

**Written Testimony of  
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Washington, DC  
For the House Subcommittee on Labor, HHS and Education Appropriations  
Public Witness Testimony for the Record  
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Mr. Chairman, I am Jill Kagan, Chair of the ARCH National Respite Coalition, a network of respite providers, family caregivers, state and local agencies and organizations across the United States who support respite. Twenty-five state respite coalitions, including the Wisconsin Respite Care Association and the New York Respite Coalition, are also affiliated with the NRC. This statement is presented on behalf of these organizations, as well as the members of the Lifespan Respite Task Force, a coalition of over 80 national and more than 100 state and local groups who supported the passage of the Lifespan Respite Care Act (P.L. 109-442). Together, we are requesting that the Subcommittee include funding for the newly enacted Lifespan Respite Care Act in the FY 09 Labor, HHS and Education Appropriations bill at its modest authorized level of \$53.3 million for FY 09.

Many Members of Congress already support funding for Lifespan Respite. We join the 26 Members of Congress who, along with Rep. Langevin (D-RI) and Rep. Ferguson (R-NJ), recently sent a letter to the Subcommittee making this same request. The Senate Budget Resolution also reserves \$53 million in the Dept. of Health and Human Services Account for Lifespan Respite.

***Who Needs Respite?***

A national survey found that 44 million family caregivers are providing care to individuals over age 18 with disabilities or chronic conditions (National Alliance for Caregiving (NAC) and AARP, 2004). In 2001, the last year federal data were collected, 9.4 million children under age 18 were identified with chronic or disabling conditions (National Survey of Children with Special Health Care Needs, U.S. Health Resources and Services Administration, 2001). These surveys suggest that a conservative estimate of the nation's family caregivers probably exceeds 50 million.

Compound this picture with the growing number of caregivers known as the "sandwich generation" caring for young children as well as an aging family member. It is estimated that between 20 and 40 percent of caregivers have children under the age of 18 to care for in addition to a parent or other relative with a disability. And in the US, 6.7 million children, with and without disabilities, are in the primary custody of an aging grandparent or other relative other than their parents.

These family caregivers are providing about 80% of all long-term care in the U.S. It has been estimated that in the U.S., these family caregivers provide \$350 billion in uncompensated care, an amount comparable to Medicare spending (\$342 billion in 2005) and more than total

spending for Medicaid, including both federal and state contributions and both medical and long-term care (\$300 billion in 2005). (AARP, 2007).

### ***What is Respite Need?***

State and local surveys have shown respite to be the most frequently requested service of the nation's family caregivers, including a recent study, "Evercare Study of Caregivers in Decline" (Evercare and NAC, 2006). Yet respite is unused, in short supply, inaccessible, or unaffordable to a majority of the nation's family caregivers. The 2004 NAC/AARP survey of caregivers found that despite the fact that the most frequently reported unmet needs were "finding time for myself," (35%), "managing emotional and physical stress" (29%), and "balancing work and family responsibilities" (29%), only 5% of family caregivers were receiving respite (NAC and AARP, 2004). It was recently found that in rural areas, the percentage of family caregivers able to make use of respite dropped to 4% (Easter Seals and NAC, 2006)

Barriers to accessing respite include reluctance to ask for help, fragmented and narrowly targeted services, cost, and the lack of information about how to find or choose a provider. Even when respite is an allowable funded service, a critically short supply of well trained respite providers may prohibit a family from making use of a service they so desperately need.

Twenty of 35 state-sponsored respite programs surveyed in 1991 reported that they were unable to meet the demand for respite services. In the last 15 years, we suspect that not too much has changed. A recent study conducted by the Family Caregiver Alliance identified 150 family caregiver support programs in all 50 states and Washington, DC funded with state-only or state/federal dollars. Most of the funding comes through the federal National Family Caregiver Support Program. As a result, programs are administered by local area agencies on aging and primarily serve the elderly. And again, some programs provide only limited respite, if at all. Only about one-third of these 150 identified programs serve caregivers who provide care to adults age 18-60 who must meet stringent eligibility criteria. As the report concluded, "State program administrators see the lack of resources to meet caregiver needs in general and limited respite care options as the top unmet needs of family caregivers in the states."

The 25 state coalitions and other National Respite Network members confirm that long waiting lists or turning away of clients because of lack of resources is still the norm.

While most families take great joy in helping their family members to live at home, it has been well documented that family caregivers experience physical and emotional problems directly related to their caregiving responsibilities. Three-fifths of family caregivers age 19-64 surveyed recently by the Commonwealth Fund reported fair or poor health, one or more chronic conditions, or a disability, compared with only one-third of non-caregivers (Ho, Collins, Davis and Doty, 2005). A study of elderly spousal caregivers (aged 66-96) found that caregivers who experience caregiving-related stress have a 63% higher mortality rate than noncaregivers of the same age (Schulz and Beach, December 1999).

Supports that would ease their burden, most importantly respite care, are too often out of reach or completely unavailable. Even the simple things we take for granted, like getting enough

rest or going shopping, become rare and precious events. One Massachusetts mother of a seriously ill child spoke to the demands of constant caregiving: "I recall begging for some type of in-home support...It was during this period when I fell asleep twice while driving on the Massachusetts Turnpike on the way to appointments at Children's Hospital. The lack of respite...put our lives and the lives of everyone driving near me at risk."

Restrictive eligibility criteria also preclude many families from receiving services or continuing to receive services they once were eligible for. A mother of a 12-year-old with autism was denied additional respite by her state DD (Developmental Disability) agency because she was not a single mother, was not at poverty level, wasn't exhibiting any emotional or physical conditions herself, and had only one child with a disability. As she told us, "Do I have to endure a failed marriage or serious health consequences for myself or my family before I can qualify for respite? Respite is supposed to be a preventive service."

For the millions of families of children with disabilities, respite has been an actual lifesaver. However, for many of these families, their children will age out of the system when they turn 21 and they will lose many of the services, such as respite, that they currently receive. In fact, 46% of U.S. state units on aging identified respite as the greatest unmet need of older families caring for adults with lifelong disabilities. An Alabama mom of a 19-year-old-daughter with multiple disabilities who requires constant care recently told us about her fears at a respite summit in Alabama, "My daughter Casey has cerebral palsy, she does not communicate, she is incontinent she eats a pureed diet, she utilizes a wheelchair, she is unable to bathe or dress herself. At 5'5" and 87 pounds I carry her from her bedroom to the bathroom to bathe her, and back again to dress her.... Without respite services, I do not think I could continue to provide the necessary long-term care that is required for my daughter...As I age, I do wonder how much longer I will be able to maintain my daily ritual as my daughter's primary caregiver."

Disparate and inadequate funding streams exist for respite in many states. But even under the Medicaid program, respite is allowable only through state waivers for home and community-based care. Under these waivers, respite services are capped and limited to narrow eligibility categories. Long waiting lists are the norm.

Respite may not exist at all in some states for adult children with disabilities still living at home, or individuals under age 60 with conditions such as ALS, MS, spinal cord or traumatic brain injuries, or children with serious emotional conditions. In Tennessee, a young woman in her twenties gave up school, career and a relationship to move in and take care of her 53 year-old mom with MS when her dad left because of the strain of caregiving. She went for years providing constant care to her mom with almost no support. Now 31, she wrote, "And I was young – I still am – and I have the energy, but – it starts to weigh. Because we've been able to have respite care, we've developed a small pool of people and friends that will also come and stand in. And it has made all the difference."

### ***Respite Benefits Families and is Cost Saving***

Respite has been shown to be a most effective way to improve the health and well-being of family caregivers that in turn helps avoid or delay out-of-home placements, such as nursing homes or foster care, minimizes the precursors that can lead to abuse and neglect, and

strengthens marriages and family stability. A recent report from the US Dept of Health and Human Services prepared by the Urban Institute found that higher caregiver stress among those caring for the aging increases the likelihood of nursing home entry. Reducing key stresses on caregivers, such as physical strain and financial hardship, through services such as respite would reduce nursing home entry (Spillman and Long, USDHHS, 2007)

The budgetary benefits that accrue because of respite are just as compelling, especially in the policy arena. Delaying a nursing home placement for just one individual with Alzheimer's or other chronic condition for several months can save government long-term care programs thousands of dollars. In an Iowa survey of parents of children with disabilities, a significant relationship was demonstrated between the severity of a child's disability and their parents missing more work hours than other employees. They also found that the lack of available respite care appeared to interfere with parents accepting job opportunities. (Abelson, A.G., 1999)

Moreover, data from an ongoing research project of the Oklahoma State University on the effects of respite care found that the number of hospitalizations, as well as the number of medical care claims decreased as the number of respite care days increased (FY 1998 Oklahoma Maternal and Child Health Block Grant Annual Report, July 1999). A Massachusetts social services program designed to provide cost-effective family-centered respite care for children with complex medical needs found that for families participating for more than one year, the number of hospitalizations decreased by 75%, physician visits decreased by 64%, and antibiotics use decreased by 71% (Mausner, S., 1995).

In the private sector, the most recent study by Metropolitan Life Insurance Company and the National Alliance for Caregivers found that U.S. businesses lose from \$17.1 billion to \$33.6 billion per year in lost productivity of family caregivers. Offering respite to working family caregivers could help improve job performance and employers could potentially save billions (MetLife and National Alliance for Caregiving, 2006).

### ***Lifespan Respite Care Program Will Help***

The Lifespan Respite Care Act is based on the success of statewide Lifespan Respite programs in four states: Oregon, Nebraska, Wisconsin and Oklahoma. A new Arizona State Lifespan Respite program will soon be up and running. Michigan passed state Lifespan Respite legislation in 2004 but has not provided the funding to implement the program, and new state Lifespan Respite legislation is currently pending in Kansas in preparation for the federal funds.

Lifespan Respite, which is a coordinated system of community-based respite services, helps states use limited resources across age and disability groups more effectively, instead of each separate state agency or community-based organization being forced to constantly reinvent the wheel or beg for small pots of money. Pools of providers can be recruited, trained and shared, administrative burdens can be reduced by coordinating resources, and the savings used to fund new respite services for families who may not currently qualify for any existing federal or state program.

The state Lifespan Respite programs provide best practices on which to build a national respite policy. The programs have been recognized by prominent policy organizations, including the National Conference of State Legislatures, which recommended the Nebraska program as a

model for state solutions to community-based long-term care. The National Governors Association and the President's Committee for People with Intellectual Disabilities also have highlighted lifespan respite systems as viable solutions. And most recently, the White House Conference on Aging recommended enactment of the Lifespan Respite Care Act to Congress.

The Lifespan Respite Task Force, a coalition of over 80 diverse national organizations, representing family caregivers, individual disabilities or chronic conditions, faith-based organizations, and social, health care and mental health services, aging and children' groups, diligently worked alongside its bipartisan congressional champions to see the legislation through to enactment in December 2006.

The purpose of the new law is to expand and enhance respite services, improve coordination, and improve respite access and quality. Under a competitive grant program, states would be required to establish state and local coordinated Lifespan Respite care systems to serve families regardless of age or special need, provide new planned and emergency respite services, train and recruit respite workers and volunteers and assist caregivers in gaining access to services.

Those eligible would include family members, foster parents or other adults providing unpaid care to adults who require care to meet basic needs or prevent injury and to children who require care beyond that required by children generally to meet basic needs.

The federal Lifespan Respite program would be administered by the U.S. Department of Health and Human Services (HHS), which would provide competitive grants to statewide agencies through Aging and Disability Resource Centers working in collaboration with state respite coalitions or other state respite organizations. The program is authorized at \$53.3 million in FY 09 rising to \$95 million in FY 2011. The program has received no Congressional funding to date.

No other federal program mandates respite as its sole focus. No other federal program would help ensure respite quality or choice, and no current federal program allows funds for respite start-up, training or coordination or to address basic accessibility and affordability issues for families. We urge you to include \$53.3 million in the FY 09 Labor, HHS, Education appropriations bill so that Lifespan Respite Programs can be replicated in the states and more families, with access to respite, will be able to continue to play the significant role in long-term care that they are fulfilling today.

*Complete references available upon request.*

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