



June 23, 2008

The Honorable Tom Harkin
Chairman, Labor-HHS-ED
Appropriations Subcommittee
United States Senate
Washington, D.C. 20510

The Honorable Arlen Specter
Ranking Member, Labor-HHS-ED
Appropriations Subcommittee
United States Senate
Washington, D.C. 20510

Re: Invest in Supporting Families and Informal Caregivers

Dear Chairman Harkin and Ranking Member Specter:

On behalf of the Consortium for Citizens with Disabilities (CCD) Long-Term Services and Supports and Developmental Disabilities Task Forces and the Leadership Council of Aging Organizations (LCAO), the following undersigned organizations ask for your support in providing appropriations for important family caregiver support programs. 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. LCAO is a coalition of national nonprofit organizations concerned with the well-being of America's older population and committed to representing their interests in the policy-making arena.

Families are the foundation of long-term services and supports for seniors and individuals with disabilities in the United States. Over 80% of all long-term services and supports are delivered informally. There are approximately 50.4 million informal caregivers in the United States that support individuals with disabilities and seniors. Needs for long-term services and supports are dramatically increasing as the US population ages. Over the next 15 years the number of individuals needing long-term services and supports is projected to increase by 30% and will double by 2050. Moreover, there are extensive and growing unmet needs of younger and older individuals with disabilities for formal services. While not all states maintain official waiting lists, in 2006 there were over 280,000 individuals in 31 states waiting for Medicaid Home and Community Based Services. The vast majority of individuals with developmental disabilities live at home with family, many with aging caregivers who have provided life-long support. In addition, the increased prevalence of certain developmental disabilities such as Autism is placing additional strain on the formal disability service system.

A broad range of flexible caregiver supports are needed across age and disability categories. One of the most frequently requested services by families is respite, which provides temporary

relief from caregiving responsibilities. A body of literature clearly indicates that respite and other caregiver supports are effective in reducing stress and increasing economic, health, and social well-being of caregivers and families. These benefits contribute to the ability of caregivers to continue providing support and reduce more costly placements in nursing homes and other institutions.

Investing in family and informal caregiver supports is fiscally wise. The economic value of informal caregiving is a staggering \$350 billion a year. In addition, American businesses lose between \$17.1 and \$33.6 billion annually in lost productivity costs related to caregiving responsibilities. While there are a number of successful programs to support family and informal caregivers, funding has not kept pace with growing demands and pressures on families. Providing additional funding for the following programs could bolster the ability of family and informal caregivers to provide supports and produce long-term savings to business and government.

National Family Caregiver Support Program

The National Family Caregiver Support Program (NFCSP) is authorized under Title III-E of the Older Americans Act of 1965 as Amended in 2006 (P.L. 109-365). The NFCSP calls for states, working in partnership with local area agencies on aging (AAAs) and service providers, to provide a continuum of caregiver services, including information about available services, assistance accessing services, individual counseling, support groups, training, respite, and supplemental services (e.g. emergency response systems, home modifications). Eligibility for the program was slightly expanded during the 2006 reauthorization. The program is currently intended to serve caregivers of older individuals, caregivers of individuals with Alzheimer's of any age, and grandparent and older caregivers of children and adults with disabilities. Since its inception in 2001, the NFCSP has received only modest increases or level funding. In FY 08 the NFCSP actually received a cut due to a 1.747% across the board cut in domestic discretionary spending. The NFCSP was funded at \$153.4 million for FY 08.

The Native American caregiving program, authorized under Title VI of the Act, offers similar supports and services to caregivers in Indian country, as well as native Alaskans and Hawaiians, who are among the most economically disadvantaged elderly minority groups in the nation. This program desperately needs increased funds in order to develop adequate caregiver programs in the tribes, as well as offer training on how to use the funds most effectively.

Recommendation:

To better meet the increasing prevalence of family and informal caregiving and increased eligibility under the NFCSP, it is recommended that the NFCSP be funded at \$250 million for FY 09. Additionally, Part C (caregiving) of the OAA Title VI should receive at least \$6.9 million in FY 09.

Lifespan Respite Care Act

The Lifespan Respite Care Act (P.L. 109-442) authorizes competitive grants to states through Aging and Disability Resource Centers in collaboration with public or private non-profit state respite coalitions or organizations. The purpose is to assist states in developing statewide respite care systems to make quality respite available to family caregivers regardless of age or disability.

It encourages grantees to identify, coordinate and build upon federal, state, and local respite resources and funding streams. It also would assist with addressing issues of planned and emergency respite, provider recruitment and training, and family caregiver training. The Lifespan Respite Care Act was signed into law on December 21, 2006. However, it has not yet received appropriations to implement it.

Recommendation:

In order to implement the Lifespan Respite Care Act, it is recommended that it be funded at \$53.3 million as authorized in FY 09.

Family Support Program

Title II of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (P.L. 106-402) authorizes the Families of Children with Disabilities Support Act of 2000. The purpose of this title is to promote and strengthen systems of family support services for families with relatives with developmental disabilities. The Administration on Developmental Disabilities (ADD) Family Support 360 initiative provides competitive family support grants to states to plan and implement one-stop centers to assist families with relatives with developmental disabilities. ADD has provided family support grants through funding from Title I, Subtitle E, Projects of National Significance (PNS). PNS was funded at \$14.2 million for FY 08, with approximately \$7.2 million allocated towards family support. Only 21 states currently receive family support grants of approximately \$250,000 each. In addition, \$2 million is provided for a national technical assistance center.

Recommendation:

In order to strengthen and expand projects to every state and US territory, it is recommended that separate funding for the Family Support Act (Title II) be provided at \$17 million for FY 09. This funding should not negatively impact appropriations for current or other initiatives within PNS.

Thank you for your consideration of these appropriations recommendations and your support of families and informal caregivers. For additional information please contact Joe Caldwell, Co-Chair CCD Long-Term Services and Support Task Force, at jcaldwell@aucd.org or Howard Bedlin with LCAO at howard.bedlin@ncao.org.

Sincerely,

Alliance for Retired Americans
American Foundation for the Blind
American Geriatrics Society
American Homes and Services for the Aging
American Psychological Association
American Society on Aging
Association for Gerontology and Human Development in Historically Black Colleges and Universities
Association of Jewish Aging Services
Association of University Centers on Disabilities

Catholic Health Association of the United States
Easter Seals
Epilepsy Foundation
Gray Panthers
Lutheran Services in America
National Alliance for Caregiving
National Adult Day Services Association
National Association of Area Agencies on Aging
National Association of Geriatric Care Managers
National Association for Home Care & Hospice
National Association of Social Workers
National Association of State Long-Term Care Ombudsman Programs
National Council on Aging
National Committee to Preserve Social Security and Medicare
National Indian Council on Aging
National Respite Coalition
NCCNHR: The National Consumer Voice for Quality Long-Term Care
OWL – The Voice of Midlife and Older Women
Paralyzed Veterans of America
Service Employees International Union
The Arc of the United States
United Cerebral Palsy
United Spinal Association