

Good morning Mr. Chairman, Mr. Ranking Member, and Members of the Subcommittee. I am Diana Autin, Executive Co-Director of the SPAN Parent Advocacy Network, home of NJ's Family-to-Family Health Information Center, or F2F. Today I am representing both SPAN and Family Voices, a national organization of and for families whose children and youth have special health care needs, which also provides support to the nation's F2Fs.

I am here today in relation to H.R. 2822, the Family-to-Family Reauthorization Act, which will extend funding for F2Fs for an additional 5 years at the current funding level of \$6 million/year.

F2Fs help families whose children have special health care needs navigate health care and other systems, advocate effectively for their children, and work as partners with providers.

Children and youth with special health care needs include those with conditions such as autism, epilepsy, traumatic brain injury, cancer, schizophrenia, asthma, diabetes, or any other condition that requires health care services beyond that required by children generally.

Throughout the U.S., there are about 14 million children with special health care needs, 19% of all children under age 18 and more than one in five families with children.

Families struggle to find the right primary and specialty care providers to treat their children, and to pay for their care. Even with insurance, out-of-pocket costs can be very high, with copayments and costs that insurance may not cover at all.

It is difficult to navigate through the worlds of public and private insurance and other sources of care and financing that all have different eligibility criteria. Children may miss getting valuable services because their families are unaware of, or are unable to access or afford, them.

This is where F2Fs come in. We are staffed by parents of children with special health care needs. Beyond their training, our staff have expertise and empathy learned through personal experience. We reach out to underserved communities, and provide our services in a culturally and linguistically appropriate manner.

F2Fs provide one-to-one assistance, such as helping a family appeal denial of coverage for needed services, get insurance coverage; or find appropriate pediatric specialty care.

For example, a father called our F2F about his 13-year old son with Down syndrome, autism, and major behavioral challenges. He was struggling to afford the prescribed medications, which were making his son's behavior worse and making him gain weight. Our F2F staff connected him to the nearby FQHC and helped him develop a behavior support plan for school and access additional support services. Within six months, his son was weaned off the medications and had lost 30 pounds, and his overall health and behavior had significantly improved.

Some families face more than the usual challenges.

Military families must relocate often, each time needing to find new providers, reapply for Medicaid, and negotiate for services in a new district. In New Jersey we help these families by embedding staff at, and working closely with Joint Base McGuire-Dix-Lakehurst.

Special challenges also arise for families who are not proficient in English or come from diverse cultural backgrounds, for urban low-income families who may need to take multiple buses to get to appointments, and for rural families, who must travel long-distances to get specialized care. Sometimes one parent may even have to relocate.

Families in the territories, and Native American and Alaska Native families, face linguistic and/or cultural barriers, *and* the complications of remote locations, often compounded by extreme poverty. This is why we were so pleased when, last year, Congress expanded the F2F program to serve these families.

There is now one F2F in each state, DC, five territories, and three tribal organizations. Each receives \$96,750 per year. Despite our modest budgets, F2Fs provided information, training and/or assistance to nearly one million families in 2018.

F2Fs provide a great value for taxpayers. We help families get the care and services their children need to survive and thrive, and to avoid medical bankruptcy, and we assist providers and policy makers to better serve children and youth with special health care needs. Our efforts result in higher-quality, more cost-effective care, and better health outcomes.

The bill before you today would extend the F2F program for an additional FIVE years, longer than ever before. Although modest, the F2F grant provides a foundation upon which other funding and activities can build. Status as a federal grantee provides credibility that makes it easier to secure additional funds and partners. However, those other funding sources – government agencies, foundations, and individual donors – and community partner organizations, do not want to invest time or money in an entity that might not survive for more than a year. Greater stability of F2F funding would be extremely valuable to our effectiveness.

Since its creation over a decade ago by Senator Charles Grassley and the late Senator Ted Kennedy, the F2F program has enjoyed strong bipartisan support. We thank Representatives Sherrill and Upton for continuing this bipartisan commitment to F2Fs so we can help families secure timely, high-quality, and family-centered care for their children and youth.

On behalf of Family Voices and SPAN, I thank the subcommittee for the opportunity to testify about the value of Family-to-Family Health Information Centers. I am happy to answer any questions.