Mr. Chairman and Members of the Subcommittee,

My name is Jill Kagan and I am chair of the ARCH National Respite Coalition. The Coalition is the policy division of the ARCH National Respite Network and Resource Center, a membership organization of respite providers, family caregivers, and representatives of public and private state and local agencies across the country. Twenty-two state respite coalitions and five State Lifespan Respite Programs are also currently affiliated with the NRC. I am honored to have this opportunity to present testimony on the importance of respite as a critical need of Family Caregivers of Veterans.

What is Respite?

Respite care provides temporary relief for family caregivers from the ongoing responsibility of caring for an individual of any age with special needs. As a preventive strategy, respite helps strengthen families, protects their health and well-being, and allows them to continue providing care at home. Respite is also an important component of a continuum of comprehensive family support and long-term services that are available to caregivers not only on a planned basis, but also in the event of a crisis or emergency situation.

Ideally, a variety of respite models would be available in a given community to provide an array of options for family caregivers, depending on their evolving needs over time. Sometimes in-home services are required so family caregivers can tend to obligations, medical or other critical appointments, or recreation outside the home. At other times, the care recipient may benefit from out-of-home services to engage in social activities or therapeutic services, which allows the family caregiver time to do household tasks, tend to other family members, or simply take a much-needed break. Out-of-home services may take place in facility-based settings, such as adult day services or hospitals, or churches, schools, camps, foster homes, or the homes of relatives, friends or neighbors. Some out-of-home services are facilities designed specifically to provide respite. In the best of circumstances, services would be available on an hourly or weekly basis, and also provide evening or weekend care. Services can be provided in-home or out-of-home by trained respite providers with varying degrees of medical or mental health expertise, volunteers, neighbors, other family members or friends.

Who Needs Respite?

In 2004, a national survey found that 44 million family caregivers provide care to individuals over age 18 with disabilities or chronic conditions (National Alliance for Caregiving (NAC) and AARP, 2004). AARP’s most recent survey estimates that in 2007, about 34 million caregivers age 18 or older are providing an average of 21 hours of care per week to adults with limitations in daily activities. The estimated 34 million caregivers represent the number giving care at any given point. An even higher number, about 52 million, provided care at some point during the year (Gibson and Hauser, 2008).

Today, we are talking specifically about the respite and support needs of family caregivers of veterans. In 2007, there were an estimated 26.3 million veterans; 9.3 million were 65 and older. Six million veterans are estimated to have a disability; 2.7 million received compensation for service-connected disabilities as of 2006. Their compensation totaled $28.2 billion (U.S Census Bureau, 2008). According to the 2001 National Survey of Veterans, the average age of the veteran population was 58 years old in 2000, with the largest group of veterans between the ages of 45 and 64.
The number of family caregivers of veterans is high and climbing. For the most recent victims, the soldiers returning from Iraq and Afghanistan, new challenges are evident because of the extremely serious nature of their disabling conditions. According to the VA Geriatrics and Extended Care Polytrauma Rehabilitation Task Force: “The care requirements of severely injured OEF/OIF veterans will vary throughout the veterans’ lives. In some instances, the care needs will diminish or cease, and in other instances the care needs will broaden and intensify. As many of these seriously injured veterans may require support and assistance for many years, the caregivers will face many physical and emotional challenges over time. VA currently provides support to caregivers through the following programs: inpatient and home respite, homemaker/home health aide, and ADHC. However, there are locations in which caregiver support is minimally available through any resource, and the Task Force anticipates considerable challenges in reliably meeting the caregiver support needs in all communities (US Dept of Veterans Affairs, Veterans Health Administration, Report of the VA Geriatrics and Extended Care Polytrauma Rehabilitation Task Force, February 2008).

It has been estimated that family caregivers overall 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). Family caregivers are providing an estimated 80% of all long-term care in the U.S. This percentage will only rise in the coming decades with increasing numbers of severely wounded veterans returning home from the ongoing wars in Iraq and Afghanistan, the greater life expectancies of individuals with Down 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. This decline is due partially to the growing number of individuals moving to privately funded assisted living facilities (about 1 million individuals are in assisted living), but even more older individuals, with fewer disabilities and more wealth, are choosing to stay at home with support from home and community-based services and supports (Alexihi, L, Lewin Group, 2006).

This trend toward home and community-based services among individuals of all ages and disabling conditions has been encouraged by the advent of the Supreme Court's Olmstead decision which required that individuals with disabilities be able to live and work in the least restrictive environment, and an emerging federal policy direction that focuses on home and community-based care rather than institutional placement. States wishing to reduce Medicaid long-term care expenditures have also refocused their policies to support home and community-based services.

**Respite Benefits Families and is Cost Saving**

Respite has been shown to be effective in improving 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).

Respite for the elderly with chronic disabilities in a study group resulted in fewer hospital admissions for acute medical care than for two control groups who received no respite care (Chang, J.I., et al, 1992). Sixty-four percent of caregivers of the elderly receiving 4 hours of respite per week after one year reported improved physical health, 78% improved their emotional health, and 50% cited improvement in the care recipient. Forty percent said they were less likely to institutionalize the care recipient because of respite (Theis, S.L., et al, 1994). Caregivers of relatives with dementia who used adult day care experienced lower levels of caregiving related stress and better psychological well-being than a control group not using the service. Differences were found in both short-term (3 months) and long-term (12 months) users (Zarit, S.H., et al, 1998). In a study to determine whether adult day service use was related to decreases in primary caregiving hours, it was found that adult day service users reported greater decreases in hours spent on behavior problems when compared to nonusers, and
decreased frequency of behavior problems in relatives who attended adult day program. Findings suggest that adult day services, if used over time, are effective in restructuring caregiving time and may offer benefits to family caregivers and to older adults with dementia (Gaugler, JE, Jarrott SE, Zarit, SH, 2003).

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 Medicaid and other federal and state government long-term care programs thousands of dollars. In the private sector, a 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 (MetLife and NAC, 2006). A family’s personal economic situation can also be drastically affected. Offering respite to working family caregivers could help improve job performance and employers could potentially save billions of dollars.

**Barriers to Respite**

While most family caregivers take great joy in helping their family members to live at home, it has been well documented they experience physical and emotional problems directly related to their caregiving responsibilities (Keller, 2004; Butler, 2005; Family Caregiver Alliance, Fact Sheet, 2006; Loretta-Secco, M, et al, 2006; 2006; Pinquart and Sorensen, 2007). Three-fifths of family caregivers ages 19-64 surveyed 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, 1999).

State and local surveys have shown respite to be the most frequently requested service of the family caregivers who ask for help. (Evercare and NAC, 2006; Brazil, K, et al, 2005; Fox-Grage, W, Coleman, B, Blanchato, R, 2001; ongoing personal communications with State Respite Coalitions). 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). In rural areas, the percentage of family caregivers able to make use of respite was only 4% (Easter Seals and NAC, 2006).

While these surveys did not specifically ask why families were not using respite services, barriers to accessing respite have been well defined in the literature. They include cost, reluctance to ask for help, failure to identify as a caregiver, fragmented and narrowly targeted services, feelings of social isolation, lack of respite options, and the lack of information about how to find or choose a provider (Whitlatch, CJ, et al, 2006; Yanitz, NM, et al, 2007; Damiani G., et al; 2004; Sharlach, S, et al, 2003). Even when respite is funded, a critically short supply of well trained respite providers may prohibit a family from using a service they so desperately need (Larson, SA, 2004; ongoing communication with state respite coalitions).

Restrictive eligibility criteria also preclude many families from receiving services or continuing to receive services they once were eligible for, especially for those in the age group 18-60. Trained respite providers and/or funding sources may not exist at all in some states for individuals, including veterans, under age 60 with conditions such as ALS, MS, spinal cord or traumatic brain injuries.

In this age group 18-60, those most at risk for limited access to respite are the families of the wounded warriors – those military personnel returning from Iraq and Afghanistan with traumatic brain injuries, post-traumatic stress syndrome and other serious chronic and debilitating conditions. A recent report from the Dept of Veterans Affairs at the Veterans Health Administration concluded: “Challenges remain, as the men and women who experience serious debilitating injuries, polytrauma, or traumatic brain injury (TBI) may require treatment spanning multiple healthcare systems and may need long-term care, personal assistance, and family support spanning decades.”

To facilitate the transition from institutional care to the home and community and plan for the ensuing needs for long term services and supports for severely injured veterans of the current war, the Geriatrics and Extended Care Polytrauma Rehabilitation Task Force (GECPR) was established in May
One of the major recommendations of the Task Force was to “Improve access to, and utilization of, respite services for younger veterans.” (US Dept of Veterans Affairs, Veterans Health Administration, Report of the VA Geriatrics and Extended Care Polytrauma Rehabilitation Task Force, February 2008).

For the growing number of veterans with TBI or other polytrauma, VA has authority to provide respite both in home and in other settings, yet respite is often underutilized. In-home providers may not be available in many communities, and inpatient respite, generally available in a community nursing home or VA hospital, may not be amenable to young veterans and their families. The shortage of well-trained staff qualified to provide respite to this population is especially critical given their complex diagnoses. Identifying and ameliorating special barriers for this population should be addressed.

Current Federal and State Resources are Limited or Nonexistent

Disparate and inadequate funding streams exist for respite in many states. The largest source of federal funds for respite outside the VA is available through various state Medicaid Home and Community-Based Waivers, but services are capped, eligibility criteria are restricted by age or disability, and waiting lists prevail (Friss Feinberg, 50-State Survey, 2004). Numerous other federal and state categorical programs have been identified which have the potential to fund respite for caregivers, but only for caregivers of individuals with specific disabilities, ages, or incomes, or for one narrow purpose. These efforts provide a critically important foundation on which to build systems of respite care, but they currently do not do enough to reduce the fragmentation, the inaccessibility, and the confusion that exists around multiple eligibility criteria, numerous funding streams, and qualified provider shortages.

In 1999, the Millennium Health Care Act was amended to expand respite services for veterans who qualify for health benefits. Public Law 106-117 expanded the array of community-based respite services available to veterans to include community nursing homes and non-institutional settings for respite care. Prior to the passage of Pub. L. 106-117, respite care authorization was limited to VA inpatient CLC (formerly known as VA nursing homes) or hospital beds. The Veterans’ Health Administration is now committed to the provision of clinically-appropriate respite care services through the use of various institutional and non-institutional programs such as: CLC, Community Nursing Home (CNH), Homemaker and/or Home Health Aide (H/HHA), Adult Day Health Care (ADHC). Respite services are primarily a resource for veterans whose caregivers are neither provided respite services through, nor compensated by, a formal care system (i.e., Community Residential Care (CRC) program agreements, Medicaid waiver programs, Hospice programs, and others for which the veteran is dually eligible). While respite options for veterans have certainly expanded in the last decade, administrative criteria still limit the type, extent and availability of services. From the VHA Handbook dated November 10, 2008:

a. Veterans seeking respite services must be enrolled for VHA health care and receive established, on-going, routine health care services from a VA or contracted VA health care provider or care team.

b. The respite care benefit provides respite services to eligible veterans for up to 30 days in a calendar year. This 30-day program limit includes the sum of all respite-specific resources provided, regardless of the setting.

c. For VA program purposes, “a day” of respite is defined as any single day in which respite services are provided to the veteran, that is, up to 6 hours of care per day in the home, greater than 4 hours of care in adult day health care, or 24 hours of care per day in an inpatient setting.

d. Veterans who are in need of respite services in excess of 30 days because of unforeseen difficulties, such as the illness or death of a primary caregiver, with the approval of the medical center Director, or designee, may be granted additional days.
e. When inpatient respite care is provided in VA CLCs or medical centers, beds may not be
designated exclusively for respite care. VA medical centers are not authorized to provide respite
services in any ambulatory care clinic settings other than the formal ADHC Programs.
f. When a veteran is admitted for respite care, services provided are subject to the applicable
standards of care for that care setting. For example, in the VA CLC, services must meet The Joint
Commission’s long-term care standards. **NOTE:** State and Federal standards must be met by VA-
contracted CNHs and in the delivery of home health services.
g. Respite care is available in a variety of settings; therefore, program access and admissions must
follow the same guidelines for admission currently applicable within VHA and non-VHA
inpatient and outpatient programs.
h. Long-term Care (LTC) co-payments apply to respite care regardless of the setting or service
that provides such care. A LTC co-payment test must be completed for each veteran requesting
extended care services, to determine the extended care co-payment exemption or non-exemption.

Eligibility criteria also mean there are veterans who would not qualify at all for respite benefits
under the Millennium Health Care Act. For admission to respite care the following criteria must be met:
a. The veteran has a diagnosed chronic disabling illness or condition.
b. The veteran lives at home and requires substantial assistance in ADL in order to continue to reside
safely in the home.
c. The veteran’s caregiver is in need of temporary or intermittent relief from day to day care tasks in order
to sustain this care-giving role.
d. The veteran must meet clinical criteria, as well as eligibility criteria for nursing home and long-term
care (Pub. L. 106-117). Clinical criteria include:
   (1) Dependence in three or more ADLs or significant cognitive impairment, and
   (2) Two or more of the following conditions:
      (a) Dependence in three or more IADLs.
      (b) Recent discharge from a nursing home.
      (c) 75 years old, or older.
      (d) Identification as a high utilizer of medical services (defined as having three or more
          hospitalizations in the past year, or utilizing outpatient clinics or emergency evaluations twelve or
          more times within the preceding 12 months).
      (e) Is clinically depressed.

In addition, the VA requires co-payments for non-exempt veterans for extended care services,
including respite. Co-payments for respite care can also be prohibitive for many veterans and their family
caregivers, especially if they are older and living on fixed incomes, or are already under financial distress
because family members have given up employment to provide continuous care and support. For these
families, respite is perceived as a luxury they cannot afford and even minimal co-payments can be
extremely burdensome. Currently, VA-required co-payments range from $15 per day for non-institutional
adult day health or respite care to $97 per day for institutional respite care.

Veterans whose household income exceeds both the current year VA national income threshold
($34,117, with one dependent), and who do not have a compensable VA service-connected disability, are
not eligible for VA care. Family caregivers of veterans who do not qualify for respite through the VA
may turn to state or local respite funding sources. However, the system is already overburdened and
unable to keep up with the increasing demand. 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 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
erelderly. 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 state respite 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.

In 2006, in the reauthorization of the Older Americans Act, the National Family Caregiver Support Program’s definition of family caregivers was expanded by including caregivers caring for anyone with Alzheimer’s or related neurological condition of any age, by lowering the eligibility age of grandparent caregivers to 55, and by allowing eligibility for grandparents or other relative caregivers to care for children over the age of 18 with disabilities (Older American Act Reauthorization, P.L. 109-365). The funding for the program, however, has not increased.

These limitations in existing respite funding streams are confusing not only to families, but to the states that rely on them. In addition, while many of these programs have the potential to fund respite, they are not mandated to do so. Competing demands for these funds or lack of information on the part of consumers often result in no or limited federal funds from these various programs being used to support respite (Day, S., ARCH, 1999; Whirrett, T., ARCH, 2002; Baker, L, ARCH 2004). The result is a complicated bureaucratic maze of services that families must navigate to find or pay for services, as well as duplication and fragmentation of respite services. Even when family resources are available to pay for respite, finding quality respite that meets a family’s needs and preferences, and is appropriate, safe, culturally acceptable, or geographically accessible may be impossible.

**States Respond with Model Lifespan Respite Systems**

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. Model statewide Lifespan Respite Programs in Oregon, Nebraska, Wisconsin, Oklahoma, and most recently, Arizona, provide easy access to an array of affordable, quality respite services; ensure flexibility to meet diverse needs; fill gaps and address barriers; and assist with locating, training, and paying respite providers (Baker, L and Edgar, M, 2004). In anticipation of funding from the new federal program, state Lifespan Respite Legislation is pending in Texas. Michigan passed Lifespan Respite legislation in 2004, but it has never been funded because of limited state dollars. The Delaware State Respite Coalition was successful in obtaining significant funds from a private foundation to begin implementing a statewide lifespan respite program this year.

Each program has been adapted to meet individual state needs, but the defining characteristic of each is the statewide, coordinated approach to ensure respite services for all who need it. Many of the lifespan respite programs have established community-based networks that rely on the development of local partnerships to build and ensure respite capacity. These local partnerships include family caregivers, providers, state and federally funded programs, area agencies on aging, non-profit organizations, health services, schools, local business, faith communities and volunteers. These networks are the central point of contact for families and caregivers seeking respite and related support regardless of age, income, race, ethnicity, special need or situation. Providing a single point of contact for families to access respite is crucial to assisting families in helping themselves. Services typically offered by Lifespan Respite Programs are providing public awareness information to the community and building diverse respite partnerships, recruitment of paid and volunteer respite providers, coordinating respite related training for providers and caregivers, identifying gaps in services and creating respite resources by building on existing services, and connecting families with respite providers and payment resources.

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 (Fox-Grage, 2001). The National Governors Association and the President’s Committee for People with Intellectual Disabilities also have highlighted lifespan respite systems as viable solutions (Friss-Feinberg, 2004; President’s Committee for People with Intellectual Disabilities, 2004). The 2005 White House Conference on Aging recommended enactment of the Lifespan Respite Care Act to Congress (2005 White House Conference on Aging, 2006).

**Oregon**

In 1997, Oregon enacted the first state Lifespan Respite Care Program into law to address the multi-faceted barriers faced by families in accessing and paying for quality respite services regardless of age or disability. The Oregon Department of Human Services (DHS) is charged by state law to develop and encourage statewide coordination of respite care services. The Department works with community-based nonprofits, businesses, public agencies and citizen groups to identify gaps in services, generate new resources and develop community programs to meet the need. The Program offers technical assistance, works directly with 22 local Lifespan Respite Networks in 36 counties, and promotes the state respite agenda.

While the Oregon Lifespan Respite program has not had staff or funding resources to conduct outcome-based evaluation, they have compiled personal testimonials from families expressing program satisfaction (Oregon Lifespan Respite Program, 2003). The Oregon Lifespan Respite program was identified by the Family Caregiver Alliance as one of five best practice models among 33 family caregiver programs surveyed in fifteen states (Friss Feinberg, Family Caregiver Alliance, 1999).

**Nebraska**

With passage of the nation’s second state lifespan respite bill in 1999, the Nebraska Health and Human Services System established the Nebraska Respite Network, a statewide system for the coordination of respite resources that serve the lifespan. Six regional entities are responsible for information and referral for families who need access to respite, recruitment of respite providers, public awareness, coordinating training opportunities for providers and consumers, quality assurance and program evaluation.

Initially, Lifespan funds appropriated by the state legislature to fund the program were used to set up the structure for a statewide respite system. The NE State Legislature saw the success of the effort and appropriated additional funds to establish a respite subsidy program to help families pay for respite. The Respite Subsidy across the Lifespan is available to families who do not qualify for any other respite services. Families choose their own providers and set their own schedules. State funds are also used to expand new respite services in each Service Area.

The six regional networks recruit respite providers, offer training for providers and consumers, provide information and referral, market respite availability and need, and match families with appropriate respite providers. More than 1400 new respite providers have been recruited since the program began. Network coordinators meet regularly with Medicaid Service Coordinators, representatives from Development Disabilities, Area Agencies on Aging, Independent Living Centers and the Early Development Network to identify gaps and barriers and to recruit providers as needed.

A survey of family caregivers receiving respite was conducted by the Munroe-Meyer Institute in Nebraska. Caregivers were identified from a diverse group of state programs including the Aged and Disabled waiver, the Nebraska Alzheimer's Association and the Area Agencies on Aging. After just one year of Lifespan, 63% of the families with family members over 21 reported they were more likely to place their family member in out-of-home placements if respite services were unavailable. Respite was shown to reduce stress and feelings of isolation, possible precursors to poor caregiver health and in extreme cases, even abuse or neglect. Two-thirds (65%) of caregivers with family members over 21 reported decreased isolation once respite services were available (Jackson, 2001).
Wisconsin

In 1999, Wisconsin became the third state to enact Lifespan legislation. The program was created through Wisconsin Act 9 (the 1999-2001 Biennial Budget Act). The legislation provided for the Wisconsin Department of Health and Family Services (DHFS) to contract with an organization for the administration of lifespan respite care projects. The statewide nonprofit, the Respite Care Association of Wisconsin (RCAW), is charged with implementing the program. Funding of $225,000 per year allowed RCAW to establish five Lifespan Respite Care pilot projects, one in each of the five Department of Health and Family Services regions of the state, with each project serving between one and three counties.

Data from an Outcomes Evaluation Project conducted in collaboration with the ARCH National Resource Center for Respite and Crisis Care and the University of North Carolina at Chapel Hill, along with data from quarterly and annual reports, collected by RCAW, demonstrate that the Lifespan Respite Care model in Wisconsin is effective. The study found that provision of respite significantly reduced caregiver stress, stress-related health problems and social isolation. Furthermore, respondents reported reduced likelihood of institutionalization of the person with special needs and reduced likelihood of divorce. Respondents also reported that respite led to significantly improved relationships with the dependent family member and with other family members and increased opportunities to build friendship and support networks. Finally, reports from the Lifespan Respite Care projects demonstrated that they effectively leveraged the relatively small amount of funding received through the program to raise additional funds locally and through other grants, that they effectively integrated local, state, federal and private sources of funds, and effectively coordinated provision of care regardless of age, disability, or other characteristic. The project serves as a "One-stop Shop" for respite care in their communities, replacing previously fragmented systems where families were forced to navigate an “alphabet soup” of funding sources and programs in order to obtain needed relief (RCAW, 2003).

However, annual funding for the program has never exceeded $225,000. Unlike other state Lifespan Respite programs, Wisconsin’s program is not statewide. While local lifespan respite programs are able to leverage additional dollars to help families pay for respite, there simply are not sufficient funds to establish programs in the remaining Wisconsin counties. In a recent statewide survey of 44 county health and human service agencies and Head Start programs conducted by RCAW, it was projected that referrals would increase 443% if the program was fully funded and staffed. (RCAW, October 2006)

Oklahoma

The Oklahoma Respite Resource Network (ORRN), as the state’s Lifespan Respite program is called, relies on an already existing statewide resource and referral system (OASIS) to link families to the program, to respite services and to training opportunities. The Network is a collaboration of 34 partners including three public agencies (Department of Human Services, the Health Department and the Mental Health Department), caregivers, advocacy agencies, private foundations and providers. The network has redirected almost $2 million in public and private funds to respite care in Oklahoma and is able to serve families across age and disability categories. The State's Family Caregiver Support Program is one of the networks most vital and supportive partners, having contributed almost $1 million to go directly to family caregivers of the aging population to help them pay for respite.

The network was built on family support principles and focuses on consumer-directed respite. Caregivers are given vouchers to purchase respite care from anyone they choose and negotiate the rate of pay. The provider can be another family member, friend, next door neighbor, day care center, home health agency, or a private provider. A survey completed in August of 2003 for the Oklahoma Respite Resource Network showed that 85% of the caregivers chose a respite provider from within their own natural support system (Moss, J, 2004). If families need help in finding a respite provider, or finding out which programs they might be eligible for, they can turn to the Oklahoma Respite Resource Network. If a family desires training for a respite provider of their choosing, the state will provide that as well. The Oklahoma model has flexible funding, so the state can find the most cost effective way to deliver services, and allow caregivers control over resources.
This program currently serves approximately 2200 caregivers annually. The average cost for the respite vouchers has been between $5.62 and $5.87 per hour, compared with $12.80 to $26.50 per hour if the caregiver had chosen a provider from a private/public agency. This program has proven that caregivers are much more cost efficient with resources and that respite is a cost effective way to meet the needs of caregivers. In Oklahoma, caregivers are eligible for $400 in vouchers every three months. A 2003 survey found that 47.7% of the caregivers said this amount was adequate to meet their needs; 52% said they could use more, but added that they needed just another $100. This means that $1600-$2000 per year would meet the needs of 97.7% of the caregivers in Oklahoma (Moss, J, 2004).

The ORRN survey found that the program has demonstrated benefits: Eighty-eight percent of caregivers agreed that respite allowed their loved one to remain at home, 98% stated that respite made them a better caregiver, 98% said respite increased their ability to provide a less stressful environment, and 79.5% of caregivers said respite contributed to the stability of their marriage (Moss, 2004).

Arizona

The Arizona Lifespan Respite Program was enacted into law in 2007 and was allocated $500,000 annually for implementation. The Arizona Dept of Economic Security is the lead state agency. Each of eight local Area Agencies on Aging are functioning as the local Lifespan Respite Program. Primary caregivers of individuals who do not currently qualify for other publicly funded respite services are eligible, including: Family Caregivers of: persons who are seriously or terminally ill, who do not currently qualify for hospice care; persons under 60 who have significant functional impairments, but are not eligible for disability services; persons with early cognitive deficit resulting in functional impairment, who have not yet received a “likely” diagnosis of dementia; grandparents or relative caregivers less than 55 years of age caring for children 18 and younger; and veterans not qualified for Veteran Administration (VA) care (e.g., no service-related disability or income eligibility) who do not qualify for other services. Although income is not a disqualifying factor, services will be targeted to individuals in greatest economic and social need. Because funding is limited and in order to offer respite to the maximum number of caregivers, cost sharing will be required and is based on the care recipient’s household income, beginning at 250% above Federal Poverty Guidelines.

State Respite Coalitions

If a state does not yet have a statewide Lifespan Respite Program, there may be a state respite coalition that can offer assistance and act as the central contact point for gathering initial respite information. At least 22 active state respite coalitions are affiliated with the ARCH National Respite Coalition and can provide varying degrees of assistance to family caregivers of veterans whether or not the veterans are eligible for VA benefits. Most of the coalitions provide networking, educational activities, and respite resource guides for providers and family caregivers. Some have developed training curricula and offer respite and family caregiver training across the state. A few, including Alabama, Iowa, and Tennessee Respite Coalitions have developed voucher systems to assist families in paying for respite and for promoting consumer choice. Consumer choice respite has been shown to offer the greatest satisfaction among families, who with the voucher in hand and acting as the employer, can select, train, hire and fire their own respite providers from their own natural support systems or from local agencies.

Lifespan Respite Care Act

The Lifespan Respite Care Act was signed into law in 2006, but did not receive any funding until this current fiscal year. The initial funding of only $2.5 million has not yet been awarded by the Administration on Aging, but will probably be targeted to states for planning purposes only.

The purpose of the Lifespan Respite Care Act is to expand and enhance respite services, improve coordination, and improve respite access and quality. Under a competitive grant program, states are 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. 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. Congressional intent requires that states ensure that respite is made more available and accessible regardless of age or disability of the care recipient (US House of Representatives, Committee on Energy and Commerce, 2006).

The federal Lifespan Respite program would be administered by the U.S. Department of Health and Human Services (HHS), Administration on Aging, which will provide competitive grants to state agencies through Aging and Disability Resource Centers working in mandated collaboration with state respite coalitions or other state respite organizations.

The NRC and its national, state and local partners are urging full funding ($71.1 million) in FY 2010. This will enable:

- State replication of best practices in Lifespan Respite systems so that all family caregivers, regardless of age or disability of the care recipient, will have access to affordable respite, and will 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 program capacity to serve more families by building new and enhancing current respite and crisis 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.

**Recommendations for Improving Respite for Family Caregivers of Veterans:**

1) VA should collaborate with State Lifespan Respite Programs, State Respite Coalitions, universities and community colleges to recruit and train respite providers and volunteers to assist families caring for veterans, especially veterans with TBI, post-traumatic stress, mental health conditions, spinal cord injuries, and other polytraumas.

2) VA should collaborate with State Lifespan Respite Programs or State Respite Coalitions to promote consumer direction and administer respite voucher programs where available.

3) VA should reduce or eliminate mandatory co-payments for respite for all veterans.

4) VA should collaborate with State Lifespan Respite Programs or State Respite Coalitions to work with family caregivers of veterans to help them find, train and pay for respite services, and to expand the range of respite options currently available to these families.

5) VA should collaborate with State Lifespan Respite Programs and State Respite Coalitions to provide public awareness and education among family caregivers of veterans about the value and availability of respite.

**References**


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