

October 25, 2011

The Honorable Patty Murray
Co-Chair
Joint Select Committee on Deficit Reduction
448 Russell Senate Office Building
Washington, DC 20510

The Honorable Jeb Hensarling
Co-Chair
Joint Select Committee on Deficit Reduction
129 Cannon House Office Building
Washington, DC 20515

Dear Senator Murray and Representative Hensarling:

The undersigned national organizations write on behalf of the nation's **65.7 million family caregivers** who are providing care to a loved one who is aged or has a disabling or chronic condition.¹ We respectfully request that the Joint Select Committee preserve vital funding for programs supporting these caregivers who provide \$450 billion in unpaid care every year.²

Specifically, we request that you maintain current funding levels for discretionary programs and protect access to services in entitlement programs, including:

The National Family Caregiver Support Program: Part of the Older Americans Act, this program funds a broad range of supports for family caregivers, including respite care, information and referral to supportive services, individual counseling, and caregiver training. In a 2010 GAO survey of Area Agencies on Aging, 66 percent reported increased requests for caregiver services since the economic downturn began.³ An evaluation of the program found that nearly half the caregivers of nursing home eligible care recipients indicated that the care recipient would be unable to remain at home without the support services offered by the NFCSP.⁴

The Lifespan Respite Care Program: Thirty states have received funding since 2009 to streamline and expand access to respite for family caregivers for children or adults of all ages with special needs. Fifty-seven percent of Area Agencies on Aging report that respite was the most-requested service by family caregivers in 2009, demonstrating the importance of respite breaks for family caregivers who have taken on a role that is often equivalent to a full-time job or greater.⁵ Lifespan Respite is especially important because it serves caregivers for adults and children of all ages. It is also the only federal program designed to help improve access to respite for those not currently served, especially adults with ALS, Multiple Sclerosis, spinal cord or traumatic brain injury, adults with developmental disabilities or mental health conditions, and children with autism, physical disabilities or serious emotional disturbances.

Medicaid: Outside of family caregivers, Medicaid is the nation's largest funder of long-term services and support. Over the past decade, states have shifted their Medicaid funding to provide more Home and Community-Based services, including adult day health care, home health

¹ National Alliance for Caregiving and AARP. (2009) *Caregiving in the U.S.*

² AARP Public Policy Institute. (2011) *Valuing the Invaluable: Contributions, Costs, and Consequences of Family Caregiving.*

³ U.S. G.A.O. (2010) *Older Americans Act: Preliminary Observations on Services Requested by Seniors and Challenges in Providing Assistance.*

⁴ Administration on Aging (2008) http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/Caregiver/index.aspx

⁵ U.S. G.A.O. (2010)

services, personal care services, and more. This shift has allowed more Medicaid beneficiaries to remain in their own homes, enabled family caregivers to stay employed, and has also saved taxpayer dollars since HCBS is less expensive than nursing home care. Cuts to Medicaid will prove far more expensive if and when nursing home placements are accelerated because family caregivers can't take on this role without adequate support.

Medicare: A number of proposals have suggested increasing cost-sharing for Medicare beneficiaries; however, half of Medicare beneficiaries have incomes below \$22,000 a year. The median out-of-pocket health spending as a share of income for Medicare beneficiaries in 2006 was 16 percent, with one in four Medicare beneficiaries spending 30 percent or more of their income on health expenses.⁶ The majority of Medicare beneficiaries are simply unable to shoulder greater premiums or out-of-pocket expenses.

VA Caregiver Support: In a survey of family caregivers caring for veterans whose illness, injury or condition is in some way related to military service, sixty-eight percent reported their situation as highly stressful compared to 31 percent of caregivers nationally who feel the same. Three times as many say there is a high degree of physical strain (40 percent vs. 14 percent). Yet, only 15 percent had received respite services from the VA or some other community organization within the past 12 months. Caregivers whose veterans have PTSD are only about half as likely as other caregivers to have received respite services (11 percent vs. 20 percent).⁷ The newly implemented VA Family Caregiver Support Program is critical to support our nation's veterans and their families.

Family Support: Projects of National Significance in the Developmental Disabilities Act provide the only source of funding for comprehensive family support services and systems change for children and adults with developmental disabilities living at home. The vast majority (60 percent) of the 4.8 million people with intellectual and developmental disabilities (I/DD) live at home with family caregivers. If the caregivers are parents, they do not qualify for the National Family Caregiver Support Program (NFCSP). Twenty-five percent live with family caregivers who are over the age of 60. A recent study from The Arc found that significantly more than 75 percent of family caregivers of adult children with developmental disabilities could not find respite or other support services.

Through our direct experiences working with family caregivers, we know that these supportive services help prevent caregiver burnout, decrease the financial burden of family caregiving, improve the quality of life for both the caregiver and the person they provide care for, and may even help avoid or delay much more costly out-of-home placements. Please preserve the funding for these vital programs in your final deliberations.

Thank you for your consideration.

Sincerely,

⁶ Kaiser Family Foundation (2011) *How Much Skin in the Game is Enough? The Financial Burden of Health Spending for People on Medicare.*

⁷ National Alliance for Caregiving (2010) *Caregivers Of Veterans - Serving On The Homefront.*

Alzheimer's Foundation of America
American Association for Geriatric Psychiatry
American Network of Community Options and Resources
American Psychological Association
Association of University Centers on Disabilities
Autism National Committee
Brain Injury Association of America
Christopher and Dana Reeve Foundation
Disability Rights Education & Defense Fund
Easter Seals
Family Voices
Epilepsy Foundation
Generations United
National Alliance for Caregiving
National Association for Home Care & Hospice
National Association of Area Agencies on Aging (n4a)
National Association of State Head Injury Administrators
National Association of States United for Aging and Disabilities
National Center on Caregiving, Family Caregiver Alliance
National Disability Rights Network
National Family Caregiver Association
National Federation of Families for Children's Mental Health
National Multiple Sclerosis Society
National Respite Coalition
OWL-The Voice of Midlife and Older Women
Paralyzed Veterans of America
Rosalynn Carter Institute for Caregiving
The Arc
United Cerebral Palsy
United Spinal Association
Well Spouse™ Association