



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