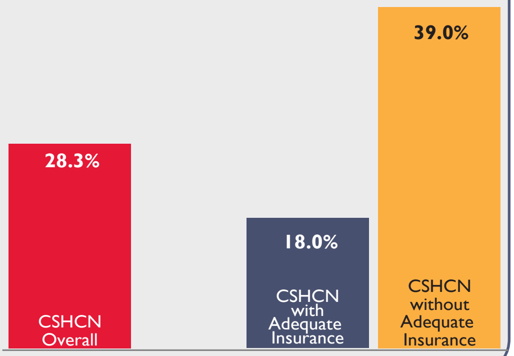
HIGHLIGHT: Family Involvement in the *Medical Home Portal*

The *Medical Home Portal* is a comprehensive website that provides reliable information and resources to help families and professionals care for CSHCN. The development of the modules about resources and services is a perfect example of parent/professional partnership. All the information is developed, vetted and published by a team that includes staff from the F2F as well as many other families throughout the state and region. All partners are committed to keeping the site current so that it can serve as a credible and informative resource for Utah and other states. The majority of the family content is written and edited by F2F staff and vetted in collaboration with the *Medical Home Portal* staff. During this year we have seen an increase in page views of 3% from the previous year. The "*For Parents & Families*" section had the highest rate of change in page views this year—a 28.61% increase representing access by 12,380 unique visitors spending an average time of 2:14 minutes on a page. The portal can be visited at http://www.medicalhomeportal.org/.

CSHCN in UT[1]

- 112,278 children (13.0%)
- 38,686 children have inadequate insurance
- 31,788 children have conditions that consistently affect their activities
- 34,087 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:

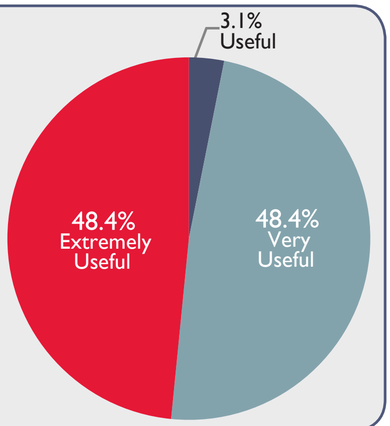


IMPACT on a Family:

A family needed to have their son seen at a pediatric specialty clinic, and had waited for 7 months to get an appointment. The day before the appointment, they received a letter indicating that due to changes in the ACO contract, the appointment would not be covered by insurance. The mom was beside herself when she contacted the F2F for help. Her son really needed this appointment and the family could not pay for it out of pocket. Our staff worked with the child's two different Health Plans to explain the situation and to look for a solution. Through our discussions, we discovered that this particular clinic was in fact covered because it was the only pediatric sub-specialty clinic of its kind. The family expressed their gratitude: *"Thank you for your help and kind concern. I really appreciate your reassurance; it's good to know that you understand the struggles. I've called and confirmed our appointment! THANK YOU. THANK YOU. THANK YOU."*

IMPACT: Family Confidence

Families rate the usefulness of the support/information/resources they received from the UT F2F in helping them feel more confident about getting their child the health care and services that s/he needs.[2]



CONTACT:

Utah Family Voices
230 West 200 South Suite 1101
Salt Lake City, UT 84101
Phone: (801) 584-8236
Toll-Free: (800) 468-1160
Fax: (801) 446-7738
Website:
http://www.utahfamilyvoices.org/
Contact: Gina Pola-Money
gina.ufv@gmail.com

FY2013 F2F OUTREACH:[2]

Total Families Served: 10,267
Total Professionals Served: 854
Web Visits: 198,877
Materials Disseminated: 7,210
Trainings: 139

---

[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 04/03/2014 from www.childhealthdata.org.

[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

F2F: Vermont Family Network (VFN)

Vermont Family Network began in July, 2008, when the Vermont Parent Information Center (VPIC) and Parent to Parent of Vermont merged, creating an expanded organization to promote better health, education, and well-being for all children and families, with a focus on children and young adults with special needs. The F2F provides families and individuals with the support they need to make informed decisions; connects families with other families; helps families navigate health care systems, and provides a family voice on boards and committees at the local and state level.

HIGHLIGHT: *Medical Education Project*

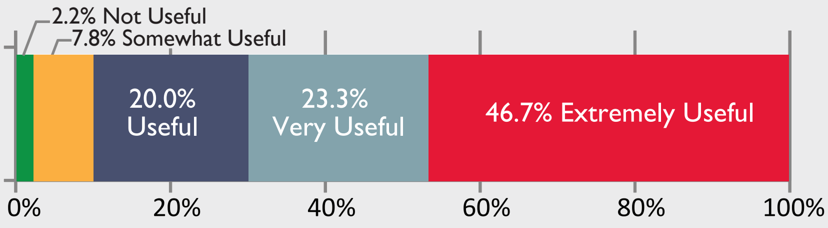
The *Medical Education Project (MEP)*, a well-established program, has reached thousands of medical professionals in training. The program engages medical students at various levels of their education (for example 1st year or 3rd year medical students, etc) and allows them to have direct experience with and feedback from families about their lives, challenges and what parts of the system have worked and what have been difficult. Reviews from both students and families are consistently very positive, with families feeling empowered and many saying that it was therapeutic to share their stories, while medical students express excitement about the contact with "real" patient experience while simultaneously reporting shock and awe at what families face and their dedication and hard work day after day. Feedback from a medical student: *"This disease didn't just mean life in a wheelchair for her son. It had implications for her entire family. In the future I will be able to give my patients a diagnosis with the full knowledge of what it means for a child and family and provide both emotional and physical support when needed."*

IMPACT on a Family:

"Please know that hosting a medical student is a pleasure for us. We want to make sure that a new generation of doctors will know how to better help kids and parents facing long term disability. It is important they know that the earlier one starts rehabilitation the better. We want them to know that there is NO WAY one should just sit and wait for a delay to occur. Any student seeing our son and knowing that a portion of his brain is not functioning will understand this, and we are happy to see their faces when they learn the story. We know they will remember the experience their entire life."

IMPACT: Family/Provider Communications

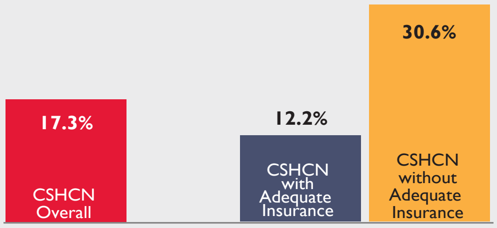
Families rate the usefulness of the support/information/resources they received from the VT F2F in helping them partner with (communicate with, talk with, work with) professionals to make decisions about their child's health care.[2]

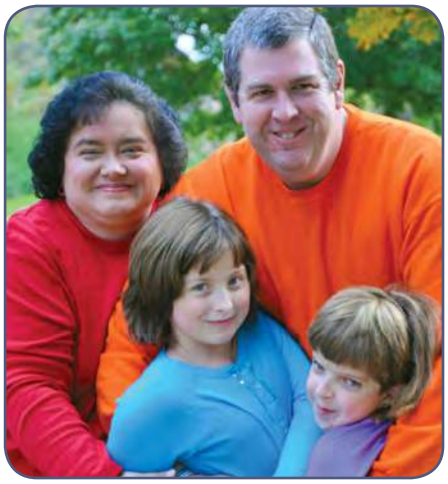


CSHCN in VT[1]

- ➢21,790 children (17.1%)
- ➢5,825 children have inadequate insurance
- ➢5,949 children have conditions that consistently affect their activities
- ➢6,825 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:





CONTACT:

Vermont Family Network
600 Blair Park Rd, Ste 240, Williston, VT 05495
Phone: (802) 876-5315
Toll-Free: (800) 800-4005
Fax: (802) 876-6291
Website:
http://www.vermontfamilynetwork.org
Contact: Lisa Maynes, lisa.maynes@vtfn.org

FY2013 F2F OUTREACH:[2]

Total Families Served:
4,991

Total Professionals Served:
1,979

Web Visits:
47,299

Materials Disseminated:
6,673

---

[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 04/03/2014 from www.childhealthdata.org.

[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

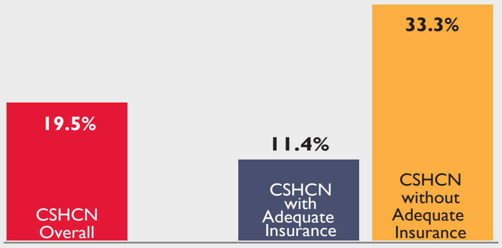
F2F: Family-to-Family Network of Virginia

The Family-to-Family Network of Virginia, an initiative of the Center for Family Involvement at Virginia Commonwealth University's Partnership for People with Disabilities Program, is a seven-site (and growing) Family-to-Family Network where family members of culturally and linguistically diverse children and young adults with disabilities have people in their own communities to call upon in their efforts to identify and obtain needed information, services and community supports. The Network's F2F project provides health-related information, referrals, training, and support to families of CSHCN and the professionals who serve them.

CSHCN in VA[1]

- 296,668 children (16.1%)
- 88,093 children have inadequate insurance
- 78,667 children have conditions that consistently affect their activities
- 99,583 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:



HIGHLIGHT: *Resource Guide for Families of Children with Hearing Loss*

Our *Resource Guide for Families of Children with Hearing Loss* is the first in a series of booklets, designed to provide information in an unbiased manner so that families can make the choice of services, intervention, therapies, and/or communication modalities that is right for them. This particular resource guide, which is easy to read and filled with graphics, is focused on infants and toddlers diagnosed as deaf or hard of hearing through newborn hearing screening and features an overview of hearing and communication, information on assistive technology, hearing aids, and cochlear implants, and sections on early intervention, special education, and state resources.

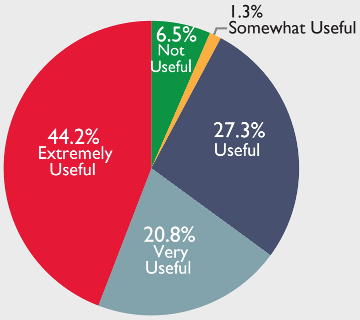
From September 2013 through March 2014, 165 families were referred to the VA F2F HIC who had children diagnosed as deaf/hard of hearing through Virginia's Early Hearing Detection and Intervention Program. In addition to enhanced 1:1 emotional support, the resource guide was reviewed with each family through home visits. Of the supported families who responded to a follow-up survey, 95% reported that the information provided was useful in making decisions about communication modalities. In addition to satisfaction and impact, we learned from these families about their timely referral to early intervention services (91% within 3 month of diagnosis).

The *Resource Guide* is available on our website and a Spanish version will be uploaded this summer. A second resource guide for families of young children diagnosed with Autism Spectrum Disorder will be published in the fall of 2014; a third resource guide for families of children with genetic disorders, is planned for release in winter 2015.

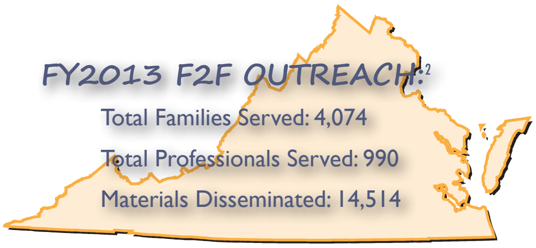
FEEDBACK: *"What a great resource - we are now connected to services." "Irene (from the F2F) came to visit us - we live over an hour away. She has been absolutely great and this resource guide has advised us about all hearing loss related things we wanted to know."*

IMPACT: Service Navigation

Families rate the usefulness of the support/information/resources they received from the VA F2F in helping them find and/or learn about community services (primary health care, intervention programs, translation services, etc.)[2]



FY2013 F2F OUTREACH:[2]



Total Families Served: 4,074

Total Professionals Served: 990

Materials Disseminated: 14,514

CONTACT:

Family-to-Family Network of Virginia
Center for Family Involvement @ VCU)
700 E. Franklin Street, 1st Floor, Richmond, VA 23219
Phone: (804) 828-0352 • Toll-Free: (877) 567-1122
Website: http://www.centerforfamilyinvolvement.org
Contact: Dana Yarbrough, dvyarbrough@vcu.edu

---

[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 04/03/2014 from www.childhealthdata.org.

[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

F2F: PAVE Family-to-Family Health Information Center
Family Voices of Washington

Pave (Partnerships for Action, Voices for Empowerment) is a non-profit organization, dedicated to sharing information and resources with people whose lives are linked to children and adults with disabilities. PAVE F2F staff provide advice based on their personal experience with health care systems. They offer a multitude of resources and connect families with a network of other families and professionals for support and information. They provide individual counseling as well as group education on health care issues. F2F staff help identify potential areas for service improvement and bring family perspective to health care improvement discussions.

HIGHLIGHT: Family, Youth, Systems Partners Round Table Project

We are working with the Washington State Division of Behavioral Health and Recovery, mental health providers, and families and youth who are receiving services to create local and regional forums that provide input and governance and recommend changes needed in the system of behavioral health services. These partners also work in roundtables with a group of representatives from all regions to provide direct recommendations to leadership and legislature. These roundtables are currently underway in 6 counties and will be expanding to 13 counties. This project has allowed families and youth to have a direct impact on their own mental health services and treatment plans. To date we have worked with 205 families and youth, as well as representatives from family organizations, State agencies, and many others. The participating families and youth have also created and presented awareness events for the community around bullying and mental health stigmas.

IMPACT on a Family:

"I am a grandmother raising my granddaughter who has needed intensive mental health services. I joined the local/regional round table (FYSPRT) because I wanted to see changes in the mental health services provided and to be able to have my voice heard. I also wanted my granddaughter to have the opportunity to learn to advocate for herself and to interact with other youth who understand her experience. Being a part of the FYSPRT group has given her more stability and new skills to support her friends who are doing unsafe things. She has gained confidence by sharing her ideas and opinions all the way up to state level meetings. This has been an important project for both of us."

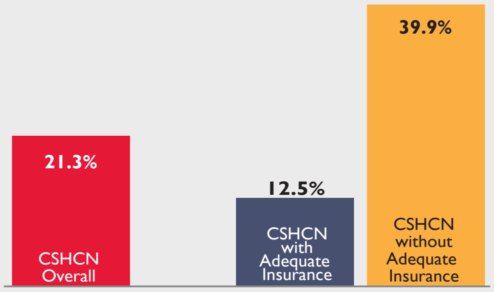
CONTACT:

PAVE
6316 So. 12th St., Tacoma, WA 98465
Phone: (253) 565-2266
Toll Free: (800) 5-PARENT
Fax: (253) 566-8052
Website:
http://www.familyvoicesofwashington.com/
Contact: Jill McCormick,
jmccormick@wapave.org

CSHCN in WA[1]

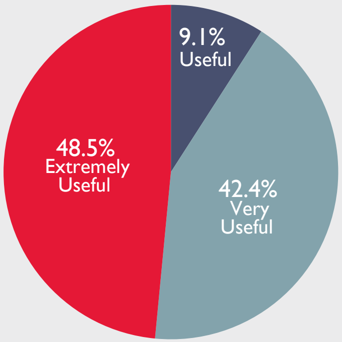
- 235,920 children (15.0%)
- 71,788 children have inadequate insurance
- 64,659 children have conditions that consistently affect their activities
- 70,338 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:

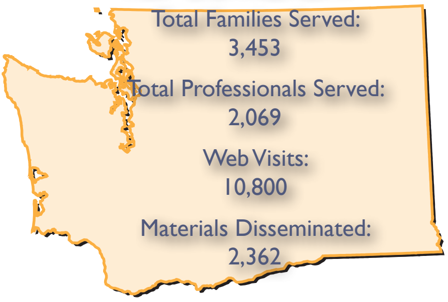


IMPACT:
Family Confidence

Families rate the usefulness of the support/information/resources they received from the WA F2F in helping them feel more confident about getting their child the health care and services that s/he needs.[2]



FY2013 F2F OUTREACH:[2]



Total Families Served:
3,453

Total Professionals Served:
2,069

Web Visits:
10,800

Materials Disseminated:
2,362

---

[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 04/03/2014 from www.childhealthdata.org.
[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

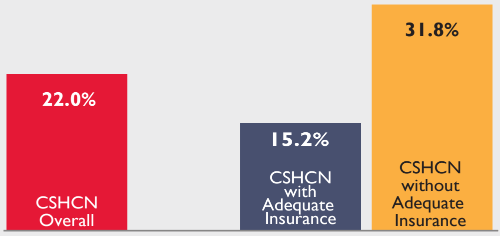
F2F: West Virginia Parent Training and Information

Established in 1991 West Virginia Parent Training and Information (WVPTI) is a statewide, cross-disability, parent/professional, and non-profit group. The F2F at WVPTI works to improve health care and health care supports throughout West Virginia for children with developmental delays, chronic illnesses and special needs by empowering families to advocate for their children and youth. The statewide Health Information Center reflects a family-directed focus.

CSHCN in WV[1]

- ➢70,609 children (18.5%)
- ➢21,901 children have inadequate insurance
- ➢19,602 children have conditions that consistently affect their activities
- ➢21,928 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:

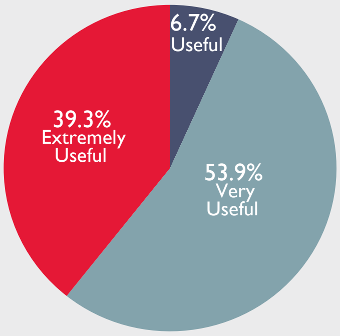


HIGHLIGHT: CSHCN - Home Visiting Program

The WV F2F in collaboration with the Parent Network Specialist Project and the West Virginia CSHCN Title V Program is completing year three of a complete system redesign, including policy and procedure to better serve families and children with special health care needs in a more comprehensive manner. The past three years progress has been made in improving services to families and CSHCN, expanding Medicaid services, Title 19 waiver services and CHIP enrollment, among others. Most importantly, the team developed new policies and procedures to improve access to services, particularly though a Medical Home and a team driven model of care coordination of services. The focus of this model was a home visit for every child entering the Title V Program done by a team that included Title V staff, a nurse, social worker, F2F staff, and Parent Network Specialists. During the visit the team, completed a "Level of Need Assessment" for the child and family, as well as provided direct assistance and referrals to assist each family. After the assessment of need, the team would follow up with the family to monitor progress. This collaboration has helped hundreds of families access health care, educational, vocational and transition services.

IMPACT: Service Navigation

Families rate the usefulness of the support/information/resources they received from the WV F2F in helping them find and/or learn about community services (primary health care, intervention programs, translation services, etc.)[2]



IMPACT on a Family:

"I never knew what it was or how hard it was to care for a handicapped child until my baby son was diagnosed with an Astrocytoma Stage 2 located in his spinal cord. The surgery left him paralyzed from the chest down and incontinent. I can honestly say that the help I have received from the F2F program has been so helpful to me. You have made my life much easier. Through your help, I have built a relationship with the companies that provide supplies for Trevor that is now much more cooperative. I appreciate that you take the time to listen to me and call even if I am not having a problem, just to see how Trevor is doing. Thank you from the bottom of my heart."

FY2013 F2F OUTREACH:[2]

Total Families Served:
13,927

Total Professionals Served:
6,181

Materials Disseminated:
21,814

Trainings:
104

CONTACT:

WV Family-to-Family Health Information Center
1701 Hamill Avenue, Clarksburg, WV 26301
Phone: (800) 281-1436 • Toll-Free: (800) 281-1436
Fax: (304) 624-1438
Website: http://www.cedwvu.org/programs/family
Contact: Todd Rundle, tarundle@hsc.wvu.edu

---

[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 04/03/2014 from www.childhealthdata.org.

[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

F2F: Family Voices of Wisconsin

As the F2F in Wisconsin, Family Voices of Wisconsin is a statewide network of families who have CSHCN and those who work on their behalf. The focus of our work is health care access, coverage and community supports and services for children and youth with disabilities and special health care needs. We work closely with the Regional Centers for Children and Youth with Special Health Care Needs around Wisconsin to make sure families find the resources they need.

HIGHLIGHT: *"What's After High School?"*

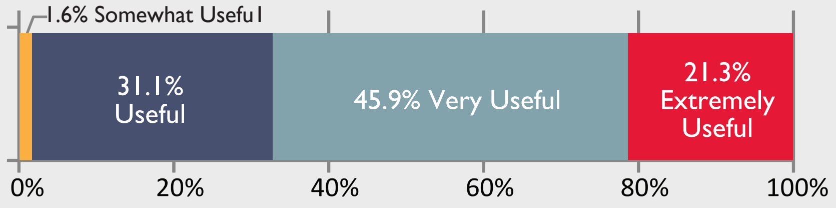
This training is a "30,000 foot" overview on considerations for transition to adult life for youth with disabilities and/or special health care needs. This is the only training in Wisconsin which looks at transition the way youth and families live their lives and experience this transition across a variety of domains. Topics include moving into adult health care, guardianship and assisted decision making, public education for youth 18 – 21, post-secondary options, employment options, residential options, community participation, self-determination and self-advocacy. This training is delivered in-person to many communities throughout Wisconsin and is also archived as a web cast on the Department of Health Services website. In 2013, "*What's After High School?*" was presented in 7 communities, reaching 166 family members, youth and professionals. Feedback from participants: *"Gave me more ideas for what to ask for to help plan for the future and also who to ask," "I'm less afraid to reach out for advice, help and connections," and "I am now aware of so many more possibilities for my son!"*

IMPACT on a Family:

In March 2014, we hosted "*Advocacy for Change: A Family Leadership Institute*" in collaboration with The Wisconsin Board for People with Developmental Disabilities, Disability Rights Wisconsin, The Survival Coalition of Wisconsin Disability Groups, Wisconsin Family Ties and Parent to Parent of Wisconsin. This Institute provided the 35 family leader participants an opportunity to be briefed on current disability issues, to frame their family story, and to receive support on how to tell their story to State Legislators and their staff. As a result of participating in Advocacy for Change, 100% of the participants reported that they felt better prepared to advocate for their concerns and 100% also reported that they felt better prepared to partner with decision makers to improve care.

IMPACT:
Service Navigation

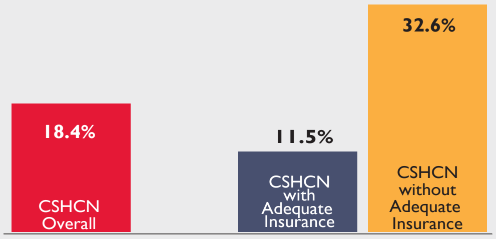
Families rate the usefulness of the support/information/resources they received from the WI F2F in helping them find and/or learn about community services (primary health care, intervention programs, translation services, etc.)[2]



CSHCN in WI[1]

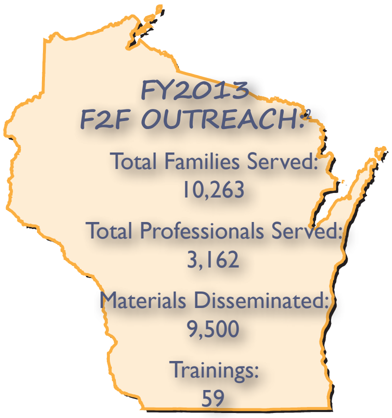
- 201,529 children (15.5%)
- 61,610 children have inadequate insurance
- 52,617 children have conditions that consistently affect their activities
- 64,691 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:



CONTACT:

Family Voices of Wisconsin
P.O. Box 55029, Madison, WI 53705
Phone: (608) 220-9598
Website: http://www.fvofwi.org/
Contact: Barbara Katz, barb@fvofwi.org



FY2013
F2F OUTREACH:[2]

Total Families Served:
10,263

Total Professionals Served:
3,162

Materials Disseminated:
9,500

Trainings:
59

---

[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 04/03/2014 from www.childhealthdata.org.

[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

F2F: Wyoming Family-to-Family Health Information Center

The WY F2F HIC at the Wyoming Institute for Disabilities (WIND, University of Wyoming) is a statewide, family-led initiative that provides information, education, training, outreach and peer support to families of CSHCN and the professionals who serve them. WIND partners with UPLIFT (WY's Federation of Families and Family Voices of WY), WY families and health professionals, the WY Department of Health's Maternal and Child Health Section and Office of Multicultural Health, and University of Wyoming faculty members to develop and provide health care information. The F2F HIC is staffed by trained family leaders who have CSHCN and expertise in navigating federal, state and local public and private health care systems.

CSHCN in WY[1]

- ➢18,194 children (14.1%)
- ➢5,750 children have inadequate insurance
- ➢5,071 children have conditions that consistently affect their activities
- ➢5,711 do not receive family-centered care

HIGHLIGHT: Video Series

The WY F2F HIC has created videos for families to learn more information about specialized health topics for CSHCN. The information in these videos is research-based and features experts, including family leaders, community professionals, and U of WY faculty. All videos are accompanied with a downloadable fact sheet with more information. Topics include: breastfeeding, developmental milestones, nutrition, medication use, socialization, well-being, mental health, autism and the DSM V, and medical home initiatives in Wyoming. These videos are available on-demand so families can access the information whenever is most convenient for them, including through smart phones. These videos have reached over 435 viewers. In our 2013 survey, families rated these videos as 'very useful'. In 2014, WY F2F HIC is collaborating with WY Department of Family Services to provide these videos to foster parents to earn continuing education units and better serve children in foster care with SHCN.

FY2013 F2F OUTREACH:[2]

Total Families Served:
6,089
Total Professionals Served:
893
Materials Disseminated:
12,712
Trainings:
94

CONTACT:

Wyoming Institute for Disabilities (WIND)
1000 E. University Ave. Department 4298
Laramie, WY 82071-2000
Phone: (307) 766-2764
Toll-Free: (888) 989-9463
Fax: (307) 766-2763
Contact: Sara DiRienzo, sdirienz@uwyo.edu

IMPACT on a Family:

"Before our family found WY F2F HIC, we were beaten down and isolated. Our adopted seven year old son, Anthony, was a survivor. He had spent his first six years in an unsafe environment, was abducted at the age of five, and lived with a new family for a year that was unable to adopt him. Anthony was angry and aggressive. He felt abandoned.

We connected with the WY F2F HIC and quickly learned that they cared about us – both our son and his struggles, and the entire family. We learned from them the F2F HIC how to protect our son at school, how to stop adults from bullying him because he was different, how to talk with our relatives to help them understand our needs and to stop offering unsolicited (and often ignorant) advice.

We made mistakes, but WY F2F HIC was there when we needed to figure out a new approach for Anthony. They prepared us for the struggles we faced as a family, and gave us the tools we needed to search for options and make hard decisions for him and for ourselves. The greatest gift WY F2F HIC gave us was removing our sense of isolation. Attending a parent panel at the children's mental health conference changed my life. We realized that we aren't alone. Other parents were struggling through the same battles. Others felt as isolated as we did. Being with other families like us, I felt normal for the first time in years. If I could send a hug out daily to the WY F2F HIC staff, I would. We love WY F2F HIC like family."

---

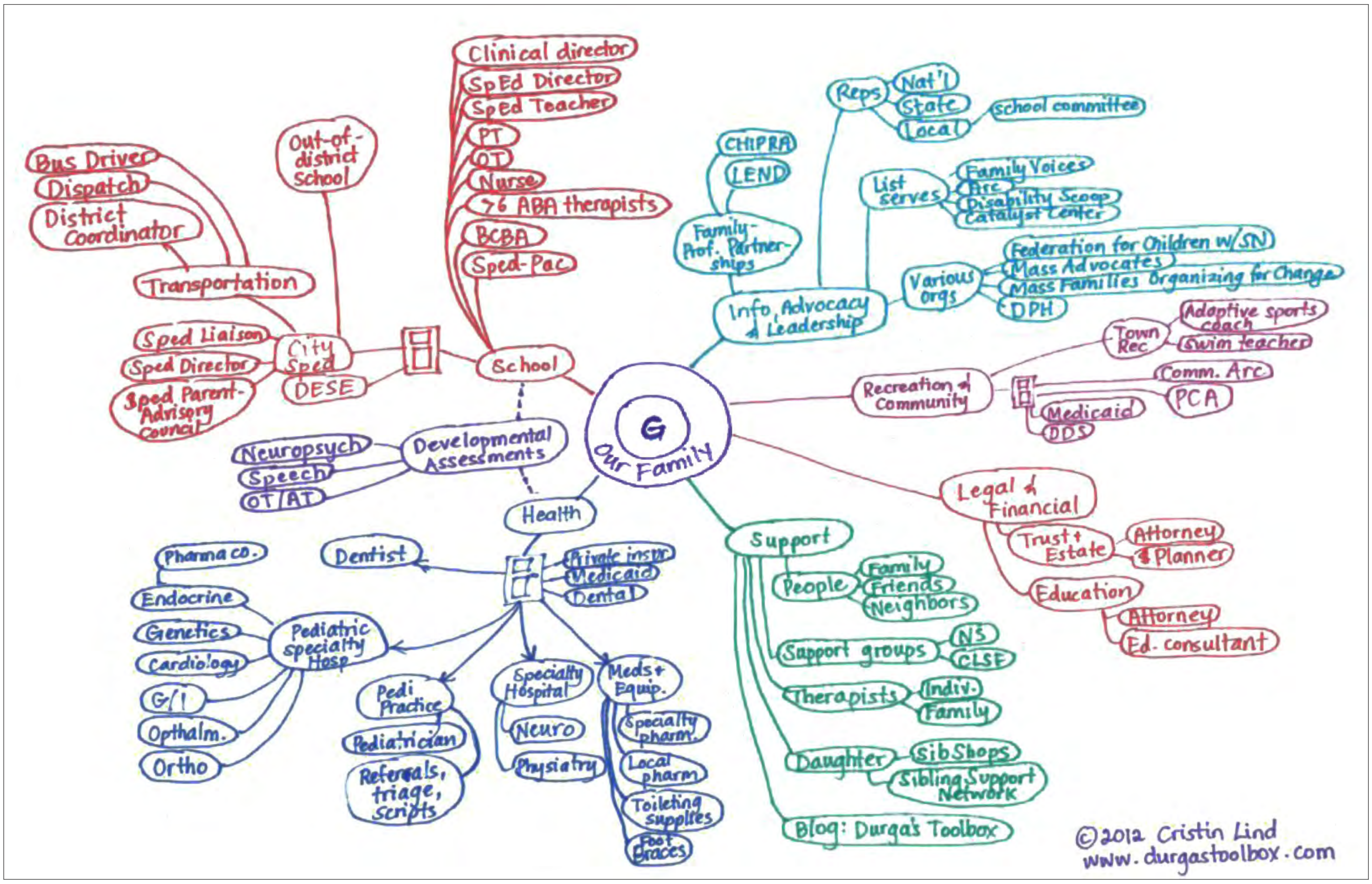
[1] National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 04/03/2014 from www.childhealthdata.org.
[2] FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.

THE FAMILY: AT THE HEART OF HEALTH CARE

The preceding pages document the outreach of the F2F in each state and the District of Columbia and highlight examples of:

- the ways in which F2Fs connect families of CYSHCN to communities resources;
- the broad range of information F2Fs give families through one to one assistance and training;
- and the mentorship and opportunities F2Fs offer to help families partner with providers, Title V, and other policy makers.

Perhaps there is no better illustration of the role of the family in caring for a CYSHCN than the diagram below, outlined by Cristin Lind, a parent of a child with special health care needs. The chart depicts the complexity of interactions with systems and people that a family such as the Linds face. F2Fs are a critical source of support and assistance to families like the Linds because F2Fs have staff with real family experiences in real communities. The help F2Fs provide is free and is offered in a culturally and linguistically competent manner.



(Used with permission of Cristin Lind, http://www.durgastoolbox.com)

F2F CHARTS: STATE BY STATE

The following pages summarize information provided by each F2F about their level of partnership with other entities; their involvement in specific initiatives; the methods they use to provide assistance, information, and training; and the sources of funding that contribute to the work of the F2F project.

F2F INVOLVEMENT with PARTNERS (AK-MO)

F2F HICs (AK-MO) rated their involvement with partners (0=None to 5=Significant):

Partner	AK	AL	AR	AZ	CA	CO	CT	DC	DE	FL	GA	HI	IA	ID	IL	IN	KS	KY	LA	MA	MD	ME	MI	MN	MO
360 Grantees	2	1	1	1	1	3	1	1		2	5	3		1	5	1	1	1	1		1	2	5	1	5
AAP (national)	1	1	2	1	1	2	1	1	2	5	2	2		2	2	4	2	1	1	4	1	1	1	3	1
Advocacy Groups (Health Care Coverage)	1	5	2	3	4	4	5	1	4	5	4	3	3	2	5	5	3	1	5		2	4	3	5	3
Child Advocacy Organizations	3	3	3	4	4	4	5	5	4	5	2	4		5	2	5	4	3	4		4	5	5		2
Child Care Agencies	2	2	2	3	3	2	2	5	2	4	2	4		2	2	3	3	2	5		2	4	1		4
Childrens Hospital/s or Pediatric Units in Hospitals	4	4	5	4	4	5	5	2	4	3	3	4	5	4	5	5	4	3	4	5	2	4	5	5	5
Community Disaster-Preparedness Groups	2	2	1	3	2	4	3	1	3	3	3	1	2	1	3	5	3	2	5		2	3	3	1	5
Community Health/Rural Health Centers	2	3	1	2	2	5	3	2	2	5	2	2		3	3	5	3	2	5		2	4	1	3	3
DD (Developmental Disability) Agency/Pgm	5	4	4	4	5	4	5	2	4	5	5	5	4	5	5	5	4	3	5	3	5	4	5	4	5
Department of Education / Schools	3	2	5	5	4	4	5	5	1	5	5	4	5	5	4	4	5	3	5	4	5	5	5	5	4
Disability Specific Organizations	3	5	4	3	4	5	5	3	4	4	3	4	4	5	5	5	3	3	5	4	5	3	5	5	5
Early Intervention	3	5	4	5	3	3	4	4	3	4	5	5	5	5	4	5	5	4	5	3	4	5	5	5	5
Emergency Medical Services	1	2	2	2	1	3	5	1	4	2	2	4		1	3	3	2	2	5		2	3	5	2	5
Ethnic/Cultural/Racial Specific Orgs	2	1	4	4	3	4	5	2	3	2	3	2	3	2	4	5	4	3	2	5	3	3	3	5	4
Faith-Based Orgs	2	3	2	3	2	2	5	4	2	2	2	3	3	2	2	5	2	3	2		1	2	3	2	3
Fathers Support Groups	1	1	1	1	2	2	3	5	1	5	2	2		1	2	5	2	1	2	4	1	3	3	2	3
Federation of Families / Mental Health Orgs	4	3	2	3	2	4	5	1	4	5	2	4	2	5	4	5	1	3	4	5	3	4	3	3	5
Foster Care Agencies	4	2	2	3	2	2	1	1	2	3	3	4	5	3	2	3	3	2	4		3	4	1	3	2
Head Start / Early Childhood Programs	3	2	3	3	5	3	2	3	2	5	5	4	4	5	5	5	5	3	5		4	4	5	5	5
Health Care Quality Organizations/ Programs	1	1	3	1	2	5	4	2	1	5	2	4		2	3	3	2	2	1	5	1	4	1	2	2
HMOs or other private insurance companies	1	2	1	1	2	2	1	1	3	5	1	5		1	5	2	2	1	1		3	2	2	4	2
HUD/Housing	2	1	1	1	2	2	1	1	1	3	1	2	4	2	2	1	1	2	1		1	2	3	2	3
Independent Living Centers	2	3	2	3	2	2	3	2	2	5	3	2	2	5	4	3	5	2	2	3	2	2	5	3	4
Indian Health Services	5	1	1	2	2	1	1	1	1	2	1			2	1	1	5	1	1		1	4	1	3	1
Integrated Systems Grantees	2	3	1	1	2	5	5	1	5	4	2	3	3	1	5	1	5	5	1		5	4	5	1	5
Juvenile Justice Programs	2	1	1	1	1	1	1	2	2	2	4	3		2	1	3	3	2	3		3	3	3	4	2
Lend Program or Univ Ctr on Disability Pgm	3	3	4	3	2	5	5	2	4	5	5	5	5	5	5	5	3	1	2	5	3	2	2	4	5
March of Dimes	1	3	1	1	2	1	1	1	1	2	3	4		1	2	5	1	2	1	4	1	2	2	1	2
Medicaid Agency	2	3	2	3	2	5	5	2	5	5	3	5	5	5	4	3	5	4	5	4	2	5	5	5	2
Mental Health Agency	2	2	3	4	3	4	5	3	3	5	3	4	2	3	4	3	5	3	5	4	4	5	5	4	5
Mental Health partners	3	2	3	3	2	4	3	3	4	5	2	3	3	5	5	5	3	3	5	4	4	3	3	5	4
NICHQ Learning Collaboratives	3	3	1	1	1	4	5	1	1	4	3	2		5	5	1	1	1	1	5	1	3	1	1	2
Nursing Associations	1	1	1	2	1	2	4	1	1	4	1	4	1	1	3	3	1	2	2		1	2	1	4	3
Oral Health partners	2	2	3	2	2	3	1	2	4	3	1	3		2	5	3	5	3	2		3	3	3	4	4
Other parent led organizations	5	5	3	3	4	4	5	5	5	5	3	5	5	5	5	5	5	3	5	5	5	5	5	5	5
P2P (Parent-to-Parent programs)	1	5	2	5	5	5	5	4	5	5	5	4	4	1	1	5	5	5	5	5	5	5	5	2	5
Protection and Advocacy Agencies	5	3	5	3	4	3	5	4	3	5	3	5	4	5	3	5	5	4	5	3	5	3	5	4	5
PTI (Parent Training and Information programs)	5	4	5	5	4	3	5	5	3	2	5	4	5	5	4	3	5	5	5	5	5	5	5	5	5
Regional Genetics Collaboratives	3	4	1	3	2	5	5	1	2	2	2	5		4	3	5	2	5	1	5	1	3	3	3	5
Regional MCH Leadership	4	4	2	4	2	4	5	2	5	5	5	3		2	2	4	4	1	2	5	2	5	5	2	2
SCHIP Program	1	3	2	2	2	5	4	1	3	5	3	5		5	2	2	4	3	3		4	4	5	4	3
State Chapter of AAP	2	3	5	4	2	3	2	1	5	4	3	5		3	5	5	2	2	1	3	5	3	3	2	2
State Title V Programs	4	5	5	5	3	4	5	2	5	5	5	5	3	5	5	5	5	5	5	5	5	5	5	5	5
Universities	2	5	5	4	4	3	5	1	4	5	2	5	5	5	4	5	3	3	5	3	4	3	2	5	5
Vocational Rehabilitation Agencies	2	5	2	2	2	2	3	3	2	5	4	3	3	5	3	3	4	4	5		5	5	5	2	3
Youth Advisory Groups/organizations	2	4	2	1	3	2	5	4	1	5	2	2		3	2	5	4	3	1		3	4	5	3	5

F2F INVOLVEMENT with PARTNERS (MS-WY)

F2F HICs (MS-WY) rated their involvement with partners (0=None to 5=Significant):

Partner	MS	MT	NC	ND	NE	NH	NJ	NM	NV	NY	OH	OK	OR	PA	RI	SC	SD	TN	TX	UT	VA	VT	WA	WI	WV	WY
360 Grantees	5	1	2	4	4	1	5	1	2	1	1	4	1	1	1	2	5	1	2		5	5		1	2	1
AAP (national)	2	1	2	3	2	1	4	1	2	3	1	1	1	3	4	2	1	3	2	3	1	3		1	1	1
Advocacy Groups (Health Care Coverage)	1	3	3	4	4	5	5	3	4	2	5	2	5	5	5	4	5	5	5	5	2	5	4	5	4	2
Child Advocacy Organizations	5	5	4	5	5	4	5	5	4	3	5	2	3	5	5	3	5	5	5	5	2	5	5	3	5	1
Child Care Agencies	1	2	2	4	4	4	5	3	2	1	2	2	2	1	4	2	5	2	2	3	3	3	2	1	2	2
Childrens Hospital/s or Pediatric Units in Hospitals	2	3	4	4	5	1	5	3	4	5	5	3	5	5	5	5	5	5	5	5	4	5	4	4	4	4
Community Disaster-Preparedness Groups	3	1	3	5	4	1	5	1	3	2	2	1	2	1	4	2	2	5	3	1	1	4	2	1	3	2
Community Health/Rural Health Centers	2	2	2	3	4	1	5	2	4	2	3	1	5	2	4	3	4	3	3	3	1	4	2	3	3	2
DD (Developmental Disability) Agency/Pgm	5	5	3	5	5	3	5	5	4	5	5	4	5	4	5	5	5	5	5	4	5	5	4	5	5	2
Department of Education / Schools	3	5	3	5	5	3	5	5	4	3	5	2	3	5	5	5	5	5	3	4	5	5	4	4	5	5
Disability Specific Organizations	2	5	3	4	5	1	5	5	4	5	5	4	5	5	4	5	5	5	4	4	5	5	3	4	5	1
Early Intervention	5	5	3	5	5	5	5	5	5	4	5	3	4	3	5	5	5	5	5	5	5	5	4	3	4	3
Emergency Medical Services	1	1	1	5	2	2	4	1	1	2	1	1	2	1	4	1	1	5	5	3	1	2	5	2	5	1
Ethnic/Cultural/Racial Specific Orgs	1	1	4	3	3	1	5	4	4	3	3	2	3	3	4	3	3	5	2	3	5	4	3	4	3	3
Faith-Based Orgs	1	1	2	3	3	1	5	2	1	1	3	2	1	3	2	5	3	4	2	3	3	3	3	2	2	1
Fathers Support Groups	2	1	2	3	5	1	5	3	1	5	1	2	1	1	4	5	3	2	2	1	2	4	3	2	1	2
Federation of Families / Mental Health Orgs	1	5	3	5	5	3	5	1	4	4	3		4	2	4	5	3	4	2	4	5	5	2	4	1	5
Foster Care Agencies	3	3	4	3	5	4	5	1	3	2	2	1	3	1	4	1	5	2	2	3	3	3	2	2	4	3
Head Start / Early Childhood Programs	5	3	5	4	5	4	5	5	4	1	5	3	4	2	4	2	5	3	2	4	3	5	3	2	4	3
Health Care Quality Organizations/ Programs	5	2	1	3	3	3	5	2	3	1	5	1	5	4	5	3	1	5	2	5	1	5	4	3	3	1
HMOs or other private insurance companies	1	2	1	4	4	2	5	5	2	2	5	1	3	1	3	4	2	3	5	3	2	3		3	3	1
HUD/Housing	5	1	1	3	3	1	4	1	2	3	5	1	1	1	4	2	3	3	2	2	1	4	2	1	3	2
Independent Living Centers	5	3	3	4	4	4	5	1	4	2	2	1	1	4	3	2	5	5	2	4	5	5	4	3	5	1
Indian Health Services	1	2	2	3	4	1	3	2	3	1	1	2	4	1	2	1	4	1	1	3	1	3	3	3	1	2
Integrated Systems Grantees	5	5	2	3	3	1	5	1	5	2	5	2	1	4	4	5	5	2	5	5	2	5	4	1	1	1
Juvenile Justice Programs	1	5	2	3	4	1	5	1	1	2	2	2	1	1	3	1	3	2	1	1	1	4	3	1	1	4
Lend Program or Univ Ctr on Disability Pgm	5	5	3	4	5	5	5	3	5	4	5	5	5	3	3	5	5	5	4	5	5	5	5	5	5	5
March of Dimes	1	5	1	4	4	1	5	1	4	3	2	1	2	1	4	4	3	2	4	3	1	3	2	1	3	1
Medicaid Agency	2	5	4	5	5	4	5	2	3	4	5	5	5	5	5	5	2	5	4	5	3	5	4	3	4	4
Mental Health Agency	2	5	3	3	5	3	5	2	3	3	3	5	4	2	4	4	5	4	3	4	5	5	3	3	3	5
Mental Health partners	1	5	3	4	5	2	5	1	2	3	3	3	5	2	4	2	5	4	3	3	2	5	4	3	3	5
NICHQ Learning Collaboratives	1	2	1	4	5	1	5	1	1	1	5	1	5	4	4	1	1	3	2	5	1	4	4	1	1	1
Nursing Associations	1	1	3	3	5	1	4	3	2	3	3	3	1	2	4	1	2	4	3	4	1	3		3	3	2
Oral Health partners	1	1	5	3	5	1	5	2	3	3	3	1	2	1	4	4	3	3	2	3	1	5		3	5	4
Other parent led organizations	3	5	4	5	5	5	5	5	5	4	5	4	5	4	5	5	5	5	4	5	5	5	5	5	5	3
P2P (Parent-to-Parent programs)	1	5	4	5	5	4	5	5	5	5	5	5	5	4	5	5	3	5	5	4	5	5	5	5		1
Protection and Advocacy Agencies	2	5	4	5	5	4	5	5	4	3	2	2	2	5	5	3	5	5	3	5	5	5	2	5	4	2
PTI (Parent Training and Information programs)	5	5	5	5	5	5	5	5	4	5	5	3	5	5	5	5	5	5	4	5	5	5	5	3	5	2
Regional Genetics Collaboratives	2	5	2	5	4	5	5	1	3	3	5	4	5	1	2	4	4	5	4	5	1	5	5	3	2	1
Regional MCH Leadership	1	2	2	5	5	1	5	5	5	3	3	3	5	4	5	5	4	5	5	4	1	5	5	1	3	5
SCHIP Program	1	3	3	5	5	4	5	3	4	2	5	2	5	1	5	5	2	3	2	4	2	5	4	3	5	2
State Chapter of AAP	5	2	2	4	2	3	5	1	2	2	2	1	3	5	5	4	1	5	3	5	1	4	4	3	2	1
State Title V Programs	5	5	2	5	5	5	5	3	5	4	5	4	5	4	5	5	5	5	5	5	5	5	4	5	5	1
Universities	5	4	5	5	5	5	5	5	4	3	3	3	2	2	4	5	5	5	3	5	5	5	5	5	5	5
Vocational Rehabilitation Agencies	3	5	3	5	5	1	5	2	2	2	2	3	1	3	4	2	5	4	2	4	5	4	4	3	5	2
Youth Advisory Groups/organizations	5	5	3	5	5	5	5	2	2	2	5	3	3	5	4	1	2	5	2	3	5	3	3	2	5	1

F2F INVOLVEMENT IN SPECIFIC INITIATIVES (AK-MO)

F2F HICs (AK-MO) reported their involvement (developing curriculum/materials, making presentations, serving on committees, etc.) in the following specific areas:

Initiative	AK	AL	AR	AZ	CA	CO	CT	DC	DE	FL	GA	HI	IA	ID	IL	IN	KS	KY	LA	MA	MD	ME	MI	MN	MO
ACA Implementation	●	●	●		●	●	●	●	●	●	●	●	●		●	●	●	●	●	●	●			●	
Assistive Technology					●	●		●	●				●	●	●	●	●		●	●				●	
Asthma								●	●										●					●	
Autism	●	●		●	●	●	●	●	●		●	●	●		●	●	●		●		●			●	●
Child Welfare/Child Protection/Child Abuse & Neglect, Prevention or Intervention					●	●				●		●		●	●	●	●		●						
Chronic Care Management		●			●				●					●	●	●							●	●	
Cultural & Linquistic Competence		●	●		●	●	●	●	●	●		●	●			●	●	●	●		●			●	●
Disaster planning/Emergency Response		●		●		●	●		●				●		●	●	●		●		●				
Domestic Violence																									
Early Hearing Detection and Treatment	●				●										●			●	●		●			●	
Epilepsy							●	●	●	●			●		●				●		●			●	
EPSDT				●		●			●	●	●	●		●	●	●	●	●	●	●				●	
Family-centered Care		●	●	●	●	●	●		●	●		●		●	●	●	●	●	●	●	●	●	●	●	●
Federally Qualified Health Centers or Other Community Health Centers/Clinics		●			●	●		●	●		●				●	●			●	●				●	
Foster care					●				●	●			●	●		●	●		●			●			
Health & Wellness Promotion/Prevention					●			●	●				●	●	●	●	●		●	●				●	
Health Information Technology						●	●					●	●				●		●	●					
Immigrant Families/Families of Diverse Cultures					●	●		●		●	●			●	●	●	●	●	●		●			●	
Improving Pregnancy/Birth Outcomes												●							●						
Limited English Proficient Families				●	●	●		●		●	●		●			●			●		●			●	
Medicaid		●			●	●		●	●		●	●	●	●	●	●		●	●	●				●	
Medicaid Buy-in						●			●			●	●						●	●	●			●	
Medicaid Managed care		●			●	●			●			●			●	●	●	●	●	●		●		●	
Medicaid Waivers	●				●	●			●		●	●	●		●	●		●	●					●	●
Medical Home		●		●	●	●	●	●	●	●	●	●			●	●	●	●	●	●	●		●	●	
Mental/Behavioral Health	●			●	●	●		●	●			●		●	●	●	●	●	●	●	●	●		●	
Military Families/Tricare						●		●	●			●				●	●				●				
Obesity Prevention/Intervention									●					●				●						●	
Other Disease-specific						●		●	●		●		●	●					●		●				
Other Healthcare Financing					●				●							●			●	●					
Palliative Care																●									
Parents with Disabilities					●		●	●		●			●		●		●		●	●					
Private Insurance/HMOs					●	●			●			●			●	●			●		●			●	
Provider Training	●	●		●	●		●	●		●		●	●	●	●	●	●		●		●			●	
Quality Improvement Initiatives		●				●	●		●	●		●		●	●		●				●				●
Reducing Hospital Readmissions/Improving Hospital Care				●		●					●								●						
Respite			●	●		●	●	●	●				●	●	●	●			●					●	
SCHIP							●	●	●	●					●	●	●		●						
State Consortium around MCH Issues		●				●			●			●			●	●			●		●			●	
Title V Block Grant		●		●	●	●	●	●	●	●	●	●		●	●	●	●	●	●	●	●				●
Title V Needs Assessment		●	●		●		●	●	●		●	●		●	●	●		●	●		●			●	●
Transition/Youth Leadership		●			●	●	●	●	●	●	●	●		●	●	●	●	●	●		●	●		●	●
Tribal Nations																			●						

F2F INVOLVEMENT IN SPECIFIC INITIATIVES (MS-WY)

F2F HICs (MS-WY) reported their involvement (developing curriculum/materials, making presentations, serving on committees, etc.) in the following specific areas:

Initiative	MS	MT	NC	ND	NE	NH	NJ	NM	NV	NY	OH	OK	OR	PA	RI	SC	SD	TN	TX	UT	VA	VT	WA	WI	WV	WY
ACA Implementation	●	●	●	●	●	●	●	●		●			●	●	●	●	●	●	●	●	●	●	●	●	●	
Assistive Technology	●	●	●				●	●				●				●				●	●	●			●	
Asthma								●			●			●		●				●			●		●	
Autism		●		●	●	●	●	●	●	●	●	●	●	●		●	●	●	●	●	●	●	●		●	●
Child Welfare/Child Protection/Child Abuse & Neglect, Prevention or Intervention	●		●		●		●	●				●			●	●	●								●	
Chronic Care Management	●						●	●		●		●			●											
Cultural & Linquistic Competence	●	●	●	●			●	●	●				●	●	●	●					●	●	●	●	●	
Disaster planning/Emergency Response				●	●	●	●		●										●	●	●		●		●	
Domestic Violence																	●									
Early Hearing Detection and Treatment				●	●		●	●		●		●			●	●	●	●	●	●	●				●	
Epilepsy					●	●	●	●	●	●						●				●						
EPSDT				●	●		●	●	●			●		●	●	●	●			●	●	●	●	●	●	
Family-centered Care	●	●	●	●	●	●	●	●	●	●	●	●	●	●		●	●	●	●	●	●	●	●	●	●	●
Federally Qualified Health Centers or Other Community Health Centers/Clinics			●		●	●	●	●	●							●	●		●		●					
Foster care					●		●	●		●						●	●			●	●				●	
Health & Wellness Promotion/Prevention			●	●		●	●	●	●			●	●		●	●	●			●	●		●	●	●	●
Health Information Technology							●	●								●									●	
Immigrant Families/Families of Diverse Cultures	●		●		●		●	●				●	●		●	●	●		●		●	●	●	●		
Improving Pregnancy/Birth Outcomes			●				●	●				●				●			●							●
Limited English Proficient Families			●				●	●	●	●		●	●			●	●		●		●		●			
Medicaid	●		●	●		●	●	●	●	●	●	●	●	●	●	●	●		●	●	●	●	●	●	●	
Medicaid Buy-in				●			●	●		●									●	●	●				●	
Medicaid Managed care	●	●				●	●	●		●	●	●	●	●	●	●			●	●			●	●	●	
Medicaid Waivers	●	●	●	●		●	●	●		●	●	●		●		●	●	●	●	●	●	●		●	●	
Medical Home	●	●		●	●	●	●	●		●	●	●	●	●	●	●		●	●	●	●	●	●	●	●	●
Mental/Behavioral Health		●	●		●	●	●	●			●	●	●	●		●	●		●	●	●	●	●		●	●
Military Families/Tricare		●	●	●	●		●	●		●		●				●				●	●		●			
Obesity Prevention/Intervention			●			●	●						●													●
Other Disease-specific									●		●					●				●			●			
Other Healthcare Financing				●	●		●	●									●			●		●				
Palliative Care	●		●												●	●			●	●						
Parents with Disabilities	●				●		●	●							●		●				●		●		●	
Private Insurance/HMOs	●			●	●		●	●					●	●		●	●		●					●	●	
Provider Training			●	●		●	●	●	●	●		●	●	●		●	●		●	●	●			●	●	
Quality Improvement Initiatives	●			●		●	●	●		●		●	●			●				●					●	
Reducing Hospital Readmissions/Improving Hospital Care							●	●							●	●										
Respite	●			●	●	●	●	●	●	●	●					●	●		●	●	●	●	●	●		
SCHIP				●			●	●		●	●	●				●	●			●				●	●	
State Consortium around MCH Issues			●	●			●	●	●			●			●	●	●		●				●	●	●	
Title V Block Grant	●		●	●		●	●		●		●	●	●		●	●	●	●	●	●	●	●		●	●	
Title V Needs Assessment	●		●	●		●	●		●	●	●	●	●		●	●		●	●	●	●			●	●	
Transition/Youth Leadership	●		●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
Tribal Nations				●				●		●		●					●						●			

F2F FUNDING SOURCES

F2F HICs reported the sources of funding that contribute to the work of the F2F:

	AAP	Conversion Foundation, or other Health Care Financing organization	Developmental Disabilities	DoH/HHS	Early Intervention/Head Start/Early Childhood	Fee-for-Service	Grants related to adults with disabilities	LEND, UCEDD, DDRC	MCH Block Grant	Medicaid Provider	Other Foundations	Other State DOE Funding	Parent-to-Parent (P2P)	PTI	SAMSHA/other mental health grants	SPDG from State DOE	State Implementation Grant for Autism & other DD	State Implementation Grant for Innovative Evidence-based Programs	State Implementation Grant for Integrated Community Systems for CYSHCN(D70)	United Way
AK				●	●	●						●		●						
AL																			●	
AR				●	●									●		●				
AZ			●	●	●	●						●	●	●						
CA			●		●				●		●	●		●						
CO		●		●		●			●		●									
CT				●					●				●				●			
DC				●					●			●		●						
DE	●		●	●			●		●				●		●				●	
FL						●					●	●		●		●				
GA			●	●	●		●	●	●		●	●	●	●		●			●	●
HI	●			●				●	●	●										
IA				●		●		●				●		●	●					
ID	●		●		●			●		●		●		●	●	●	●			
IL																				
IN								●	●											
KS			●	●	●								●	●		●				
KY																			●	
LA			●	●	●							●	●							
MA				●																
MD									●					●		●	●			
ME				●					●				●	●	●	●				
MI																				
MN											●	●		●		●		●		
MO			●		●			●					●					●		
MS				●	●			●	●											
MT			●		●	●					●	●		●					●	
NC					●				●		●	●		●		●				
ND									●		●	●	●							●
NE			●	●	●			●	●	●			●	●			●			
NH				●	●			●	●			●	●	●	●	●	●		●	
NJ		●	●	●	●	●		●	●	●	●	●	●	●	●		●	●	●	
NM		●	●	●	●				●	●		●	●	●						●
NV		●	●	●			●		●		●		●							
NY			●																	
OH																			●	
OK			●	●						●	●		●		●					
OR								●	●		●						●	●		
PA			●								●			●		●		●		●
RI	●		●	●	●			●	●		●		●	●				●	●	
SC	●		●	●	●			●	●	●	●	●	●		●		●		●	●
SD			●	●					●			●		●					●	
TN				●				●					●	●					●	
TX				●	●			●	●				●				●	●	●	
UT			●	●	●			●	●					●	●		●			
VA				●				●	●			●				●	●			
VT			●	●					●				●	●						
WA									●						●					
WI			●	●					●											
WV				●				●						●						
WY			●		●		●	●								●			●	

F2F FUNDING SOURCES - Additional Information

The F2F HICs below reported additional sources of funding that contribute to the work of the F2F:

State	**Additional Funding Source**	**Additional Funding Source**
AZ	First Things First (Arizona tobacco tax) birth-5 grant for Parent Training for homeless families	Dignity Health for Smooth Way Home NICU project
CA	City Funding	
CO	Hospital Family Navigators	Colorado Health Care Exchange
GA	ACA Navigator Grant	
HI	Private Insurance	
IL	Support from The Arc of Illinois	
KY	Kentucky Infant Sound Start	
MD	Improving Access to Services for Children and Youth with Epilepsy and other Seizure Disorders	Early Hearing Detection and Intervention
NC	Combined Campaign, Federal	
NM	OSEP Federal Funding	DOH Funding/FIT Program
NV	Community Fundraisers	Web-Based Fundraisers
NY	Sub-contract with our state's PTIC program	
OR	Learn the Signs Act Early Grants	MCHB Action Learning Collaborative
PA	Developmental Disability Council grant on Children in Congregate Care	Developmental Disability Council grant on Inclusive practices in non-traditional schools (charter, cyber charter, private, parochial, home-schoolers)

F2F METHODS of ASSISTANCE/TRAINING

F2F HICs reported the methods they use to provide assistance and training:

	Blogs	Care Notebook	Conference Calls	Conferences	Direct Assistance In Person	Direct Assistance Telephone or Email	Distance Learning	Facebook	Family Surveys	Focus Groups	In-person training	Library/Lending Program	Listservs	Newsletters	Online Courses/Training	Parent Matching	Pinterest	Public Service Announcements	Materials: Resource Guides, Tip Sheets, etc,	Resource Tables at Community Events	Support Groups	Topical Calls	Twitter	Videos/Youtube Channel	Webinars	Website
AK	●	●	●	●	●	●		●			●	●	●	●					●	●						●
AL		●	●	●	●	●		●			●			●					●	●						●
AR			●	●	●	●		●	●	●	●		●	●		●			●							●
AZ		●	●	●	●	●		●	●	●	●		●	●		●	●		●	●			●			●
CA	●		●	●	●	●	●	●	●	●	●	●	●	●	●	●		●	●	●	●				●	●
CO		●	●	●	●	●		●	●	●	●		●	●	●				●	●	●	●			●	●
CT		●	●	●	●	●		●	●	●	●	●	●	●	●	●	●	●	●	●	●		●	●		●
DC	●		●		●	●		●	●		●	●	●	●	●	●			●	●	●		●		●	●
DE	●	●	●	●	●	●		●	●	●	●	●		●		●	●		●	●	●	●	●	●		●
FL	●		●	●	●		●	●	●	●	●	●		●	●	●		●	●	●	●	●	●	●	●	●
GA			●		●	●		●	●	●	●		●	●	●	●	●		●	●	●		●	●	●	●
HI				●		●		●		●	●		●			●			●		●				●	●
IA	●		●	●	●	●	●	●	●	●	●	●	●			●			●		●				●	●
ID		●	●	●	●	●	●	●	●	●	●	●	●	●	●	●			●	●	●			●	●	●
IL			●	●		●		●	●	●	●		●	●					●	●			●		●	●
IN	●		●	●	●	●	●	●	●	●	●		●	●	●		●		●	●	●		●	●	●	●
KS		●	●	●	●	●	●	●	●	●	●	●		●		●		●	●	●	●			●	●	●
KY		●	●		●	●		●		●			●			●	●		●	●	●					●
LA			●	●	●	●		●	●	●	●	●		●	●	●			●	●	●		●		●	●
MA			●	●	●	●		●		●	●		●	●					●	●			●		●	●
MD		●	●	●	●	●		●	●	●	●		●	●		●	●		●	●	●	●	●		●	●
ME			●	●	●	●		●			●	●	●	●	●	●			●	●	●					●
MI						●					●			●						●						●
MN			●	●	●	●	●	●	●	●	●	●	●	●		●			●	●			●	●	●	●
MO			●	●	●	●		●		●	●		●	●	●	●			●	●					●	●
MS			●	●	●						●	●	●												●	●
MT			●	●	●	●	●	●			●	●	●	●	●	●			●	●	●	●	●	●	●	●
NC		●	●	●	●	●		●	●	●	●	●	●	●			●		●	●		●			●	●
ND	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●		●	●	●	●	●		●		●
NE			●	●	●		●	●		●	●		●		●				●	●		●	●		●	●
NH			●	●		●		●	●	●	●	●		●	●	●	●		●	●			●	●		●
NJ	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
NM	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●		●	●	●	●		●	●	●	●
NV		●	●	●	●	●		●	●	●	●		●	●		●			●	●		●	●			●
NY		●			●	●	●	●			●		●	●	●	●			●	●			●		●	●
OH		●	●	●	●	●		●			●	●	●	●	●	●			●	●	●		●			●
OK		●	●	●	●	●		●	●	●	●			●		●			●	●	●				●	●
OR		●	●		●	●		●		●	●		●	●					●	●					●	●
PA			●	●		●	●	●	●		●	●	●	●	●				●	●				●	●	●
RI		●	●	●	●	●		●	●		●		●	●		●		●	●	●	●	●	●		●	●
SC	●	●	●	●	●	●		●	●	●	●	●	●	●		●		●	●	●	●	●			●	●
SD		●	●	●	●	●	●		●	●	●		●	●	●	●		●	●	●	●			●	●	●
TN		●		●	●	●					●		●			●										●
TX		●	●	●	●	●		●	●	●	●	●	●	●		●			●	●		●	●			●
UT	●	●	●	●	●	●	●	●	●	●	●		●	●		●			●	●	●			●	●	●
VA		●	●	●	●	●	●	●	●	●	●		●		●	●			●	●				●	●	●
VT		●		●	●	●		●	●			●	●	●		●				●	●		●	●	●	●
WA		●		●	●	●		●	●	●				●					●	●	●		●			●
WI			●	●		●	●	●	●	●	●		●	●					●	●		●			●	●
WV		●	●	●	●	●		●	●	●	●		●	●		●		●			●					●
WY		●	●	●	●	●	●	●	●		●	●	●	●					●	●	●		●	●	●	●