

Nevada Lifespan Respite Coalition
Legislative Proposal Plan

Executive Summary

Respite, which is defined as "*planned or emergency care provided to a child or adult with special need in order to provide temporary relief to the family caregiver of that child or adult*¹", is an underfunded resource for caregivers in the state of Nevada. Respite services are provided to in-home caregivers, which of whom are described as an individual, such as a family member or guardian, who takes care of a child or dependent adult with chronic illness. The importance of respite and its expansion of resources is a key component of family support and community-based long-term services that correlate with the needs of patients with chronic illness and home health care.

Respite resources are in temporary settings:

- Family home
- Adult day centers
- Respite centers
- Residential care facilities

Deterrent in the quality of care administered by in-home caregivers caused by:

- Lack of balance of regular respite and training for caregivers themselves
- Lack of financial funding to support home needs of full time caregivers and patients.

Mission of the Nevada Lifespan Respite Coalition: To support caregivers in the community by promoting awareness and access to, as well as coordination and advocacy for, respite services in Nevada throughout the lifespan. Our main objective is to show what occurs during ill-managed care between the caregiver and the patient that leads to a rapid decline of health in the caregiver as well as further strains our healthcare systems. We also want to show how an increase in general funding for respite services and vouchers that financially support the caregiver and family will support much needed balance to the home health care system. This form of conjoined effort helps the state to determine the effectiveness of its state funding and indicates where further support needs to be allocated to ensure patients are properly supported in home rather than being transferred to nursing facilities that strain cost of living expenses for families and state.

According to the US National Library of Medicine and National Institute of Health Journal article on 'When the Caregiver Needs Care: The Plight of Vulnerable Caregivers':

*An estimated 15 million to 25 million adults in the United States currently provide informal care (i.e., unpaid care) to relatives and friends. Recognition of informal caregivers' contributions was heightened recently by estimates that project the economic value of their services to be \$196 billion a figure that far exceeds national spending for home health care and nursing home care. With ongoing public and private sector efforts to limit post-acute and long-term care payments, the health care system's reliance on family caregivers will inevitably intensify*²

¹ Arch National Respite Network And Resource Center", The Lifespan Respite Care Act of 2006

² [http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1447090/When the Caregiver Needs Care: The Plight of Vulnerable Caregivers](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1447090/When%20the%20Caregiver%20Needs%20Care%3A%20The%20Plight%20of%20Vulnerable%20Caregivers)

This is significant considering that from 2000 to 2030 the Nevadans aged 65 and over is expected to increase by 578,250 people, a 264% increase. Many of these people are at or below 100% the Federal Poverty Level, currently \$972.50 for a single person.³

Ripple Effect of Caregiver Community in Relation to Medical Community

Providing adequate respite across the board helps to ensure that conflict of care, financial stress, and further stress medically for both patient and caregiver does not occur frequently. With consistent respite scheduling, resources, and proper financial assistance for full time in home caregivers, home healthcare can yield promising results in the near future in the state of Nevada. Supporting a higher standard of respite and resources in the state of Nevada needs to be pushed to expand over the next 3-5 years due to case studies showing that patients remaining in the home will save the state overall funding by avoiding placing individuals in nursing homes. The activities of an in home caregiver are similar but not limited to those performed at nursing facilities:

- *Provide physical care during & after hospitalization & monitor change in the condition*
- *Caring for the central lines administered in hospital (catheter in a vein in the chest)*
- *Helping administer oral medications and recording the medications taken*
- *Giving intravenous fluids and medications using a pump device*
- *Providing transportation to and from the hospital for follow-up care⁴*

“Helping individuals remain in their home is the most cost effective option for the individual and Nevada. On average, the same dollars will support 3 individuals with community-based services for every one person placed in a nursing home. Yet, our current system is inadequate to meet the existing and growing needs for community-based services”⁵

Expansion of Financial Provision and Educational Needs of the Caregiver In the State of Nevada

The Lifespan Respite Grant that was currently funded will only meet a temporary and limited need for the state of Nevada and still runs the risk of an extensive waiting list for services that correlate with voucher programs that are offered in Nevada. With funding through the new respite grant we are hopeful in expanding our reach and support but our efforts to alleviate financial and medical hardship- not just in inner city but in rural caregiver communities as well - relies upon greater supply for the demand. We are looking to decrease waitlisted individuals for respite services and vouchers through 2015-2017. The state of Nevada reaches and surpasses this goal by:

*Capitalizing on the existing outreach capacity of our community partners

*Targeting marketing to Nevadans ages 18-64 who live in rural communities or who have limited English proficiency

*Encouraging and expanding funding up to 100k biannually for grant funding to increase advanced training and respite resources

³ Reference from the LutzWhitePaper/ Provided by member of Nevada Lifespan Respite Coalition

⁴ Responsibilities of Caregivers:nbmtlink.org/resources_support

⁵ Elder Issues in Nevada Commission On Aging Legislative Subcommittee Information Sheet for Legislators 2015

*Bringing awareness to the importance & expansion of funding of respite services and financial support for caregivers

In conclusion, the Nevada Lifespan Respite Coalition views this plan as a living document. It is important to continue this research and monitor the implementation of the recommendations.

“Caregivers can get to a point, when one more minute of giving, is too much. Nothing of the self is left except a charred frame. This is burn-out, the ultimate negative reaction for the caregiver...This is critically important for both persons. Elder abuse has become a big issue. The victim of a disease should not become the victim of an overwrought caregiver. From the caregiver’s perspective, self sacrifice to the point of ill health serves nobody.”⁶

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⁶ Jennings, Judy (2012) Excerpt from Lewy Body Dementia: One Caregiver's Personal, In-Depth Experience