



April 11, 2012

The Honorable Robert Menendez
U.S. Senate
Washington, DC 20510

The Honorable Frank Pallone
U.S. House of Representatives
Washington, DC 20515

Dear Senator Menendez and Representative Pallone:

The undersigned national organizations would like to commend you for introducing the Family-to-Family Health Information Resource Center Extension Act (S. 2123, H.R. 4083) to extend funding for Family-to-Family Health Information Centers (F2FHICs) through FY 2015 at the current level of funding (\$5 million per year).

As you know, there are approximately 11 million children and youth with special health care needs (CYSHCN) throughout the country, constituting almost 14 percent of the child population. These children have physical disabilities (such as cerebral palsy or muscular dystrophy), chronic illnesses (such as epilepsy, asthma or HIV/AIDS), developmental or intellectual disabilities (such as autism or Down syndrome), or mental illnesses. The needs of these children and youth are chronic and complex and, thus, 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 – provided through private insurance, Medicaid, SCHIP, the school system, or other organizations – is difficult to navigate and often involves multiple eligibility criteria and coverage standards. As a result, children may miss out on valuable services because they are unable to access or afford them.

F2FHICs help these children and their families by guiding them through the maze of services and programs available to them. Most of the staff at F2FHICs are family members of CYSHCN with extensive personal experience and professional training in accessing and financing health care for such children. Their unique perspective allows them to provide advice, offer a multitude of resources, and tap into a network of other families and professionals for support and information. In addition, they help health care professionals understand the various public programs available to the children in their care and assist in dealing with private insurers. The centers also aim to ensure that each child has a “medical home” and that partnerships are built between health care professionals and the families of CYSHCN, thereby improving the quality of care.

When children with special health care needs receive medical care and therapies in a timely fashion, it can enable them to avoid costly medical crises, thus reducing costs for our nation’s health care systems. In addition, early intervention, and coordinated and thorough care, helps many of these children in their educational pursuits. This kind of care often enables these children to avoid use of the special education system – thus saving local, state, and federal funds – and helps them to reach their full potential as members of society.



The Deficit Reduction Act of 2005 mandated and funded the establishment of F2FHICs in every state and the District of Columbia. The 2009 level of funding -- \$5 million -- was extended for an additional three years in 2010. At this level of funding, each center receives about \$95,700 per year, a very small amount considering the number of families served by F2FHICs (980,000 last year) and the invaluable assistance they provide. Without this funding, many F2FHICs would not be able to survive.

By extending the current level of funding for an additional three years, your legislation will enable F2FHICs to help several million more families with the challenges of addressing their children's special health care needs.

As organizations concerned about child health and/or representing individuals with disabilities and chronic health conditions, we thank you for your commitment to ensuring the survival of F2FHICs.

Sincerely,

ACCSES

American Academy of Pediatrics

American Association on Health and Disability

American Music Therapy Association

American Speech-Language-Hearing Association

Association of Maternal and Child Health Programs

Association of University Centers on Disabilities

Autism Speaks

Bazelon Center for Mental Health Law

Brain Injury Association of America

Division for Early Childhood of the Council for Exceptional Children (DEC)

Easter Seals

Family Voices

First Focus Campaign for Children

IDEA Infant Toddler Coordinators Association (ITCA)

National Assembly on School-Based Health Care

National Association of Councils on Developmental Disabilities

National Down Syndrome Congress

National Respite Coalition

The Arc of the United States

The National Alliance to Advance Adolescent Health

United Cerebral Palsy