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## Improving Policies for Caregiver Respite Services

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This paper provides a template for the decade ahead regarding the delivery, supply, and funding of caregiver respite services. Policy changes are needed to address these issues as concerns about our country's ability to meet future caregiving needs are growing along with our aging population. Federal initiatives and state-level policies and programs affecting respite are reviewed and directions for policy advancement are highlighted. Much more work is needed to educate caregivers and the general public about the necessity for respite beginning early in the caregiving career to prevent burnout and other adverse effects. Because it is unlikely that there will be a sufficient number of direct-care workers to replace unpaid caregivers, improved policies are needed to ensure that their situation is sustainable through increased availability of high-quality respite and other services vital to caregiver health and well-being. Among the 2015 White House Conference on Aging's priorities in the next decade, policies on long-term services and supports will require focused attention on family caregivers and the direct-care workforce to strengthen their ability to give care now and support their own physical, emotional, and financial needs in the future.

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Family caregiving across the lifespan is a critical public health issue that will affect virtually all individuals personally (Talley & Crews, 2007), yet essential supports for caregivers are often lacking. Prominent among vital but scarce supports for caregivers is respite. The Lifespan Respite Care Act of 2006 defines respite as “planned or emergency care provided to a child or adult with a special need in order to provide temporary relief to the family caregiver of that child or adult.” However, definitions of respite can vary and respite care can take many forms (Evans, 2013; Reinhard, Bemis, & Huhtala, 2005). For example, caregivers may get respite when the care receiver attends a day program or a home care worker provides services that free up the caregiver. Thus, respite may be an outcome (not a service) for caregivers who get a break from caregiving when their relative receives a service with another name. In addition, eligibility for services is frequently tied to the care receiver rather than the caregiver.

As researchers, practitioners, and policymakers continue to grapple with this definitional conundrum, respite remains an important yet underutilized preventative resource. Indeed, respite has been recognized as the most commonly requested type of caregiver assistance (Commission on Long-Term Care, 2013; National Alliance for Caregiving & AARP, 2009). With caregiving occurring over the lifespan, diversity in caregiving situations necessitates flexibility in respite arrangements that may be qualitatively different for younger families caring for children with disabilities; those caring for older adults or adults with disabilities; and military and veterans’ caregivers. However, in order to focus on issues most pertinent to the 2015 White House Conference on Aging (WHCoA) and urgent concerns about our country’s ability to meet future caregiving needs growing along with our aging population, the rest of this discussion will address caregivers assisting older adults.

Recent evidence suggests that respite has tangible benefits for caregivers, care receivers, and their families (ARCH National Respite Network and Resource Center, 2014), even though research findings over the years about the effects of respite have been limited and inconsistent. Lawton, Brody, and Saperstein’s (1989) landmark early study of respite for caregivers of persons with Alzheimer’s disease attempted to address the lack of empirical evidence, but findings were inconclusive. Subsequent studies have also shown mixed results (Commission on Long-Term Care, 2013); however, many have reported positive outcomes, associating respite with reduced caregiver stress, caregiver burden, and risk of abuse and neglect; improved quality of life for caregivers and care recipients; and fewer out-of-home placements (ARCH National Respite Network and Resource Center, 2014). Most recently, a new and promising finding using physiologic stress biomarkers clearly

demonstrated decreased caregiver stress as a result of care receivers’ use of adult day care (Zarit et al., 2014). To bring greater clarity to the impact of respite, the Administration for Community Living, in a cooperative agreement with the Technical Assistance Center for Lifespan Respite Care Programs, has convened an expert panel on respite research to build on new findings and develop a stronger evidence base for respite care.

The conclusion of Lawton et al.’s (1989) study that caregivers required a great deal of “time, education and encouragement” to gain an understanding of and willingness to use respite has been consistently confirmed by many studies (ARCH National Respite Coalition, 2009; Hong, 2010). Thus, caregivers may wait to seek respite until late in the caregiving process or a crisis occurs (Montgomery, 1995), making the preventative goal of respite—to reduce or delay burnout and/or institutionalization—less likely to be realized. Consequently, caregivers must have ongoing and timely education and training to carry out caregiving tasks effectively while preserving their own health and well-being from the chronic stresses of caregiving (Wagner, 2005). This is particularly important in the changing health care environment in which caregivers are expected to provide complex medical care in addition to help with personal care and activities of daily living (Reinhard, Levine, & Samis, 2012).

Effective respite guidelines call for well-qualified, well-trained, and geographically accessible providers who can competently meet diverse and highly individualized family and care recipient needs (ARCH National Respite Network and Resource Center, 2011). Such well-trained respite providers are in critically short supply, raising the pressing issue of workforce adequacy. To meet projected demands for direct-care workers such as nurse aides, home health aides, and personal care aides—some of whom provide respite—another 1.6 million new positions will need to be filled by 2020 (a 48% increase compared to 2010). Yet, the main labor pool for filling these positions, women aged 25–54 entering the labor force, is projected to grow only 1% in the same time period (Paraprofessional Healthcare Institute, 2013). Given demographic changes leading to declining numbers of family caregivers, even more attention must be given to novel and workable ways to support caregiving (Institute of Medicine of the National Academies [IOM], 2008).

## Public Policies Related to Respite Services

Respite services developed informally in the 1950s and 1960s during the first wave of deinstitutionalization in the United States (Caregiving issues, 2011). Beginning in 1982 with the Katie Beckett Waivers for children with special

care needs (Family Voices, n.d.), the Medicaid Waiver program started a trend toward home- and community-based services (HCBS) supplanting institutionalization. This shift was further reinforced by the U.S. Supreme Court's 1999 *Olmstead* decision (527 U.S. 581), holding that the American with Disabilities Act of 1990 requires public entities to provide community-based services to persons with disabilities under specified circumstances (United States Department of Justice, Civil Rights Division, n.d.). Continued emphasis on HCBS, shorter stays in acute care settings, and efforts to avoid long-term institutional care and to de-institutionalize, when possible, are bound to increase demands on family caregivers.

The 1995 WHCoA identified implementation strategies for recommendations to support family caregivers, one of which was respite care services, and the Federal Real Choice Systems Changes Grants in 2001–2005 funded state efforts to expand respite for children and adults. The first federal legislation focused on family caregivers independently of care recipients was the National Family Caregiver Support Program (NFCSP), established by the Older Americans Act of 2000. Respite care is one of five basic services that NFCSP funds to enable primarily older and low-income caregivers to care for elderly relatives at home.

Federal legislation to support family caregivers continues to be proposed, often focusing on tax incentives for working caregivers and their employers, paid family and medical leave, and respite care (IOM, 2008). Because caregiving places substantial financial burdens on female caregivers in particular, who are estimated to lose a total of \$324,044 in wages and Social Security benefits (MetLife Mature Market Institute, 2011), proposed federal legislation has recently addressed issues of financial compensation. For example, the Family and Medical Insurance Leave (FAMILY) Act and the Social Security Caregiver Credit Act were introduced in 2014 to help mitigate the negative impact on future Social Security benefits for family caregivers who temporarily leave the workforce.

A WHCoA Mini-Conference's recommendations to the 2005 WHCoA Policy Committee included passage of the Lifespan Respite Care Act and increased NFCSP funding (Wagner, 2005). In its proceedings, an appendix entitled, "Family Caregiving and Public Policy: Principles for Change," specified that "Family caregivers must have access to affordable, readily available, high quality respite care as a key component of the supportive services network." Ultimately, the final 2005 WHCoA report included a recommendation to Congress to enact the Lifespan Respite Care Act. Signed into law in December, 2006, it is the only federal program that solely addresses family caregiver respite issues, regardless of age or disability. Lifespan Respite Care programs are mandated to be "coordinated systems of

accessible, community-based respite care services for family caregivers of children and adults of all ages with special needs" (Administration for Community Living: Center for Disability and Aging Policy, 2013).

Several recent attempts to expand respite availability have been highlighted in policy reports and proposed legislation. A RAND Corporation report commissioned by the Elizabeth Dole Foundation about challenges facing military and veteran caregivers (Ramchand et al., 2014) recommended increased availability of respite care for military caregivers and consideration of alternative respite strategies. In response, Sen. Patty Murray introduced the Military and Veteran Caregiver Services Improvement Act of 2014 (S. 2243), with a companion bill (H.R. 4892) introduced in the House by Reps. Langevin, Mike Michaud, and Elizabeth Esty, to extend eligibility and enhance benefits in the Comprehensive Assistance for Family Caregivers Program of the Department of Veterans Affairs (VA). It also reauthorizes the Lifespan Respite Care Act through 2019 with funding of \$15 million per year and expands respite options for military caregivers and others. Rep. Jim Langevin, a lifespan respite champion since 2003, recently reintroduced the Lifespan Respite Care Reauthorization Act (H.R. 4683), with funding of \$15 million per year for 5 years, to expand coordinated respite services for family caregivers. This type of legislation reflects the need for government policies that support families in general and caregivers in particular and illustrates that one piece of legislation by itself can not sufficiently address the complexity of caregiving.

At the state level, legislative interest in caregiving and respite has led advocates to support paid family leave, sick leave, tax credit, and other legislation. Efforts are underway in at least 12 states to establish task forces to recommend legislative and administrative action to help family caregivers, and some 75–100 state bills of benefit to family caregivers are currently in the pipeline across the country. For example, AARP's multistate caregiving campaign is promoting state legislation such as the Caregiver Advise, Record and Enable (CARE) Act, which would require hospitals and care facilities to formally acknowledge and directly involve a patient's family caregiver in developing a plan of care. The CARE Act was passed by the Oklahoma state legislature in May, 2014.

Oklahoma has also been a leader among the states in offering respite care programs for caregivers. Established in 1998, the Oklahoma Respite Resource Network's collaborative efforts led to the development of respite voucher programs in the Oklahoma Department of Human Services for various populations (Fenrick & Percival, 2014). Respite systems tailored to the political environments in other states have also been developed, some supplemented with federal

funding. Legislation to establish Lifespan Respite Programs to coordinate the availability of respite services statewide was passed in Oregon in 1997, Nebraska and Wisconsin in 1999, Arizona in 2007, and Texas in 2009 ([ARCH National Respite Network and Resource Center, 2010](#)). As a result, government agencies with purviews such as health, family, human, economic security, aging, and disability services in these states established formal respite networks, information and referral mechanisms, provider registries, training programs, and/or new caregiver resources.

There are currently 33 respite coalitions at the state level; these are comprised of grassroots membership organizations representing individuals of all ages with disabilities or chronic conditions; family caregivers; community- and faith-based organizations; and respite, social service, and health care providers. Many are associated with the National Respite Coalition Lifespan Respite Task Force, a leading force for respite advocacy, representing more than 100 national and state organizations that envision “respite that is readily available and easily accessible to all caregivers” across the country. Recently, successful Lifespan Respite Program activities conducted by respite coalitions in states such as Arizona, Colorado, South Carolina, and Texas have enabled them to secure state budget line items for respite or fiscal partnerships with other state agencies to sustain respite initiatives.

### Federal Legislation and Funding for Respite

Congress first appropriated \$125 million for the NFCSP, which includes respite care services, in FY 2001; the maximum ever appropriated was \$156.2 million in FY 2007. Despite increasing needs, funding declined to \$145.6 million in FY 2014, a fraction of the economic value provided by unpaid family caregivers, estimated at \$450 billion in 2009 ([Feinberg, Reinhard, Houser, & Choula, 2011](#)).

While the [Lifespan Respite Care Act \(2006\)](#) authorized spending ranging from \$30 million in FY 2007 to \$94.8 million in FY 2011, it was one of the only new federal programs to be funded when it received its first appropriation of \$2.5 million in 2009 (the maximum annual funding it has ever received), shortly after President Obama took office. Its FY 2014 appropriation declined to \$2.36 million due to the national budget crisis and across-the-board sequestration cuts in discretionary programs ([Administration for Community Living, 2014](#)).

Efforts to increase funding significantly for these programs have been complicated by the fact that the last year of authorization for both the NFCSP and Lifespan Respite Care Act was FY 2011. It is critically important that both be reauthorized and fully funded; because they have technically expired, their funding could be in jeopardy without

bipartisan support in the current environment of federal government gridlock. A Lifespan Respite authorization of \$15 million per year for 5 years is needed for states to sustain progress made since 2009. With increasing attention to veterans’ needs at the federal level, reauthorization of the Lifespan Respite Care Act in conjunction with bills such as Sen. Murray’s and Rep. Langevin’s may be a key to increased funding for caregiver respite.

### Respite Policies and Programs in Other Countries

There are lessons to be learned about respite care policies and programs from other nations, where respite is known as “short break care.” (The first International Short Break Conference was held in Canada in 1995 and the International Short Break Association was established in 2006.) Most OECD (Organisation for Economic Co-operation and Development) countries have policies for “carers” that include respite care, with wide variation in legal entitlement to respite services ([OECD, 2011](#)). Among 27 countries that provided information in 2009–2010, respite care services were reported as available nationwide in 17; the United States reported availability in some states and counties ([OECD, 2011](#)). Respite-related benefits in various countries that could serve as models for the United States include grants to family caregivers to pay for respite, tax credits for families who pay for respite care, and long-term care insurance coverage for respite. In Germany, for example, a beneficiary family caregiver may be eligible for coverage of his/her social security premiums, respite care for a vacation ([Campbell, Ikegami, & Gibson, 2010](#)), and respite care for 4 weeks a year ([Heinicke & Thomsen, 2010](#)). In Japan, long-term care insurance provides services, including respite care, home help, adult day care, and visiting nurses ([Campbell et al., 2010](#)).

In the United Kingdom, caregiver assessment is mandated as part of a “community care assessment” focused on the care recipient ([NHS choices, 2013](#)); the caregiver can request an assessment of carer needs also. Some government funding for respite breaks is available and respite services may be provided in lieu of direct payments. In Sweden, all carers are entitled to 4 hr a week of respite at no charge, other caregiver supports, and a Carer’s Allowance payment equivalent to the amount a private provider would receive ([Collins, Wacker, & Roberto, 2013](#)).

### Recommendations

Families have historically borne primary responsibility for eldercare, supplemented with a “patchwork quilt of [government] services” ([Achenbaum & Carr, 2014](#)). Since



these circumstances are unlikely to change, the upcoming WHCoA affords an opportunity to propose policies that will organize existing aging services into a more efficient and accessible network. Although respite has generally been politically acceptable, some fear that even broader caregiver support programs, essential to an effective long-term services and supports (LTSS) system (Kaye, 2014), will be abandoned in the current factious federal political climate. As a core component of caregiver support, respite services function as a bridge for building relationships with family caregivers, leading to their engagement with a broad continuum of services enabling them to continue in the caregiving role.

Increasing public awareness and education about caregiving is needed to help caregivers (and legislators) understand the connection between respite and services for care receivers. When individuals come to realize they are acting as caregivers, they are likely to buy into discussions about caregiving issues and respite. Much more work is needed to educate caregivers and the general public about the necessity for respite beginning early in the caregiving career to prevent burnout and other adverse effects and the necessity for including a respite component in all programs for and about caregivers. Increasing public awareness and educating family caregivers are core components of both the Lifespan Respite Care Program and the NFCSP upon which upcoming discussions of enhancements to caregiver services and support should be built.

Another critical support component is initial and periodic follow-up assessment of the caregiver's needs in tandem with the care receiver's needs. This is consistent with a final rule issued by CMS (Centers for Medicare & Medicaid Services, 2014) requiring person-centered care planning in Medicaid HCBS settings (Feinberg, 2014), though it relates only to the 1915(i) state plan option regarding targeted services for specific populations. Depending on what assessment of the caregiver's life stage, socio-economic status, cultural background, and other characteristics identifies as most needed, services could be offered, including support groups, training to carry out complex medical tasks, help with transitions from hospital to home, and support for employed caregivers.

Family caregivers often have significant financial concerns, given that they incur an average of about \$5,500 annually in out-of-pocket expenses related to providing care, and typically forfeit some or all of their salaries from paid employment and future Social Security benefits due to reduced hours in the workforce (MetLife Mature Market Institute, 2011). Some of these concerns could be allayed if caregivers, including legally responsible relatives, could be hired and paid by the care recipient, an arrangement that has worked successfully with participant-directed services

(Simon-Rusinowitz, Loughlin, Ruben, & Mahoney, 2010). Similarly, the VA Program of Comprehensive Assistance for Family Caregivers pays family caregivers a living wage to care for qualified post-9/11 veterans and provides respite, mental health services, health insurance coverage, and caregiver training. In addition to respite care for at least 30 days a year and when emergency respite needs arise for caregivers of veterans from all eras, the VA's model caregiver support services also include a caregiver support line, a caregiver support coordinator, adult day health centers, and home-based services such as primary care, skilled care, homemakers and home health aides, telehealth, and hospice care (United States Department of Veterans Affairs, 2014).

Congress established a Commission on Long-Term Care after the CLASS Act's demise to prepare a plan for delivery and financing of LTSS (Commission on Long-Term Care, 2013). Family caregivers, figuring prominently in its vision of an effective service delivery system, were targeted in four workforce-related recommendations; the recommendation regarding caregiver interventions mentioned respite explicitly. The Commission also recommended that respite be addressed in a larger context of caregiver support services, including information and referral, education, and training. Another recommendation for strengthening LTSS financing through social insurance entailed creating a Medicare benefit for LTSS, including adult day center services and respite care options. This could be a vehicle for emulating models used by other countries to provide respite benefits, as would tax credits and credits toward Social Security for family caregivers.

Embedding respite in discussions and decisions about LTSS provided at the state level might be another formula for political success. While Medicaid waivers are currently the largest funding source for respite for all ages, some states are considering Medicaid state plan amendments for HCBS, ensuring that services are an entitlement for those covered and helping eliminate waiver waiting lists. Respite vouchers in modest amounts for non-Medicaid-eligible families are provided by some states, and others have used child and adult protective services programs to make emergency respite available to vulnerable families. Many states were eligible to participate in the Balancing Incentive Program, authorized by the Affordable Care Act of 2010, to increase access to noninstitutional LTSS. They received an increased Federal Matching Assistance Percentage in exchange for making structural reforms to promote rebalancing and HCBS. Lifespan respite grantees in Texas and New Hampshire used these funds to help sustain their respite infrastructures and train respite workers.

In states implementing Medicaid LTSS in partnership with managed care organizations (MCOs), some involving integrated care initiatives for dual eligibles, MCOs may offer added benefits to gain a competitive edge in marketing

to consumers. Lifespan respite organizations can offer (and have been offering) MCOs information and referral to respite care services across funding streams and populations, caregiver assessment capabilities, and respite workforce training. A good case can be made for the connection between respite service use and the health and well-being of the caregiver and the care recipient, or at the very least, the consumer's and caregiver's satisfaction with the plan.

An adequately trained workforce of sufficient size to provide high-quality respite will require better training; policies supporting specialized training are urgently needed in areas such as behavioral and mental health, dementia, and complex medical conditions. One of the 2015 WHCoA's priorities in the next decade, LTSS for older Americans, will require a commitment to supporting a caregiving network and workforce (Munoz, 2014), with implications for respite care. Since it is very unlikely that there will be a sufficient number of low-paid direct-care workers to replace family caregivers, ensuring that the situation of unpaid caregivers is sustainable will demand adequate attention to effective policies and resources for that purpose. Many Lifespan Respite grantees have been at the forefront of state initiatives to recruit and improve training for new respite providers and volunteers.

To address the shortage of respite providers, several states have developed successful volunteer respite programs (some involving faith-based organizations), especially in rural areas, or expanded the national TimeBanks model for voluntary family respite cooperatives. Alternatively, a Caregiver Corps, like a Peace Corps for family caregivers, could be established to recruit volunteers of all ages, including high school graduates without higher education plans, indebted and unemployed college graduates, and healthy older adults who want to remain in the workforce (Schuster, 2013). In exchange for service at community-based organizations or as in-home respite providers in their communities, they could earn college tuition credits, student loan forgiveness, or a stipend. Federal legislation to support this type of initiative was introduced separately in 2014 by Rep. Michelle Lujan Grisham of New Mexico and by Sen. Bob Casey of Pennsylvania, and the [Commission on Long-Term Care \(2013\)](#) recommended volunteer efforts along similar lines. However, volunteer efforts alone will not be sufficient without government support for addressing respite care needs, as demonstrated by other countries, where respite is seen a government responsibility to ensure its universal availability in supporting families, older adults, and their quality of life.

Finally, reauthorization of the Lifespan Respite Care Program and the NFCSP is critical. State Lifespan Respite programs, in collaboration with their state respite coalitions, have already proven that partnerships, infrastructure,

and best practices promoted by the program are essential to addressing many issues relating to the recommendations above. The NFCSP is key to sustaining a focus on family caregivers as a population in need of distinct direct services and supports.

As our society is becoming increasingly aware, population health is determined by many factors in addition to medical care. Since so many are or will be family caregivers, supports such as respite are crucial. It is a public health imperative to improve the availability, accessibility, acceptability, appropriateness, and affordability of lifespan respite care services. And as a nation, we can no longer put off developing a plan for financing long-term care, which will soon become catastrophic for millions of Americans. Any discussion toward that end must necessarily address respite services, which are essential for family caregivers.

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