

June 3, 2019

The Honorable Mikie Sherrill
U.S. House of Representatives
Washington, D.C. 20515

The Honorable Fred Upton
U.S. House of Representatives
Washington, D.C. 20515

Dear Representatives Sherrill and Upton:

The undersigned organizations commend you for introducing H.R. 2822, the “Family-to-Family Reauthorization Act of 2019,” to extend funding for Family-to-Family Health Information Centers for an additional five years, through FY 2024.

Throughout the US, there are about 14 million children and youth with special health care needs (CYSHCN), constituting 19 percent of all children under age 18. These children have physical disabilities (such as cerebral palsy or muscular dystrophy), chronic illnesses (such as epilepsy, asthma or diabetes), developmental or intellectual disabilities (such as autism or Down syndrome), or mental illnesses. The needs of these children and youth 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 their numerous 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 out on valuable services because their families are unaware of them, or unable to access or afford them.

More than one in five households with children has at least one child with special health care needs. Family-to-Family Health Information Centers (F2Fs) help these families navigate the maze of programs available to their children. As the name of the program 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. F2Fs also help families effectively advocate for their children and work as partners with health care providers. In addition, they 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.

When children with special health care needs receive family-centered health care and therapies in a timely and coordinated fashion, they can avoid costly medical complications and crises, thus reducing costs for our nation’s health care systems. Helping families find ways to finance care for their children also helps to reduce medical bankruptcies.

The staff of F2Fs bring their personal experience as parents of CYSHCN to their roles. Extremely dedicated, they work tirelessly, often traveling long distances and working well beyond the hours for which they are paid. As a result, federal taxpayers get great value from the F2F program. Despite their modest budgets, F2Fs provided information, training and/or assistance to nearly one million families in 2018.

Since its inception, the F2F program has enjoyed bipartisan support. We greatly appreciate your continuation of 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.

Sincerely,

AIDS Alliance for Women, Infants, Children, Youth & Families
American Academy of Pediatrics
American Academy of Physical Medicine & Rehabilitation
American Association on Health and Disability
American Medical Student Association
American Medical Women's Association
American Network of Community Options & Resources (ANCOR)
American Physical Therapy Association
Association of Maternal & Child Health Programs
Association of State Public Health Nutritionists
Association of University Centers on Disabilities (AUCD)
Association of Women's Health, Obstetric and Neonatal Nurses
Autism Society of America
Autistic Self Advocacy Network
Children's Defense Fund
Children's Dental Health Project
Children's Hospital Association
CityMatCH
Division for Early Childhood of the Council for Exceptional Children (DEC)
Epilepsy Foundation
Expecting Health at Genetic Alliance
Family Voices
First Focus Campaign for Children
IDEA Infant Toddler Coordinators Association (ITCA)
Lakeshore Foundation
Military Special Needs Network
NAPHSIS
National Association for Children's Behavioral Health
National Association of Councils on Developmental Disabilities
National Association of Pediatric Nurse Practitioners
National Association of State Head Injury Administrators
National Partnership for Women & Families
National Respite Coalition
Prevention Institute
Public Health Institute
TASH
The Arc of the United States
The National Alliance to Advance Adolescent Health