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POLICY BRIEF: Lifespan Respite Care Reauthorization Act

Produced by the 2015-2016 Cohort of New Hampshire Leadership Education in Neurodevelopmental and Related Disabilities (NH LEND) Program Trainees.

Executive Summary

The Lifespan Respite Care Act (PL 109-442) provides critical support for families caring for loved ones at home. Family caregivers in the United States provide an estimated \$470 billion worth of uncompensated care—a figure that exceeds the total Medicaid budget for 2013 (NAC Task Force, 2016). According to the National Respite Coalition, access to respite care helps protect caregiver health, strengthens families, keeps marriages intact, and prevents the need for expensive institutional long-term care. Reauthorization of the Lifespan Respite Care Act is essential to the well-being of individuals in need of long-term care and their families affected by long-term health care needs. Respite services are utilized by a variety of populations: individuals with disabilities, individuals living with chronic illness, veterans, and the aging population (NAC Task Force, 2016). Research consistently indicates positive outcomes of respite care and reduces the need for costly residential care.

PL 109-442 was introduced by Congressman Jim Langevin (D-Rhode Island) with bipartisan support and passed into law in 2006. The purpose is to promote state coordination of community-based respite care services for family caregivers of individuals in need of long-term care. Congress has appropriated approximately \$3.36 million per year to Lifespan Respite Programs (Reinhard, Feinbert, Choula, & Howser, 2015). Reauthorization will prevent costly long-term care, enhance quality of life for individuals and family caregivers, and support productivity and financial stability for families.

Importance of Respite Care for Families

Nationally, respite is the most frequently requested service from family caregivers (The Arc, 2011). “Respite provides temporary relief to caregivers from the ongoing responsibility of caring for individuals of all ages with special needs” (Fox, Duggan, & Purcell, 2013). An unintended consequence of deinstitutionalization and other federal policy changes in the 1990s resulted in the burden of caregiving being shifted to families. Based on a report published in 2009 by the National Alliance for Caregiving in collaboration with AARP, on average, caregivers spend 20.4 hours per week providing care and this increases to 29.7 hours for those caring for a child under the age of 18. As a result, the majority of long-term care services for individuals are provided by family caregivers, however, 85% of those families do not receive respite care (Reinhard, Feinbert, Choula, & Houser, 2015). Caregiver stress costs U.S. businesses more than \$25 billion annually through increased absenteeism, lower productivity and missed career opportunities. In Maine in 2013, there were about 178,000 caregivers who provided about \$2.2 billion of uncompensated care (NAC Task Force, 2016). The potential for abuse and neglect increases when caregivers do not get a break from the emotional and physical stress of caregiving. Additionally, family caregivers are at increased risk for mental and physical health conditions (American Psychological Association, n.d.).

The legislation has wide support from the following national and professional organizations and their local chapters: AARP/National Alliance for Caregiving; Administration on Aging; Aging and Disability Resource Center Program (ADRC); National Respite Coalition (NRC)/Access to Respite Care & Health (ARCH); Family Caregiver Alliance, National Center on Caregiving (NCC); National Family Caregiver Support Program (NFCSP); The ARC; Centers for Medicare and Medicaid Services/PACE; and Easter Seals.

Other Reasons to Support Reauthorization of the Lifespan Respite Care Act

- Bill has wide bipartisan support and precedence.
- Currently, there is a lack of overarching policy leading to duplication of services and confusing funding structure.
- It is cost-effective. For example, after one year of family-centered respite care for children with complex medical needs, the number of hospitalizations decreased by 75%, physician visits decreased by 64%, and the use of antibiotics decreased by 71% (Mausner, 1995).
- For every \$1,000 states spent on respite services, there was an 8 percent drop in the odds of hospitalization (Mandell, et al., 2012).

Reauthorization of the Lifespan Respite Care Act is essential to the well-being of individuals receiving long-term care and their families. Respite services are utilized by a variety of populations, from children to the elderly, veterans, and individuals with disabilities. Reauthorization will save healthcare dollars and enhance quality of life for caregivers and the family members who receive their care, therefore, **we urge you to:**

- Support the reauthorization of The Lifespan Respite Care Act (PL 109-442), and
- Support the increase in the appropriations, from \$3.36 million to \$5 million, in the President's budget for fiscal year 2017.

Thank you so much for your support and consideration of quality respite services for individuals and families in need. If you have questions or would like more information about the Lifespan Respite Care Act or other legislation impacting individuals with disabilities, please feel free to contact Susan Russell at srussell@maine.edu or Alan Kurtz at kurtz@maine.edu

About the New Hampshire Leadership Education in Neurodevelopmental and Related Disabilities Program Partnership

The University of New Hampshire Institute on Disability, the University of Maine Center for Community Inclusion and Disability Studies, and the Geisel School of Medicine at Dartmouth, are partners in the New Hampshire Leadership Education in Neurodevelopmental and Related Disabilities (NH LEND) Program. The NH LEND Program provides graduate-level interdisciplinary training for students and professionals from diverse disciplines, including developmental pediatrics, early childhood education, social work, psychology, occupational therapy, health management and policy, and speech language pathology. This partnership is made possible through the NH LEND Program and is supported by a grant (#T73 MC00024) from the Maternal and Child Health Bureau, Health Resources and Services Administration, U.S. Department of Health and Human Services; and administered by the Association of University Centers on Disabilities.

References

- American Psychological Association. (n.d.) *Caregiver briefcase: Family caregiver well-being is important to care recipient health*. Retrieved from <http://www.apa.org/pi/about/publications/caregivers/faq/well-being.aspx>
- The Arc. (2011, June). *Still in the shadows with their future uncertain: A report on family and individual needs for disability supports (FINDS), 2011*. (PDF). Retrieved from <http://www.thearc.org/document.doc?id=3140>
- Fox, S., Duggan, M., & Purcell, K. (2013). *Family caregivers are wired for health*. Pew Research Center. Washington, DC. Retrieved from <http://pewinternet.org/Reports/2013/Family-Caregivers.aspx>
- Mandell, S.D., Xie, M., Morales, K.H., Lawer, L., McCarthy, M., & Marcus, S.C. (2012). The interplay of outpatient services and psychiatric hospitalization among Medicaid-enrolled children with autism spectrum disorders. *Archives of Pediatric and Adolescent Medicine*, January 2012.
- Mausner, S. (1995). Families helping families: An innovative approach to the provision of respite care for families of children with complex medical needs. *Social Work in Health Care*, 21(1): 95-106.
- NAC Task Force. (January, 2016). Legislative Alert from National Alliance for Caregiving and AARP Public Policy Institute. *Caregiving in the U.S. 2015 Report*.
- Reinhard, S. C., Feinberg, L. F., Choula, R., & Houser, A. (2015). *Valuing the invaluable: 2015 update*. (PDF). AARP Public Policy Institute. Washington, DC. Retrieved from <http://www.aarp.org/content/dam/aarp/ppi/2015/valuing-the-invaluable-2015-update-new.pdf>