



TESTIMONY
on
Investing in America's Health Care
before the
Health Subcommittee
House Committee on Energy & Commerce
June 4, 2019

Good morning Mr. Chairman, Mr. Ranking Member, and Members of the Subcommittee. My name is Diana Autin and I am the Executive Co-Director of the SPAN Parent Advocacy Network (SPAN), home of New Jersey's Family-to-Family Health Information Center (F2F), one of 59 such parent-led organizations across the country, territories and tribes. I am here today representing SPAN and Family Voices, the national, family-led organization that has provided guidance for the development of the F2Fs since 1999, and technical assistance since the first federal funding for F2Fs in 2007.

Each F2F receives an annual grant amount of \$96,750 from the Maternal and Child Health Bureau to assist families of children and youth with special health care needs (CYSHCN) in their state, territory or tribal community. Family Voices, under a cooperative agreement with the federal Maternal and Child Health Bureau, receives funding of \$600,000 per year to provide technical assistance and support to the F2Fs and to promote partnerships between health professionals and families of CYSHCN so that these children receive "family-centered," appropriate, and cost-effective care. SPAN has collaborated in this national technical assistance project as a sub-contractor of Family Voices for the past three years and I serve as one of three Co-Directors of this project.

Family Voices and SPAN strongly support the bill introduced by Representatives Sherrill and Upton -- the *Family-to-Family Reauthorization Act of 2019* (H.R. 2822) -- which will extend funding for Family-to-Family Health Information Centers for five more years, through 2024.

Family-to-Family Health Information Centers (F2Fs)

As explained in more detail below, F2Fs help families whose children have special health care needs to navigate the health care system, effectively advocate for their children, and work as partners with health care providers. They reach out to underserved communities and provide their services in a culturally and linguistically appropriate manner. F2Fs also assist providers, state and federal agencies, legislators, and other stakeholders to better understand and serve CYSHCN and their families. Ultimately, these efforts result in higher quality, more cost-effective care, and better health outcomes. All F2F services to families and professionals are provided without charge.

There has been one F2F in each state and the District of Columbia since 2009, when the program was fully phased in. Thanks to a 2018 amendment to the program, there are now additional F2Fs in American Samoa, Guam, Puerto Rico, the Northern Mariana Islands, and the U.S. Virgin Islands, plus three F2Fs dedicated to serving American Indian and Alaska Native families. These new F2Fs are serving particularly vulnerable and underserved communities.

The Maternal and Child Health Bureau (MCHB) has long recognized the importance of partnering with families to create effective health care services and systems and, since 1999, has funded Family Voices to provide technical assistance and training to families of children with special health care needs to become effective partners at all levels of health care. The focus of this national family network has evolved as the strength of family leadership has grown and

federal funding for F2Fs in the states has been put in place. For the past nine years, Family Voices has provided technical assistance and training to the F2Fs through a project called the National Center for Family Professional Partnerships (NCFPP); as of June 1 of this year, this national project supporting the F2Fs is called “Leadership in Family Professional Partnerships.”

As its name indicates, the F2F program is based on the idea that families who have experience navigating the health care system for their own children are the best guides for other such families. By statute, F2Fs are staffed by family members of children and youth with special health care needs. Beyond their training, they bring expertise and empathy learned through their personal experiences to their F2F work.

Federal taxpayers get great value from the F2F program, the total cost of which is only \$6 million annually. Extremely dedicated, F2F staff work tirelessly, often traveling long distances and working long hours. Despite their modest budgets, F2Fs provided information, training and/or assistance to nearly one million families in 2018.

Background on children and youth with special health care needs

Children and youth with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.¹ They may have physical, developmental, or intellectual disabilities (e.g., cerebral palsy or autism), chronic health conditions (e.g., diabetes or epilepsy), serious illnesses (e.g., cancer), rare genetic diseases (e.g., mitochondrial disorders), severe injuries (e.g., traumatic brain injury), mental health conditions (e.g., serious depression or schizophrenia), or other conditions requiring frequent health care services.

Throughout the U.S., there are about 14 million CYSHCN, constituting 19 percent of all children under age 18. More than one in five families with children has at least one child with special health care needs.

Challenges faced by families of CYSHCN

The health conditions of CYSHCN can be chronic and complex, and finding the pediatric specialists to provide appropriate care can be a struggle. Moreover, necessary care is often extremely expensive; even people with insurance struggle to afford copayments and to pay for therapies and equipment that are not covered. The web of available services – covered through private insurance, Medicaid, CHIP, the school system, state Title V maternal and child health programs, or other agencies and organizations – is difficult to navigate and involves multiple eligibility criteria and coverage standards. As a result, children may miss valuable services because their families are unaware of them, their eligibility criteria, and financing options to pay for them, or are unable to access or afford them.

¹ This is the definition used by the Health Resources and Services Administration. From: McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck P, Perrin J, Shonkoff J, Strickland B. A new definition of children with special health care needs. *Pediatrics*, 102(1):137–140, 1998.

Health care systems do not always work well for CYSHCN, particularly children with complex needs, and for those whose families are not proficient in English or come from diverse cultural backgrounds. Rural families also have particular difficulties accessing care for their children. Many children with special health care needs are eligible for Medicaid because of their conditions or family income, but may face complications in establishing eligibility or procuring services. Some challenges faced by families of CYSHCN include:

- a scarcity of subspecialty providers, especially in rural areas, or those who take Medicaid, resulting in the need to travel long distances and/or wait long times for an appointment;
- problems with insurance plans, including Medicaid managed care plans,² such as inadequate provider networks; failure to cover or slow approval of out-of-network or out-of-state care; lack of continuity of care due to changing provider networks; and lack of plan experience in adequately serving this population;
- inadequate coverage of medications, medical equipment, medical supplies, hearing aids, medical foods, and other necessities;
- inadequate coverage of nursing services, therapeutic services (e.g., occupational, physical and speech therapies), and non-medical services (e.g., transportation, respite, home or vehicle modifications, family lodging for out-of-area care);
- insufficient access to home and community-based care, including a shortage of home nurses, sometimes forcing children into nursing homes rather than allowing them to be cared for at home, or preventing them from attending school (if they need a nurse to accompany them);
- failure to integrate mental health and medical services and lack of provider expertise in treating children with co-occurring diagnoses;
- lack of or ineffective care coordination among the child's providers;
- long waiting lists for and incomplete information about Medicaid waivers;
- for families not proficient in English, a lack of interpreters during medical appointments, and a lack of informational materials and communications from insurance companies and Medicaid agencies in the family's language;
- lack of understanding about different cultures' views of health care on the part of health care providers, insurance companies and Medicaid agencies; and
- inadequate preparation for transition to adult-care services.

F2Fs help families

F2Fs help families in a variety of ways to access care, advocate for their children, partner with providers, and find ways to afford the care their children need. F2Fs provide one-to-one assistance, which might entail helping the family appeal a denial by their private insurance company, Medicaid or CHIP for services, equipment or supplies; helping the family gain

² From the National Academy for State Health Policy: "The first wave of Medicaid managed care in the 1990s saw many states carving out services for children and adults with special needs through fee-for-service arrangements. However, these trends have changed dramatically since that time. Recent CMS data and a 2010 [Kaiser Family Foundation survey](#) indicate that 32 states mandatorily enroll at least some children and youth with special health care needs (CYSHCN) in managed care, 20 states enroll CYSHCN in managed care on a voluntary basis, and about half of states mandate managed care for at least some children who receive Supplemental Security Income (SSI)." (Source: <http://www.nashp.org/early-highlights-of-what-the-final-managed-care-rule-for-medicaid/>)

Medicaid eligibility under a state home and community-based services waiver or other eligibility pathway; helping the family get early intervention services, find an appropriate pediatric subspecialist or facility, or meet other needs, such as speech or other therapy services, home-nursing services, transportation, home modifications, or translation services. Since F2F staff are parents who have “been there” themselves, they can also offer emotional support and encouragement.

F2Fs also help families learn skills and gain confidence to communicate more effectively with health care professionals and to advocate for their children within hospitals and other provider settings. They disseminate information via fact sheets, manuals, toolkits, newsletters/e-newsletters, websites, and social media, and hold workshops for families on numerous topics, including those related to MCHB’s six core outcomes for a system of care for CYSHCN -- early and continuous screening to identify needs, access to a medical home to coordinate care, help finding community services, access to adequate health care financing, preparation for transitions to adulthood, and effective partnerships with professionals.

Ninety-two percent (92%) of families helped by F2Fs report that they are better able to partner with providers and navigate systems as a result of the assistance received from their F2F, and 90 percent report increased confidence in their ability to access the services their child and family need.

F2Fs also help families financially, and thereby help their children. They assist families to access adequate health care financing, such as Medicaid, CHIP, and private insurance. F2Fs understand the particular health care financing issues faced by families of CYSHCN as well as special health care financing resources that might be available to them, such as State Catastrophic Illness in Children Relief Funds. In addition, many F2Fs have special expertise in helping diverse and underserved families understand complex financing systems. A family that is impoverished, in debt, or actually driven to bankruptcy due to out-of-pocket medical expenses, can have their financial and emotional well-being revived when their child gets Medicaid coverage, perhaps through a special waiver for technology-dependent children or developmental disabilities that the family would not have known about had they not received services from their F2F. A family that cannot afford both physical and speech therapy for their child can see their child learn to walk *and* talk once they gain public or private health insurance coverage. Parents who are unsure whether they can afford to fill a prescription for a critical medication can breathe more freely when an F2F helps them get their insurance company to pay for the drug. Parents who had to stay home to care for their child may be able to go back to work if they can get coverage for home-nursing services.

One example of how F2Fs help CYSHCN and their families comes from a father in New Jersey: “Losing my insurance turned out to be a blessing in disguise! I have a 13-year old with Down syndrome and autism. He has major behavioral challenges and at the suggestion of his neurologist, he was taking three different medications that made his behaviors worse and made him gain 40-50 pounds. I was desperate when I contacted SPAN because I could no longer afford the medications and was overwhelmed with his other health challenges. SPAN recommended the Federally Qualified Health Center near my home and over time we were able to wean him off the medications. I worked with SPAN to develop a positive behavior support

plan for school and they helped us get connected with Special Child Health Services and the Family Support Organization. I am so amazed that my son is now a totally different kid! He lost 30 pounds in six months and his overall health and behavior has significantly improved. He can run around the park without wheezing!”

As discussed below, some families face more than the usual challenges experienced by those whose children have special health care needs. F2Fs assist these families as well.

Military Families

Military families must relocate more often than most other families. When they move to another state, they must find new medical specialists, reapply for Medicaid waivers, and negotiate for school-based health services with a new school district. Moreover, they might find that the military insurance program, TRICARE, makes different coverage decisions in different regions, and they must coordinate coverage between TRICARE and any new employment-based coverage the military spouse might have. On top of that, one parent may be deployed, meaning the parent at home is a single parent, possibly caring for multiple children without family, friends or support networks in the new area.

Resiliency for members of the military members and their families must be a priority; it's difficult for military members to concentrate on the important work they do if their family is not able to access what they need. Some F2Fs in areas with many military families have developed expertise in serving them. SPAN is an example of such an F2F, and has worked hard to establish and maintain a deep partnership with Joint Base McGuire-Dix-Lakehurst. In fact, there are F2F workers embedded on the base, co-located with the Exceptional Family Military Program (EFMP) Medical, Family Support, and School Liaison Office, the on-base clinic, and all the on-base supports for military families of children with disabilities. To date, SPAN's one-stop program has served well over 1,000 military-connected families, and has been recognized as a Department of Defense best practice.

Military families come to SPAN's F2F with issues ranging from a child with a transplant needing hands-on advocacy to facilitate their return to a safe educational placement, to a child with Prader-Willi Syndrome and other significant health complications with a need for nursing supports, to a young student in 5th grade bullied to the point of suicidal ideation, who needed access to effective providers and support. For this child and family, SPAN went with the family to the school to make a harassment/intimidation/bullying report and worked with the base's Security Police to get a mental-health mobile response team onto the base without requiring the parents to leave their struggling child to sign them in.

Other F2F grantees that offer special help to military families include the Rhode Island Parent Information Network and Washington State's PAVE (Partnerships for Action, Voices for Empowerment).

Underserved and culturally diverse families

Almost 40 percent of the families served by F2Fs reported that they were non-white, and almost 16 percent were Hispanic/Latino/Latina. F2Fs reach families of diverse backgrounds in many ways—hosting support groups and leadership conferences for families in multiple languages,

facilitating focus groups to learn about outreach and service delivery strategies and to create culturally competent materials, participating in community meetings serving diverse communities, and partnering with community-based “cultural liaisons.” F2Fs also help develop the leadership skills of diverse families, which has been a major focus of the last three years of the NCFPP project. F2Fs partner with agencies that serve a high percentage of underserved families, such as Federally Qualified Health Centers (FQHCs). For example, in Georgia, the F2F houses regional coordinators in clinics serving underserved populations. After a family sees the doctor, the regional coordinator connects the family to local resources, matches them to another family for emotional support, and provides them with information. In New Jersey, SPAN partnered with three FQHCs in low-income, high-immigrant communities. Trained Family Resource Specialists provided training to the FQHCs and to immigrant, limited-English-proficient parents served by those FQHCs, leading to statistically significant improvements in outcomes. Several of the FQHCs continue to facilitate ongoing parent-support groups for families of CYSHCN in their practice. F2F staff and trained parent leaders work with the 20 FQHCs with which SPAN has written linkage agreements to provide ongoing support to families of CYSHCN.

Family Voices supports multiple opportunities for F2Fs to expand their cultural competence and outreach to diverse families through conference sessions, webinars, materials and sharing of best practices. Family Voices projects offer F2Fs chances to engage families from diverse cultures in leadership roles, such as the Family Wisdom project, federally funded through a Patient Centered Outcomes Research grant. This project supported diverse family leaders from 16 F2Fs in an 18-month “Community of Practice” activity in which participants met monthly to share strategies for how to facilitate participation in health research by members of diverse communities.

Native American and Alaska Native Families

Native American and Alaska Native CYSHCN and their families face particularly difficult circumstances. They experience high levels of poverty, and many live in extremely sparsely populated areas lacking basic services like water, electricity, and heat. It may take many hours to get to a health care facility, let alone a pediatric subspecialist, and transportation options may be very limited. In some areas, roads are impassable in bad weather. In addition, these families must navigate the Indian Health Service, as well as the private or public insurance they might have. Since reservations may span multiple states – the Navajo Nation spans three –they may have to obtain out-of-state or out-of-network services more frequently than other families, which can be difficult with Medicaid (or even private) coverage. (Other rural and border-state families have the same problem.)

As you know, in early 2018 Congress authorized the establishment of F2Fs for five U.S. territories and at least one tribal community, a goal toward which Family Voices had been working for a long time. It is extremely exciting that in October 2108, grants were awarded to establish F2Fs in five U.S. territories (discussed in the next section), and three F2F grants were awarded to serve Native Americans and Alaska Natives:

Navajo Nation

Indian Country Grassroots and Navajo Family Voices has been designated the F2F for the Navajo Nation. The Navajo Nation straddles the states of Arizona, New Mexico and Utah, each

with its own state-based set of resources for families as well as resources provided by tribal government and community groups. Integrating these resources and understanding how they work together is fundamental to Nahat'á (planning for balance and harmony). The F2F will develop and provide peer-to-peer connections, support, resources, and training for parents, family members, providers, and communities to better support children and youth with special health care needs on the Navajo Nation. Their goal is to establish a holistic information and support system incorporating Diné cultural practices and principles in planning and decision-making for wellness and success. *Álchíní hózhóóji bá Nahat'á* means "planning for the children in a blessing manner."

Parents Reaching Out (NM) and Raising Special Kids (AZ)

Project CARES (Cultivating American Indian Resource Expansion in the Southwest) is a collaboration between two experienced state F2Fs, Raising Special Kids and Parents Reaching Out, to provide culturally appropriate resources, support, training, and technical assistance to families of CYSHCN within seven medically underserved tribal communities. Communities to be served include the Hopi, Mescalero Apache, Navajo Nation, Salt River Pima-Maricopa Indian Community of the Salt River Reservation, Tohono O'odham Nation, White Mountain Apache Tribe, and Zuni Pueblo.

Alaska F2F at Stone Soup Group

Stone Soup Group, an experienced F2F, serves as Alaska's designated Alaskan Native F2F. The project is staffed primarily by parents and family members of CYSHCN who understand the systems and processes from a unique first-hand perspective. F2F staff will assist families to navigate through the often-overwhelming maze of programs and services, facilitate productive, healthy relationships between families and professionals to promote family-centered, culturally appropriate care, and assist families, health care providers, social workers, government entities, and other community organizations to partner to improve systems.

Families in U.S. Territories

Families in U.S. territories, particularly those who have CYSHCN, face special challenges for several reasons, including high levels of poverty, a scarcity of local health care providers, the need to travel long distances to obtain pediatric subspecialty care, capped Medicaid funding, substandard infrastructure, and high incidences of certain health conditions. In October 2018, F2F grants were awarded in Puerto Rico, the U.S. Virgin Islands, American Samoa, the Commonwealth of the Northern Mariana Islands, and Guam. Family Voices has been able to make in-person technical assistance visits to each of these new F2Fs in the current year and all these new F2Fs sent representatives to the May 2019 Family Voices Leadership Conference in Washington DC.

Puerto Rico

The Puerto Rico F2F is a Project of the Puerto Rico University Center for Excellence in Developmental Disabilities (UCEDD), part of the Graduate School of Public Health, School of Medicine of the University of Puerto Rico. Staffed with parents of CYSHCN, this F2F focuses on providing support, information, resources, tools and training to empower families to advocate for services and improve systems. Professionals, and students from a variety of fields, will

receive training and information to learn about the needs of families and how to engage families as partners.

The U.S. Virgin Islands

The F2F at the Developmental Disabilities Center in the U.S. Virgin Islands was funded in 2018 in response to the needs of the families in this territory. In this eight-month planning year the F2F staff has convened key partners across the territory, engaged parents of CYSHCN to assess their needs, and is informing and educating key elected officials about the needs of CYSHCN. The goal of the F2F is to support and empower families to seek appropriate services to address the needs of their CYSHCN while being attentive to the diverse cultures that exist on the islands.

American Samoa

American Samoa is a U.S. territory located in the south Pacific with over 55,000 residents. The American Samoa Department of Health received funding to plan for and develop an F2F. During this eight-month planning year, American Samoa has undertaken a comprehensive formative assessment, meeting with families, self-advocates, service providers, and agency and government leaders to evaluate the community's needs and assets. The results of that assessment will inform F2F activities aimed at building family leadership capacity, facilitating interagency collaboration, improving collection and sharing of data on CYSHCN, and promoting public awareness of disability issues.

Commonwealth of the Northern Mariana Islands (CNMI)

The Commonwealth of the Northern Mariana Islands (CNMI) is a U.S. territory in the northwestern Pacific with about 55,000 residents. The CNMI Department of Health received funding to plan for and develop an F2F. They have used this planning period to develop and implement an extensive assessment to determine the needs of families by meeting with all stakeholders, including families, providers and government officials. The assessment results will inform the next steps for developing the activities of the F2F, which include goals of building the capacity of families to advocate for their needs and for improvements in the system of care. Activities to improve interagency collaboration, collect and share data on CYSHCN and to promote public awareness of disability issues will be an essential aspect of the work.

Guam

Guam is a U.S. territory located in the western Pacific with 162,000 residents. Through Guam's Department of Health, this newly funded F2F will focus on the development of a centralized data system and on developing a health resource center that will benefit families of CYSHCN. The Center will provide information and resources to these families and direct them to the appropriate programs or agencies to receive the assistance they need.

Family Voices staff member Glenn Gabbard, who is of Samoan heritage, has been assisting health agencies and family organizations prepare for F2Fs in the three Pacific territories – American Samoa, CNMI, and Guam. His observations on recent trips to the territories are valuable:

Each of the three Pacific territories that I am working with demonstrate the diversity of colonial history and current socio-economic status between and among the territories themselves. While visiting, I was deeply impressed with how important the presence of

the Family to Family Centers will be. Having met with over 30 different families as well as the territorial legislators and public offices designed to serve them, it became very clear that the current health care delivery systems do not adequately represent the aspirations and challenges which these families have. There are significant cultural challenges to building the capacity of families to actively engage in the various systems which are intended to serve them; however, I was convinced by the passion and dedication of families for their children and their hopes for a healthy, fulfilling future for their children.

F2Fs improve health outcomes for children and youth

Parents who advocate effectively on behalf of their children's health care, and who have the partnership skills to communicate and work with health care providers in meaningful ways, report improved health outcomes for their children as a result of that parent involvement. A growing body of evidence demonstrates that parents are more likely to be able to advocate effectively when they are provided with support by peers.

For example, in the Rhode Island Pediatric Primary Care Enhancement Project, a federally funded pilot project, trained parents of CYSHCN were placed in primary care practices for 20 hours per week to provide support to individual families (those with and without children with special health care needs) in navigating across and advocating in multiple systems. These family leaders also worked with primary care providers on partnering more effectively with families and connecting families to available resources and supports. A study of the project's impact found that placing trained parents of CYSHCN in pediatric practices reduced the cost of care, reduced inappropriate utilization of services, including inpatient care, and increased parent and provider knowledge and satisfaction.

F2Fs improve health systems and cost-effectiveness of care

Often, state Medicaid agencies, managed care organizations, and health care facilities do not meaningfully engage or consider the input of families and family organizations in the development, implementation and evaluation of their organizational policies, procedures, programs, and practices. As a result, they are missing opportunities to address some of the problems and inefficiencies in their systems, and thus to improve patient care, family satisfaction, and health outcomes.

Families have critical insights about how institutions and systems can best serve their children, and do so more efficiently. F2Fs promote family engagement with health care providers and government agencies with the aim of improving institutional and government policies affecting CYSHCN and their families. The NCFPP (now LFPP) and F2Fs train parents and professionals to become more effective partners in the treatment of CYSHCN, and train parents and youth of diverse backgrounds to meaningfully engage with policymakers at the individual, community, state and federal levels. They provide feedback to health care providers; participate on the advisory boards of health clinics, hospitals, and health maintenance organizations; work with state agencies on policies to ensure that they effectively meet the needs of diverse families; and participate in national-level partnership activities to improve policies and systems. Outcomes research provides evidence of the value of such participation at all levels of health care.

The importance of federal funding and the Family-to-Family Reauthorization Act of 2019

Each F2F receives a federal grant of \$96,750, regardless of the state's population or geographic size. This small amount of funding can support only one or two employees, but it also provides something else of great value. As a federal grantee, an F2F has a certain degree of credibility that can help it secure other funding from foundations, state and local agencies, or private donors.

That credibility comes from the designation as the federally-recognized F2F, from the fact that organizations must apply for this funding and score high enough to be awarded an F2F grant, and from the results of the qualitative and quantitative evaluation that F2Fs must undergo. For example, at least 30 F2Fs also receive funding from their state Title V Maternal and Child Health Program via the block grant and/or other state funding, to supplement the individual assistance the F2Fs can offer or to support the F2F's role in other initiatives to improve quality and outcomes at the program and policy levels. For example, SPAN is funded by our Title V and other state agencies in the domains of maternal/infant health (Community Doula pilot); adolescent health (Parents As Champions for School Health); and child health (Parent Lead on Help Me Grow, Early Childhood Comprehensive Systems grant, and Home Visiting).

F2Fs can also use the credibility and data from their F2F status to secure funding from county and local agencies and foundations. For example, SPAN is funded by the NJ Bar Foundation to provide individual assistance to families and training to families, youth and professionals about the health and education rights of CYSHCN in the child welfare and juvenile justice systems and the resources available to support them. SPAN training is part of the professional preparation for every new social worker at our state's child welfare agency. And the recognition of SPAN as the state's F2F has also led to numerous fee-for-service contracts with local, county and state agencies to train their staff.

The information above provides clear evidence of the importance of continued funding for the nation's 59 F2Fs. But the proposed legislation does more than that. It extends the funding for five years rather than fewer. The length of the grant period is critically important. Although modest, the F2F grant provides a foundation upon which other funding can build. However, those other funding sources – state Title V programs, local government agencies, foundations, and individual donors – want to fund and partner with organizations that have stable base funding.

It is also difficult to recruit and retain staff when you have to tell them every other year that their job may disappear. All families need a sense of stability in their employment but this is even more critical for families of CYSHCN; they must maintain health insurance and they already face many challenges in their lives.

Finally, trusting and effective partnerships with community-based groups – such as FQHCs, hospitals, and other nonprofit organizations – require time and effort to develop and nurture. This can happen only if the partner agencies have confidence that their relationships and shared work with the F2F will continue for a meaningful period; otherwise, it's not worth their investment of time and energy.

It's important to note that some F2Fs are part of a larger organization, like SPAN, through which they may be able to receive in-kind support. Other F2Fs essentially stand alone, relying primarily on their federal F2F grant to keep their doors open. For both of these types of F2Fs, being able to rely on the continued existence of F2F funding is critical.

Since its inception over a decade ago, when it was created by Senator Charles Grassley and the late Senator Ted Kennedy, the F2F program has enjoyed strong bipartisan support. We are very grateful to Representatives Sherrill and Upton for continuing this bipartisan effort to ensure that families can secure timely, high-quality, family-centered care for their children and youth with special health care needs.

On behalf of Family Voices and SPAN, I would like to thank the Chairman, Ranking Member, and Subcommittee Members for the opportunity to testify about the value of Family-to-Family Health Information Centers. I would be happy to answer any questions you might have.

ATTACHMENTS

Below:

- F2F funding history
- F2F fact sheet
- The Value of F2Fs

Separate document:

- [FY2018 F2F Data Brief](#) [hyperlink]

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**FUNDING HISTORY FOR
FAMILY-TO-FAMILY HEALTH INFORMATION CENTERS**

1999-2006: Family-to-Family Health Information Centers were developed in some states with the support of Family Voices and funding from the Robert Wood Johnson Foundation, the Maternal Child Health Bureau (MCHB), and the Centers for Medicare and Medicaid Services (CMS).

FYs 2007-present: The Family Opportunity Act (part of the Deficit Reduction Act of 2005), *as amended subsequently* (see table below), has authorized and funded F2Fs. After a phase-in period, one grant has been awarded in each state and DC since 2009. Through FY 2017 total program spending was \$5 million per year. Beginning in 2018, an F2F was established in five of the U.S. territories - American Samoa, Guam, Northern Mariana Islands, Puerto Rico, and the U.S. Virgin Islands) and three have been established to serve Indian tribes. Funding is automatic (not appropriated) once authorization is extended. Total program funding for FYs 2018-19 is \$6 million per year.

Law Soc. Sec. Act §501(c) [42 U.S.C. 701(c)] as amended by:	Federal Fiscal Year funded (10/1-9/30)	Grant cycle funded (June 1-May 31)	Amount (per Federal FY)
Family Opportunity Act (FOA)/Deficit Reduction Act of 2005 (2/8/06) <i>(Grassley/Barton/Bush)</i>	FFYs 2007, 2008, 2009	Through May 2010	FFY 2007 - \$3 million FFY 2008 - \$4 million FFY 2009 - \$5 million
Affordable Care Act (ACA) (3/23/10) <i>(Baucus/Waxman/Obama)</i>	FFYs 2010, 2011, 2012	Through May 2013	FFY 2010 - \$5 million FFY 2011 - \$5 million FFY 2012 - \$5 million
American Taxpayer Relief Act of 2012 (ATRA) (1/1/13) <i>(Baucus/Upton/Obama)</i>	FFY 2013	Through May 2014	\$5 million
Bipartisan Budget Act of 2013 (BBA) (12/26/13) <i>(Baucus/Upton/Obama)</i>	“Portion of FY 2014 before April 1, 2014” (first half FFY 2014)	Through November 2014	\$2.5 million
Protecting Access to Medicare Act of 2014 (4/1/14) <i>(Wyden/Upton/Obama)</i>	“Portion of FY 2014 on or after April 1, 2014” (2 nd half FFY 2014) + “Portion of FY 2015 before April 1, 2015” (first half FFY 2015)	Through May 2015 Through November 2015	\$2.5 million + \$2.5 million
The Medicare Access and CHIP Reauthorization Act of 2015 (MACRA) (4/16/15) <i>(Hatch/Upton/Obama)</i>	FFYs 2015, 2016, 2017	Through May 2018	FFY 2015 - \$5 M (total) FFY 2016 - \$5 M FFY 2017 - \$5 M
The “Advancing Chronic Care, Extenders, and Social Services (ACCESS) Act” within the Bipartisan Budget Act of 2018 (Sec. 50101) (2/9/18) <i>(Hatch/Walden/Trump)</i>	FFYs 2018 and 2019	Through May 2020	FFY 2018 - \$6 million FFY 2019 - \$6 million + amendment to develop at least one F2F for Indian tribes and an F2F in each of five U.S. territories (American Samoa, Guam, Northern Mariana Islands, Puerto Rico, U.S. Virgin Islands)



Family-To-Family Health Information Centers (F2Fs)

- Throughout the US, there are nearly 14 million children and youth with special health care needs (CYSHCN), constituting 19 percent of all children under age 18. More than one in five households with children has at least one child with special health care needs. Nearly a third of these families who have insurance report that it is inadequate to meet their children's needs.
- It is very difficult for families to figure out how to finance their children's care, given the great expense and complexity of potential funding sources – including private insurance, Medicaid, CHIP, state Maternal and Child Health programs, and the Individuals with Disabilities Education Act (IDEA) – each with different eligibility and coverage criteria.
- The Maternal and Child Health Bureau (MCHB) administers a grant program to fund one Family-to-Family Health Information Center (F2F) in each state, the District of Columbia, and five U.S. territories, plus three F2Fs to serve tribal communities.
- Family-to-Family Health Information Centers (F2Fs) –
 - help families of CYSHCN learn how to navigate the complex health care system, advocate for their children, and make informed choices about health care in order to promote good treatment decisions, cost-effectiveness and improved health outcomes.
 - work with families, youth, and health care providers to help youth with special health care needs transition to adult services and independence.
 - provide training and assistance to health care providers and public agencies to promote family-centered, culturally competent, and linguistically appropriate care and medical homes for CYSHCN.
 - work to engage families and youth in efforts to improve the health care system.
- F2Fs are staffed by families of CYSHCN who have extensive personal experience and professional training in accessing and financing health care for CYSHCN.
- Each F2F receives less than \$97,000 per year to serve its entire state/territory/tribal community. (The grant amount has not increased substantially since the inception of the program in FY 2007.)
- Despite their shoestring budgets, F2Fs provided information, training and/or assistance to nearly one million families and over 374,000 health professionals in 2018.
- The F2F grant program was established with bipartisan support by the Family Opportunity Act, part of the Deficit Reduction Act of 2005.
- After a three-year phase-in period ending in 2009, the program was extended through FY 2017, with level funding of \$5 million per year, through amendments in various other laws.
- In 2018, the “Advancing Chronic Care, Extenders, and Social Services (ACCESS) Act” within the Bipartisan Budget Act of 2018 (Sec. 50101) extended F2F funding through FY 2019, at \$6 million per year, and allowed grants to be awarded for U.S. territories and Indian tribes. For the work of F2Fs to continue beyond this fiscal year, additional legislation will be needed.

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The Value of Family-to-Family Health Information Centers

Imagine a family that is suddenly confronted with a very premature baby likely to have multiple health problems or disabilities, or discovers that their child needs a kidney transplant, or has autism, diabetes, epilepsy or a serious mental illness. They are likely to be at a loss for information about how to get the best treatment for their child – how to find the right specialists, therapists, or caretakers – and how to pay for that costly care (autism therapies, private-duty nursing, and specialized medications, for example, can cost tens or even hundreds of thousands of dollars per year.)

When a family receives help from a Family-to-Family Health Information Center, they can get this vital information, emotional support, and help in navigating the complex maze of health care financing. Your state's Family-to-Family Health Information Center can provide examples of how they have helped families in one or more of these ways.

The assistance that F2Fs provide:

- (1) improves health outcomes for kids;
- (2) reduces government health care spending (i.e., to Medicaid, public clinics, public hospitals) or costs to the health system in general (e.g., to families, insurance companies) by ensuring that children get timely, appropriate care, and cost-effective care;
- (3) reduces government education spending (i.e., where early intervention helps to avoid or reduce the need for special education);
- (4) enables families to get care for their kids without having to face bankruptcy or spend all their college or retirement savings;
- (5) enables parents to continue to work (e.g., because they can get nursing care for their child); and/or
- (6) keeps children at home with their families, and out of costly and psychologically harmful institutional care.

*For national and state-specific information about F2Fs, see
<http://familyvoices.org/ncfpp/f2fs/> or
contact Janis Guerney (jguerney@familyvoices.org or 202-669-5233)*

Family Voices is an organization of and for families whose children have special health care needs.

www.familyvoices.org

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