



**Lifespan Respite
Transition Issue Brief
Presented by
ARCH National Respite Coalition and National Partners
December 15, 2008**

Recommendations for Administration's First 100 Days

The ARCH National Respite Coalition and its national and state partners applaud President-elect Obama for his proposals in support of family caregivers in the context of long-term care and health care reform. *We urge the in-coming Administration and Congress to consider the following recommendations:*

- **The new Administration should encourage and support \$53.3 million for Lifespan Respite in the final FY 09 Labor, HHS, Education appropriations bill; and**
- **The President's proposed budget for FY 10 should include \$71.1 million for Lifespan Respite, the amount authorized by the legislation for FY10.**

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.

Lifespan Respite Care Act

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), which would provide competitive grants to state 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 regardless of age or disability issues.

Organizational and Congressional Support for Lifespan Respite Funding

The ARCH National Respite Coalition is a network of respite providers, family caregivers, and representatives of state and local agencies and organizations across the country who support respite. Twenty-five state respite coalitions are also affiliated with the NRC. This transition brief is presented on behalf of these organizations, as well as the national organizations which support funding for the Lifespan Respite Care Act (P.L. 109-442). Many Members of Congress already support funding for Lifespan Respite. In fact, the FY09 Senate Budget Resolution reserves \$53 million in the Department of Health and Human Services Account for Lifespan Respite.

What is Respite?

Respite care provides temporary relief for 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.

Who Needs Respite?

In 2004, 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). 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 represents 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).

It has been estimated that these 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).

The overall number of family caregivers, when considering parents of children with disabilities is even larger. In 2006, the last year federal data were collected specifically for children with disabilities, 13.9 percent of US children (approximately 10 million) had special health care needs and 21% of households with children included at least one child with a special health care need. These rates represent a modest increase since the last survey conducted in 2001. (National Survey of Children with Special Health Care Needs U.S. Health Resources and Services Administration, 2008). Since the parents or other family members of these children are providing comprehensive long-term care for years or even decades, they should be considered family caregivers as well. Therefore, these surveys suggest that a conservative estimate of the nation's family caregivers who provide significant amounts of care does indeed exceed 50 million.

Compound this picture with the growing number of caregivers known as the “sandwich generation” who are caring for young children as well as an aging family member. An estimated 20 to 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. One-third of all women are providing some help to both their parents and their children; 9% of women ages 44-56 offer a significant amount of money to their children and significant time to their parents (Pierret, Charles R., Sept. 2006).

In addition, 6.7 million children in the US, with and without disabilities, are in the primary custody of an aging grandparent or other relative other than their parents. Parental substance abuse, HIV/AIDS, incarceration, poverty, death, or military deployment are the reasons more children are now in kinship care. Moreover, the children are likely to exhibit difficult behaviors or have disabilities themselves (Generations United, Grandparents and Other Relatives Raising Grandchildren: Caregiver Support Groups, 2004; Generations United, Grandparents and Other Relatives Raising Grandchildren: Respite Care, 2004). Significant percentages of these grandparent caregivers are poor and have access to few resources or supports (Ehrle, J, et al, Urban Institute, 2001).

Another emerging subgroup of family caregivers is the young caregivers. Nationwide, approximately 1.3 to 1.4 million child caregivers between the ages of 8-18 are providing care; 25% are providing this care on their own. Seven in ten child caregivers are caring for a parent or grandparent (72%) and 11% are caring for a sibling. Over half (58%) help their care recipient with at least one activity of daily living, such as bathing, dressing, getting in and out of bed and chairs, toileting and feeding (National Alliance on Caregiving, Sept 2005). The effects of caregiving on this population have been documented (Siskowski, C, 2006)

The growing group most at risk for limited access to respite is the families of the wounded warriors – those military personnel returning from Iraq and Afghanistan with traumatic brain injuries 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 2007. A major recommendation 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) The National Respite coalition is currently serving on a VA Advisory group to help implement this recommendation.

Together, these 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 an expected increase in the number of chronically ill veterans returning from war, 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 (Alexih, L, Lewin Group, 2006). This trend 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 a new federal policy direction focusing on home and community-based care. States wishing to reduce Medicaid long-term care expenditures have also refocused their policies to support home and community-based services. The President's New Freedom Initiative recognized that increased reliance on home and community-based services for all age groups was going to require new family caregiver supports, such as respite (US Dept of Health and Human Services, Delivering on the Promise, 2004)

Barriers to Respite

State and local surveys have shown respite to be the most frequently requested service of the nation's family caregivers, including a study by Evercare (Evercare and NAC, 2006; Brazil, K, et al, 2005; Fox-Grage, W, Coleman, B, Blancato, 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. In a study of a nationally representative profile of noninstitutionalized children ages 0-17 year of age 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 needs for respite (Rupp, K, et al, 2005-2006). 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)

Barriers to accessing respite include reluctance to ask for help, fragmented and narrowly targeted services, feelings of social isolation, lack of respite options, cost, 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 making use of a service they so desperately need (Larson, SA, 2004; ongoing communications with state respite coalitions).

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 (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 age 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, 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. At a Lifespan Respite Summit on Capitol Hill in 2005, a Massachusetts mother of a seriously ill child spoke to the demands of constant caregiving: "I recall begging for some type of in-home support...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 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. She said, "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 (AUCD, 2005). 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." Even with recent changes to the National Family Caregiver Support Program, this mom would not qualify for respite.

For the growing number of veterans returning home with TBI or other polytrauma, VA has authority to provide respite both in the home and in various other settings, yet respite is often underutilized. Home respite may not be available in many communities, and inpatient respite - generally in a community nursing home - may not be amenable to veterans and their families. The shortage of staff qualified to provide respite to this population is especially critical. Identifying and ameliorating special barriers for this population will have to 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 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 or support respite care 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, 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.

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 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 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.

Respite may not exist at all in some states for 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, “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.”

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 and crisis care, they are not mandated to do so. Competing demands for these funds or lack of information on the part of consumers as well as state agency heads often results in no or limited federal funds from these various programs being used to support respite care (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.

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 their 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).

In the most recent meta-analysis on respite effectiveness, respite was shown to provide small positive effects for family caregivers of the frail elderly in terms of burden, and mental or physical health, and family caregivers were satisfied with the respite they received (Mason, et al, 2007).

In terms of avoiding or delaying out-of-home placements for children and sustaining marriage, respite has shown some promise. An evaluation of the Iowa Respite Child Care Project for families parenting a child with developmental disabilities found that when respite care is used by the families, there is a statistically significant decrease in foster care placement (Cowen, PS, 1998). A study of a Vermont respite program for families of children or adolescents with serious emotional disturbance found that participating families experience fewer out-of-home placements than nonusers and were more optimistic about their future capabilities to take care of their children (Bruns, E, 1999). Data from an outcome based evaluation pilot study show that respite may also reduce the likelihood of divorce and help sustain marriages (Wade, C., Kirk, R., Edgar, M., & Baker, L., 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. 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 (MetLife and NAC, 2006). A family's personal economic situation can also be drastically affected. 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). Offering respite to working family caregivers could help improve job performance and employers could potentially save billions of dollars.

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 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.

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). And most recently, the 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 needs. The Program offers technical assistance, works directly with Lifespan respite networks, and promotes the state respite agenda. All of Oregon's counties are currently served.

Approximately 5000 respite referrals are made for more than 3000 families each year. Over 3700 individuals receive respite as a result. The population served represents all age groups: adults ages 18-59 (11%), children ages 0-12 (34%), adolescents ages 13-17 (8%), seniors ages 60-75 (19%), and elderly ages 76+ (28%). Care recipients also represented a wide range of disabilities including developmental disabilities (27%), physical disabilities (13%), mental illness, emotional or behavioral conditions (15%), Alzheimer's (14%), chronic illness (5%), medial fragility (7%), frail elderly (7%), individuals at risk of abuse or neglect (7%), and other or not reported (5%) (Martin, 2008).

While the Oregon Lifespan Respite program has not had staff or funding resources to conduct client satisfaction surveys or 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 availability and need for respite, 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 and with 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.



The networks identify where specific gaps in respite occur in their communities and address that need. For example, in the southwestern service area, special respite was established for families caring for someone with behavior disorders, emotional disturbances or mental illness. In the Central and Northern Service areas, the lifespan networks collaborated with the Alzheimer's Association in 2004 to provide over 50 hours of respite. The Eastern Area of the Nebraska Respite Network in collaboration with the Area Office on Aging assisted 15 family caregivers in receiving financial assistance for respite during the last fiscal year. All of these families were caring for women with high levels of care needs. The Lifespan network determined that if all the 15 family caregivers who received funding for respite had placed their loved ones in a nursing facility, just for the requested respite time, the needed financial assistance would have totaled \$23,410. In using in-home respite, volunteers and other family members to give the needed break, the financial assistance necessary for 15 family caregivers to give them the respite they requested was less than half that amount. The needs of these 15 caregivers were more involved than for most family caregivers -- they needed time to work, to care for other family members, or had serious health issues of their own that needed to be addressed (personal communication, Linda Sands, Nebraska Lifespan Respite Program, 2005).

A survey of family caregivers receiving respite was conducted by the Munroe-Meyer Institute at the end of 2000. Caregivers were identified from a diverse group of state programs ranging from Early Intervention, the Foster and Developmental Disabilities Program, and the Medically Handicapped Children's program to the Aged and Disabled waiver, the Nebraska Alzheimer's Association and the Area Agencies on Aging. After just one year of the program, almost twice as many caregivers of family members over 21 as compared to caregivers of family members under 21 indicated the likelihood of out-of-home placement without respite support; 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 (Jackson, Barbara, January 2001).

In this survey of a sampling of NE's family caregivers, respite was shown to reduce stress and feelings of isolation, the precursors to poor caregiver health and in extreme cases, even abuse or neglect. One half to two-thirds -- 58% of the families with children under 21 and 65% of the caregivers with family members over 21 -- reported decreased isolation once respite services were available. Ten percent of families with children under 21 indicated that a divorce was directly related to their caregiving responsibilities and respite helped in improving their relationship with spouses and other family members (Jackson, 2001).

Wisconsin

In 1999, Wisconsin became the third state in the nation 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 the \$225,000 received in 2000. Unlike other state Lifespan Respite programs, Wisconsin has not dedicated sufficient resources to extend the Lifespan Respite Program 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. This 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 about \$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).

This program currently serves approximately 2200 caregivers annually. For the past 4 years 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. The 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).

If families need help in finding a respite provider, or finding out what 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.

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 local Area Agency on Aging (8) is functioning as the local Lifespan Respite Program. Primary caregivers of individuals who do not currently qualify for other publicly funded respite services are eligible.

The following are examples of who might qualify for services through the program. 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 respite services from the Veteran’s Administration. 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.

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