

April 22, 2024

The Honorable Cathy McMorris Rodgers
Chair
Committee on Energy and Commerce
United States House of Representatives
Washington, DC 20515

The Honorable Frank Pallone
Ranking Member
Committee on Energy and Commerce
United States House of Representatives
Washington, DC 20515

Dear Chair Rodgers and Ranking Member Pallone:

On behalf of 27 organizations dedicated to advancing the interests of families of children with special health care needs, we write to respectfully request the Committee pass H.R. 7300, the “Family-to-Family Reauthorization Act of 2024,” and provide a robust increase in funding for the Family-to-Family Health Information Centers (F2F HICs) program.

More than one in four families in the United States has a child with special health care needs.¹ The needs of these children are unique and complex, and finding pediatric specialists to provide appropriate care can pose challenges. The expense of accessing care is out of reach for many families, and nearly half of these families don’t seek proper care for their children because of the high cost.² As a result, children often do not receive adequate care, and families experience higher levels of chronic stress and are at risk for additional adverse health and social-emotional outcomes.

Established by Congress in 2002, the F2F HICs program operates as a family-led nonprofit organization serving over 204,000 families of children with special health care needs nationwide, including those in every state, the District of Columbia, five U.S. territories, and three tribal communities. This program offers critical support, resources, and confidential guidance to families free of charge, assisting them in managing the complexities of the health care system. F2F HIC services include aiding families in understanding treatment options; coordinating appointments, services, and medications; facilitating access to peer-to-peer counseling and emotional support; navigating insurance; and promoting leadership training and development, all with the overarching goal of enhancing the well-being of the child and the entire family unit.

Despite the impact of the F2F HICs program on families of children with special health care needs, it receives only \$6 million annually from the Health Resources and Services Administration (HRSA), or less than \$96,000 per state, equating to \$29 per family served. Due to budget sequestration further limiting funding, F2F HICs have been forced to remove or limit essential services, such as translation services and leadership training, hindering their capacity to serve vulnerable communities effectively. The disparity between the program’s importance and its limited funding curtails its ability to adequately support families facing complex health care challenges and serves as a barrier to adequate care.

¹ Congressional Research Services, Family to Family Health Information Centers: Current Status and Policy Considerations (Feb. 6, 2024), <https://crsreports.congress.gov/product/pdf/IN/IN12317/2> (last accessed Feb. 27, 2024).

² Health Resources and Services Administration, Maternal and Child Health Bureau, *Children and Youth with Special Health Care Needs* (June 2022), <https://mchb.hrsa.gov/sites/default/files/mchb/programs-impact/nsch-data-brief-children-youth-special-health-care-needs.pdf> (last accessed Feb. 27, 2024).

Since its inception, the F2F HICs program has enjoyed strong bipartisan support. We respectfully urge you to reauthorize this program by passing H.R. 7300, the “Family-to-Family Reauthorization Act of 2024,” and significantly increasing funding to ensure families of children with special health care needs continue to have access to this critical program.

We appreciate the Committee’s dedication to children and youth with special health care needs and look forward to working together to ensure that more families can secure timely, high-quality, family-centered care.

Sincerely,

Access Ready Inc.

AIDS Alliance for Women, Infants, Children, Youth & Families

American Academy of Pediatrics

American Association of People with Disabilities

American Association on Health and Disability

American Music Therapy Association

Association of Maternal & Child Health Programs

Association of University Centers on Disabilities

Autism Society

Autism Speaks

Autistic Women & Nonbinary Network

Children's Hospital Association

Easterseals

Family Voices

Lakeshore Foundation

MomsRising

National Association of Councils on Developmental Disabilities

National Association of Pediatric Nurse Practitioners

National Center for Parent Leadership, Advocacy, and Community Empowerment (National PLACE)

National Disability Rights Network (NDRN)

National Down Syndrome Society (NDSS)

National Federation of Families

National Respite Coalition

Prevent Blindness

The Arc of the United States

The National Alliance to Advance Adolescent Health

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