



Commemorating 40 Years
Of Disability Advocacy
1973-2013

May 22, 2013

The Honorable Bernie Sanders
Chair, Subcommittee on Primary Health and Aging
Committee on Health, Education, Labor, and Pensions
428 Senate Dirksen Office Building
Washington, DC 20510

Dear Senator Sanders:

Thank you for your Older Americans Act reauthorization bill and its many improvements to help aging parents caring for their adult children with disabilities. The Developmental Disabilities, Autism and Family Support Task Force of the Consortium for Citizens with Disabilities (CCD) greatly appreciates the proposed amendments to the National Family Caregiver Support program (NFCSP) and the Aging and Disability Resource Centers (ARDCs).

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 only available to caregivers of persons age 60 and over. Your bill would make the program available to the increasing number of Americans who need it 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 730,000 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 aging of the caregiver population is central to another welcome provision in the bill – the addition of ADRCS assisting aging caregivers and adults with disabilities with 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.”

More than at any other time, when Medicaid, Medicare, and Social Security are being severely 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 reauthorization of the Older Americans Act that will improve services for our nation's caregivers.

CCD is a coalition of national disability organizations working together to advocate for national public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society.

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