Public Witness Testimony of Jill Kagan

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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 Kansas Lifespan Respite Coalition, are also affiliated with the NRC. This statement is presented on behalf of the these organizations, as well as the members of the Lifespan Respite Task Force, a coalition of over 80 national and 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 Lifespan Respite Care Program administered by the US Administration on Aging in the FY 2011 Labor, HHS, and Education Appropriations bill at its modest authorized level of $94.8 million. This will enable:

- State replication of best practices in Lifespan Respite systems to allow all family caregivers, regardless of the care recipient's age or disability, to have access to affordable respite, and to be able to continue to play the significant role in long-term care that they are fulfilling today;
- Improvement in the quality of respite services currently available;
- Expansion of respite capacity to serve more families by building new and enhancing current respite options, including recruitment and training of respite workers and volunteers; and
- Greater consumer direction by providing family caregivers with training and information on how to find, use and pay for respite services.

We join the 37 House Members, including the Chairman and Subcommittee Chairman of the program's authorizing committees and five other Committee and Subcommittee Chairmen, who, along with Rep. Langevin (D-RI), recently sent a letter to the Subcommittee urging full funding for Lifespan Respite in FY 2011.

Who Needs Respite?

In 2009, a national survey found that over 65 million family caregivers are providing care to individuals of any age with disabilities or chronic conditions (Caregiving in the U.S. 2009. Bethesda, MD: National Alliance for Caregiving and Washington, DC: AARP, 2009). It has been estimated that family caregivers provide $375 billion in uncompensated care, an amount almost as high as Medicare spending ($432 billion in 2007) and more than total spending for Medicaid, including both federal and state contributions and both medical and long-term care ($311 billion in 2005) (Gibson and Hauser, 2008).

While the aging population is growing rapidly, increasing the need for family caregiver support for this age group, the **majority** of family caregivers are caring for someone **under age 75 (56%)**; 28% of family caregivers care for someone between the ages of 50-75, and 28% are caring for someone under age 50, including children (NAC and AARP, 2009). Family caregiving is not just an aging issue, but also a lifespan issue for the majority of the nation's families.

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.

Families of the wounded warriors – those military personnel returning from Iraq and Afghanistan with traumatic brain injuries and other serious chronic and debilitating conditions- are at risk for limited access to respite.

Together, these family caregivers provide an estimated 80% of all long-term care in the U.S. This percentage will only rise in the coming decades with an expected increase in the number of chronically ill veterans returning from war, greater life expectancies of individuals with Down's Syndrome and other disabling and chronic conditions, the aging of the baby boom generation, and the decline in the percentage of the frail elderly who are entering nursing homes.

What is Respite Need?

State and local surveys have shown respite to be the most frequently requested service of the nation's family caregivers (Evercare and NAC, 2006). Yet respite is unused, in short supply, inaccessible, or unaffordable to a majority of the nation's family caregivers. The 2009 NAC/AARP survey of caregivers found that a majority (51%) have medium or high levels of burden of care, measured by the number of activities of daily living with which they provide assistance, and 31%of all family caregivers were identified as "highly stressed". Half of all family caregivers (53%) say that their caregiving takes time away from family and friends. Of those who sacrificed this time, 47% feel high emotional stress. Moreover, the 2009 survey found that despite the fact that among the most frequently reported unmet needs of family caregivers were "finding time for myself" (32%), "managing emotional and physical stress" (34%), and "balancing work and family responsibilities" (27%), only 11% of caregivers of adults 18+ use respite. This represents an increase from 5% in 2004, but still far less than the percentage who could benefit from respite. Of six proposed national policies or programs that could help caregivers, 3 in 10 selected respite as the preferred service (NAC and AARP, 2009). According to another survey in 2006, the percentage of family caregivers able to use respite in rural areas was only 4% (Easter Seals and NAC, 2006). In a study of a nationally representative profile of noninstitutionalized children ages 0-17 who were receiving support from the Supplemental Security Income (SSI) program because of a disability, only 8% reported using respite care but three quarters of families had unmet respite needs (Rupp, K, et al, 2005-2006).

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. 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. A 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, primarily serve the aging, and provide only limited respite, if at all. Only about one-third of the 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."

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, 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 for which they once were eligible. 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, was not 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, utilizes a wheelchair, 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, I do not think I could continue to provide the necessary long-term care that is required for my daughter. As I age, I 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 the 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, 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. Delaying a nursing home placement for just one individual with Alzheimer's or other chronic condition for several months can save 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. It was also found that the lack of available respite 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 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. (MetLife and National Alliance for Caregiving, 2006). A more recent study from the National Alliance on Caregiving and Evercare demonstrated that the economic downturn has had a particularly harsh effect on family caregivers. Of the six in ten caregivers who are employed, 50% of them are less comfortable during the economic downturn with taking time off from work to care for a family member or friend. A similar percentage (51%) says the economic downturn has increased the amount of stress they feel about being able to care for their relative or friend. Respite for working family caregivers could help improve job performance and employers could potentially save billions.

Lifespan Respite Care Program Will Help

The Lifespan Respite Care Act is based on the success of statewide Lifespan Respite programs in Oregon, Nebraska, Wisconsin and Oklahoma. Arizona and Texas both recently passed state legislation to establish Lifespan Respite Programs, but Arizona's program was cut due to state budget shortfalls. Twelve states, including AZ, began implementation in 2009 with the first wave of federal Lifespan Respite funding.

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 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 savings used to fund new respite services for families who may not qualify for existing federal or state programs. For the growing number of veterans returning home with TBI or other polytrauma, the shortage of staff qualified to provide respite to this population is especially critical. Lifespan Respite systems can make all the difference by ameliorating special barriers for this population

The first state Lifespan Respite programs in OR, NE, WI and OK provide best practices on which to build a national respite policy. The programs have been recognized by 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. The White House Conference on Aging recommended enactment of the Lifespan Respite Care Act to Congress.

The purpose of the 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 is administered by the U.S. Administration on Aging, Department of Health and Human Services (HHS). AoA provides competitive grants to state agencies in concert with Aging and Disability Resource Centers working in collaboration with state respite coalitions or other state respite organizations. The program was authorized at $53.3 million in FY 09 rising to $95 million in FY 2011. Congress appropriated $2.5 million in FY09 and again in FY 2010. In FY 09, twelve states received 36-month $200,000 grants to implement Lifespan Respite. In these states, that represents less than $.18 per caregiver.

The Administration recommended $5 million for Lifespan Respite as part of its Middle Class Initiative. We are heartened to see that support for family caregiving is recognized as a critical component of a typical family's economic and social well-being. However, the focus of the Administration's request was on support for family caregivers of the aging population. While this is an issue of growing concern, we must not neglect that fact that at least half of the nation's family caregivers are caring for someone with MS, ALS, traumatic brain or spinal cord injury, mental health conditions, developmental disabilities or cancer who are under the age of 60 and $5 million will not address their need for respite. This is also the population most likely to be ineligible for any existing state or federal respite resources.

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 $94.8 million in the FY 11 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. Prepared by Jill Kagan, Chair, National Respite Coalition, 4016 Oxford Street, Annandale, VA, 22003; 703-256-2084; jbkagan@verizon.net; www.archrespite.org.