



October 20, 2014

Re: Older Americans Act Reauthorization

Dear Senator:

We, the undersigned members of the Consortium for Citizens with Disabilities (CCD) Task Force on Developmental Disabilities, Autism, and Family Support, urge you to reauthorize the Older Americans Act (OAA), which expired in 2011, and ensure that two critical improvements make it into the final legislation. 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.

While the OAA primarily serves to help older adults maintain their independence, the law also authorizes two important programs that also serve family caregivers of persons with disabilities:

National Family Caregiver Support program (NFCSP)

The NFCSP was the first federal program to recognize the needs of the nation's family caregivers who provide the vast majority of long-term services and supports. NFCSP not only funds respite, but individual counseling, support groups, and caregiver training for family caregivers, primarily for those who are caring for the aging population.

Unfortunately, the NFCSP currently is not available to parent caregivers of adult children with disabilities. We urge that this problem be remedied for the increasing number of Americans who need family support services by including caregivers of their adult children (age 19 to 59) with disabilities.

This needed improvement would not come a moment too soon. There are over 800,000 caregivers of persons with intellectual and developmental disabilities who are over the age of 60 and this number is projected to grow substantially with the aging of the baby boom generation. People with intellectual and developmental disabilities are also living longer due to medical advances. As parents of these individuals age, they will require more support to be able to continue providing care to their adult children and avoiding costly and unwanted institutional placement.

The current Senate reauthorization bill (S. 1562) passed by the Senate HELP Committee last October includes the needed fix to the NFCSP.

Aging and Disability Resource Centers (ARDCs)

The aging of the caregiver population is central to another key issue for caregivers of persons with disabilities – future planning. The lack of family future planning often results in inappropriate residential placements, loss of intended inheritance, and jeopardizes access to needed services for adults with disabilities as they age. For instance, long waiting lists preclude appropriate community-based residential options for many individuals with lifelong disabilities. Providing future planning services will provide immense relief to aging caregivers who frequently report that they are “afraid to die” because of their fears about who will look after their disabled child when they are gone.

When the ADRC program was originally created, it was designed to meet the needs of caregivers of their older parents. As such, ADRCs did not focus on distant future planning for senior citizens. As the program has evolved, it has expanded to provide services for caregivers of younger people, such as adult children with lifelong disabilities. This population, however, typically has needs that extend decades into the future. Consequently, future planning must be an essential service provided by ADRCs.

A previous Senate version of the OAA Reauthorization (S. 1028) includes the addition of future planning services provided by ADRCs. We urge you to include similar language that specifically ensures future planning for adults with disabilities, particularly intellectual and developmental disabilities, in the final legislation. CCD suggests language such as, “Future planning for adults with disabilities residing with older family caregivers, including legal, financial, and residential planning” under (c) of the Aging and Disability Resource section.

Our organizations hope that the OAA can be reauthorized in a bipartisan manner before this Congress ends. More than at any other time, when Medicaid, Medicare, and Social Security are being threatened, helping family caregivers to continue providing long-term services and supports is good public policy. We look forward to working with you on the OAA reauthorization to improve services for our nation’s caregivers.

Sincerely,

ACCSES

American Dance Therapy Association

American Music Therapy Association

Association of University Centers on Disabilities

Autism National Committee

Family Voices

Lutheran Services in America Disability Network

National Association of Councils on Developmental Disabilities

National Association of State Directors of Special Education

National Respite Coalition

Parent to Parent USA

The Arc