January 23, 2018

The Honorable Susan Collins  
United States Senate  
413 Dirksen Senate Office Building  
Washington, DC 20510

The Honorable Tammy Baldwin  
United States Senate  
709 Hart Senate Office Building  
Washington, DC 20510

The Honorable Lisa Murkowski  
United States Senate  
522 Hart Senate Office Building  
Washington, DC 20510

The Honorable Michael Bennet  
United States Senate  
261 Russell Senate Office Building  
Washington, DC 20510

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

Dear Senators Collins, Baldwin, Murkowski, and Bennet:

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