

Silver Haired Legislative Forum  
May 22, 2018 Meeting  
Chair Yacenda, Committee Members  
Re: Personal Care and Respite  
Connie McMullen, PCAN Lobbyist

Thank you for the opportunity to provide an overview of respite services and the need for caregivers in Nevada. I represent the Personal Care Association of Nevada(PCAN) on legislative matters, but on a daily basis since 1993, I have been on the frontline working, interacting, and telling the stories of aging adults living in our state as the proprietor of Senior Spectrum Newspaper. In 2000, I was appointed by the Governor to work as a volunteer on the Strategic Health Care Plan for Senior Services, and have since helped develop the Commission on Aging – NRS 439 Report, the ADSD Integration Plan, and Nevada’s Olmstead/Strategic Plan for Older Nevadans and Persons with Disabilities, roughly 18 years of service.

Caregiving is the backbone of long-term supportive services in our country. In Nevada, 500,000 identify themselves as a “family caregiver” providing care to a family member, neighbor or friend. These dedicated people spend countless unpaid hours, sometimes 24/7, making sure their care receivers needs are being met.

The need for respite care can mean the difference between a caregivers health declining or a well-balanced life because of the work they do day and night often without breaks. Family caregivers face many challenges that include burnout, lack of assistance to go grocery shopping, do personal errands and chores. The demands of caregiving is extremely stressful for an entire family, often finding little time for personal needs, time for other family members such as younger children or another aging adult, or a spouse. Caregiving is time consuming and financially draining; oftentimes causing a family caregiver to loose a job because they cannot juggle their time. Family caregivers are forced to spend lifesavings and spend down assets that took a lifetime to acquire. It is emotionally, financially, and spiritually heartbreaking for the entire family with long lasting repercussions that can worsen when there are no resources to help in the community. The situation is extremely difficult for the aging or disabled family caregiver who has little financial resources to pay for extra help, and cannot raise funds because of age, physical limitation, and cognitive disability.

Personal care “attendants” are employed by a licensed “Personal Care Agency” and are called upon to provide services in the home to relieve family caregivers, to give them a break or *respite*. It is the bulk of personal care activities assuring that those with a chronic illness or disability continue to live independently in the community, instead of a costly nursing facility, assisted living, or residential facility for groups.

Attendant caregivers are in great demand today because of the growing aging and disabled population. One could say that the personal care industry is in a state of crisis because of the shortage of attendants and the great demand for services.

Another crisis on the horizon is the need for attendants for low-income Medicaid clients. Many agencies are not accepting State Medicaid Plan Services due to the low reimbursement rate. <sup>(1)</sup>

Personal care attendants provide respite care daily. They are educated and trained to safely provide services for those who need help to leave the bed, eat, bath, and get dressed. Throughout my years of writing about respite, I did a story about a wife whose husband was so completely disabled that he could not leave his bed, could not feed himself, sit up or talk. He had to physically be lifted by a hoist type of mechanism attached to his bed. She was exhausted and tired but short periods of respite improved her health. The simple fact that someone was there to relieve her, meant everything. She was able to pay her attendant for services given because she qualified for the ADSD Respite Grant.

The ADSD Respite Grant provides \$1,000 a year to family caregivers who care for someone age 65 and older, and who are challenged financially. There are other respite grants offered in Nevada that include the Lifespan Respite Grant that is funded through the Administration on Community Living for people who self-direct their own care, grants from the Alzheimer's Association, and grant funding from the VA. The ADSD Respite Grant is funded through Older American Act Title III, National Family Caregiver Support Program funds and Tobacco Settlement Independent Living Grants. Respite is additionally offered through state waiver services such as the ADSD Home and Community Based Waiver for the Frail Elderly. Waiver services vary among Nevada's Health and Human Services divisions depending on age and demographic. Additionally, the ADSD Community Service Options Program for the Elderly and Personal Assistance Services Program provide respite for people who meet the eligibility criteria.

While respite grants have been successful in connecting families to services, family caregivers have difficulty obtaining them because they lack knowledge the grants exist or fail to recognize they have a need for respite. And while respite benefits recipients, the \$1,000 offered is spent easily. Many nonprofit providers who offer respite are now building a wait list due to increasing demand.

According to the 2016 ILG Report, consumers eligible for respite and other services meet the criteria for disability. "More than 42 % of ILG consumers (7,691) had three or more deficits in Instrumental Activities of Daily Living (could not perform the tasks of housework, shopping, use a telephone, etc.). Without social supportive services, these consumers are at risk for deteriorating to institutionalization."

Another concern of consumers needing in-home care is that state funding has not kept pace with population growth especially in rural areas where there are few family caregivers and attendants, but demand for services is extremely high. In talking to an ILG grantee who administers the Respite Grant, state and local agencies are not providing adequate support for rural family caregivers. "Educating families on resources available can be daunting for those who need assistance and are given

a lot of information of which they become confused by,” states Mary Brock, Executive Director of Seniors in Service. “In urban areas there is sufficient educational resources to help family caregivers with self-care and care of a loved one, but in the rural communities this is again a challenge. Who watches their loved ones while education is offered?”

Finally, there is also concern as to how information and resources are disseminated. Continuing outreach to rural family caregivers is a problem with constant turnover in state and local agency caseworkers. Workforce turnover and shortages in certain professions has created a very real problem accessing care.

In-home care typically is paid for by families and individuals, not insurance unless the consumer has long-term care. Luckily many recipients of home care are seniors who can afford to pay for the service out-of-pocket. The larger concern is attendant wages; they tend to be on the lower end of the income scale, earning between \$13 and \$17 an hour according to the Genworth Cost of Care 2017 estimate for Nevada. As Nevada’s cost of living continues to climb and the affordable housing market becomes scarcer to find, many attendants are being priced out of neighborhoods they once lived and worked in and are leaving the caregiving industry altogether.

As baby boomers are now reaching senior age, the need for in-home care to age in place will continue to drive demand. Attendants play a vital role and provide a safety net that keeps people living in their homes and keeps families together. In-home care helps healing and facilitates better health outcomes. Attendant respite care saves money as it is more affordable care than expensive skilled nursing care, for both the family and state agencies.

In closing, the shortage of attendant caregivers is in a state of crisis. Finding qualified eligible workers who must pass background checks, finger printing, and other requirements for the job is becoming more difficult. Attendants are looking to other professions that pay more, and are easier jobs to do. In Nevada, agencies have not had an adequate reimbursement rate increase to keep pace with the work that attendants actually do in over 12 years, causing many agencies to not accept Medicaid clients. The increasing regulatory requirements such as the Personal Identifier Number and the Electronic Visit Verification system that is being mandated by the federal government is driving up the costs to do business along with other challenges mandated in state statute requiring training, education, and competency testing. All of these stipulations are impacting Nevadans access to care and their ability to live in the community in a home setting of choice. The need for respite and in-home care will only become more of a concern as the baby boomers age and strain the system. If the state is going to make any changes to get ahead of a looming public safety crisis, now is the time.

I believe this statement taken from a Nevada Division of Health Care Financing and Policy 2015 Report to the legislature sums up the situation nicely:

“When the number of Nevadans with health care coverage

increases and the statewide provider pool remains the same, access to care becomes a statewide issue.”

**1:** The Medicaid reimbursement rate for Personal Care Services of \$17/hour has not been adjusted from the current \$17 per hour since 2008 when it was reduced by \$1.50 from \$18.50. The last increase in this rate was over 12 years ago in 2006.