CCD
CONSORTIUM FOR CITIZENS
WITH DISABILITIES

June 24, 2019

The Honorable Anna G. Eshoo
Chairman
Energy and Commerce Committee
Health Subcommittee
United States House of Representatives
Washington, DC 20515

The Honorable Michael C. Burgess
Ranking Member
Energy and Commerce Committee
Health Subcommittee
United States House of Representatives
Washington, DC 20515

Re: Lifespan Respite Care Reauthorization Act of 2019 (H.R. 2035)

Dear Chairman Eshoo and Ranking Member Burgess,

Thank you for holding a hearing on "Reauthorizing Vital Health Programs for American Families" which includes the Lifespan Respite Care Reauthorization Act. We, the undersigned members of the Developmental Disabilities, Autism and Family Support Task Force of the Consortium for Citizens with Disabilities (CCD) are writing to express our strong support for the Lifespan Respite Care Reauthorization Act. CCD is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society.

More than 65 million Americans provide care for a loved one who has a disability, is chronically ill, or is elderly and spend an average of 20 hours per week providing care. For caregivers of people with intellectual and developmental disabilities (I/DD), the levels of responsibility are not only greater, but frequently lifelong. There are approximately 3 million family caregivers of persons with I/DD in the U.S. According to The Arc’s Family and Individual Needs for Disability Supports (FINDS) survey, the majority of these family caregivers provide more than 40 hours of care per week.

Respite services are desperately needed to help family members continue to provide this level of care in the community instead of more costly and unwanted institutions. Unfortunately, changing demographics are placing even greater demands on extremely limited respite services. The aging of the baby boom generation is resulting in an increasing number of people with I/DD living with aging caregivers who have greater need for respite to address their own physical and mental health care needs.

The grants provided under the Lifespan Respite Care Act give states resources they need to improve their system of respite care. These grants can be used to train respite care providers, implement marketing campaigns to inform families of available respite care options, or implement a respite voucher program, among other options. Furthermore, states are able to give priority to family caregivers who are caring for individuals with disabilities and chronic illness of all ages who are not currently eligible for existing public programs, on Medicaid waiver waiting lists, or for whom finding qualified providers is especially difficult. This population includes individuals between the ages of 18-60; grandparents raising grandchildren; rural family caregivers; culturally diverse groups and others identified as having unmet needs.

Thank you for your leadership in supporting our Nation's caregivers and we look forward to working with you to help ensure the reauthorization of the Lifespan Respite Care Act.

Sincerely,

American Network of Community Options and Resources
American Therapeutic Recreation Association
Easterseals
Family Voices
National Association of Councils on Developmental Disabilities
National Respite Coalition
The Arc of the United States