January 23, 2018

The Honorable Gregg Harper  
United States House of Representatives  
2227 Rayburn House Office Building  
Washington, DC 20515

The Honorable Kathy Castor  
United States House of Representatives  
2052 Rayburn House Office Building  
Washington, DC 20515

The Honorable Michelle Lujan Grisham  
United States House of Representatives  
214 Cannon House Office Building  
Washington, DC 20515

The Honorable Elise Stefanik  
United States House of Representatives  
318 Cannon House Office Building  
Washington, DC 20515

Re: Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act

Dear Representatives Harper, Castor, Lujan Grisham, and Stefanik:

The undersigned members of the Developmental Disabilities, Autism, and Family Support Task Force of the Consortium for Citizens with Disabilities (CCD) write to thank you for your leadership on the RAISE Family Caregivers Act that was signed into law yesterday. The strong bipartisan support of this legislation is a heartening reminder that Members of Congress can work well together to address the urgent needs of the over 40 million caregivers in this country.

CCD is a coalition of national disability-related organizations working together to advocate for national public policy that ensures full equality, self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society. Our membership includes organizations that represent individuals with a range of genetic, developmental, and acquired conditions.

Caregiver responsibilities for persons with developmental disabilities are frequently substantial and can last for several decades. These family caregivers provide assistance with activities such as eating, bathing, dressing, transportation, managing finances, administering medications, and coordinating care among multiple providers and settings. According to The Arc's Family and Individual Needs for Disability Supports (FINDS) survey, family caregivers often provide more than 40 hours of care per week (including 40% of surveyed family caregivers who provided more than 80 hours of care per week).

The RAISE Family Caregivers Act directs the Department of Health and Human Services to develop, maintain, and periodically update a Family Caregiving Strategy, a recommendation of the Commission on Long-Term Care. The Department is also charged with convening a Family Caregiving Advisory Council for the joint development of the strategy. Elements of the strategy are to include recommended actions that Federal State, and local governments and other entities may take to promote person and family-centered care, family involvement in assessment and service...
planning, information sharing and care coordination with service providers, respite options, financial security and workplace issues, and efficient service delivery.

By supporting our family caregivers, we can help people with developmental disabilities to have meaningful lives in the community and avoid unwanted and costly institutionalization. Again, we sincerely thank you for leadership of the RAISE Caregivers Act and look forward to being involved in the implementation of this law.

Sincerely,

ACCSES
American Academy of Pediatrics
American Network of Community Options and Resources
American Psychological Association
Association of University Centers on Disabilities
Autism Society
Autistic Self Advocacy Network
Easterseals
Family Voices
Lutheran Services in America Disability Network
National Alliance for Caregiving
National Association of Councils on Developmental Disabilities
National Association of State Directors of Developmental Disabilities Services
National Association of State Directors of Special Education
National Disability Rights Network
National Respite Coalition
Parent to Parent USA
The Arc of the United States
United Cerebral Palsy