

NLRCC Position Statements

The Nevada Lifespan Respite Care Coalition (NLRCC) serves family caregivers typically providing uncompensated care for someone else for 20 hours or more per week. Family care includes kinship and grand families (extended family providing care) but can also refer to unrelated members, such as friends and neighbors. Providing this level of care can negatively impact family caregivers' physical, emotional, and financial well-being. Too often overlooked by the Long-Term Services and Support (LTSS) system, family caregivers deserve to be recognized as key partners and providers of healthcare and long-term supports and services.

Because family caregivers are overlooked, their own needs are not assessed, and they are often not provided with the information, training, and supports they need to perform in their role. Caregiving can also strip away freedoms, connections, and resources. Family caregivers will eventually reach a level of burnout that causes exhaustion, collapse, or failure in their caregiving role. It is imperative that protective and emergency supports are available and accessible to these caregivers, including regular respite breaks, for the health of the entire Long-Term Services and Support (LTSS) system.

Many family caregivers have limitations of their own, yet still provide invaluable care. Even if they are fully capable of care, caregiving depletes them physically, emotionally, and mentally. Caregiving often requires that they cancel commitments or obligations to make themselves available for care, ultimately forcing them to sacrifice their own needs to meet the care needs of others. At a minimum, they need regular respite to continue to provide long-term care.

The Long-Term Services and Support (LTSS) system identifies care needs presented by persons with disabilities or special healthcare needs themselves. The LTSS works to address those needs, provided the person needing care meets narrow or limited criteria for eligibility. Some criteria include the individual's income and available financial resources. Financial resources of a care recipient are not measured against the costs of the care they need. Family caregivers may rush in to prevent the impoverishment required to qualify for services and end up carrying many of the care recipient's financial obligations in addition to their own. Over time, these costs can irreversibly damage the financial freedom of family caregivers.

When people in need of care do not meet eligibility criteria, a gap in support is created. When family caregivers attempt to fill that gap, they often do not receive the supports they need. The burden assumed by caregivers of ineligible care recipients is no different than the care burden of eligible care recipients, but the long-term resources available to them are nonexistent. Caregivers are left standing alone.

While paid staff and systems are in place to assist eligible care recipients to find and access services and supports, the administrative responsibilities (such as applications, paperwork, and locating and selecting care providers) often falls to caregivers. In addition, care recipients often require decision-making and advocacy support, assistance in managing their finances, case management and care coordination. These additional needs place significant demands on caregivers. Every other individual providing support and/or assistance to a care recipient is employed to do so, but caregivers are expected to assume these additional responsibilities, in addition to all the care duties, for no compensation at all.

Even when funding is available to support caregivers with services and supports, those resources are untapped unless direct support service workers can be found. Given workforce shortages, providers are struggling to find workers - even with funding to pay them. Waiting for a provider to find and properly train adequate workers often means waiting on a list. There is no system to bypass providers and advertise a care need directly. When community providers do not exist, caregivers are then tasked with community organizing and/or engaging with potential workers directly, all without a knowledge of the Long-Term Services and Support (LTSS) system and its funding sources, regulations, required qualifications, or limitations on types of assistance. Caregivers, with or without funding, need ways to advertise their need, connect with direct care workers, and successfully compete with funded community programs seeking workers too.

Family caregivers may view treatment or discharge as assurance that the person needing care will recover, the support of the family caregiver is temporary, and/or that they will receive sufficient services and support to continue care at home. This causes family caregivers to overestimate their ability, stamina, and strength and assume that care supports will automatically follow the care recipient back into the home and community. Family caregivers need to have partners in providing care, especially to get a reasonable, regular break from care.

The Nevada Lifespan Respite Care Coalition (NLRCC) recognizes caregivers for their role in the Long-Term Services and Support (LTSS) system and honors that role by:

- Increasing the number of individuals that self-identify as caregivers and supporting them as LTSS key partners - with access to training services and resources.
- Engaging them in design and delivery of services and treating them as essential members of the care recipient's care team.
- Promoting strategies that reduce the impact on family caregivers' financial and employment security.
- Promoting the importance of caregivers finding and maintaining supportive relationships with people in their communities beyond paid providers.
- Empower individuals and caregivers by embracing the principles of self-direction and self-determination, and in applying person-centered practices to the delivery of services.
- Ensure access to information about services and supports that individuals & caregivers need to make informed choices.

Policy Recommendations:

- Address inequities in access to and funding for direct support caregiver services for all care recipient populations; including incentives for direct support professionals - to create a more stable and qualified workforce.
- Ensure the availability of respite care for families with members of all ages, disabilities or healthcare conditions, geographic location, socio-economic status, or cultural identity.
- Ensure the movement of individuals with long-term care needs from institutional settings to community come with the necessary supports for primary caregivers.

The Nevada Lifespan Respite Care Coalition (NLRCC) strategic plan will focus on areas such as person and family-centered care; assessment and service planning; information, education and training supports; respite options; and financial and workplace security issues. Family caregivers' physical, emotional, and financial well-being will improve because of expanded awareness, outreach, and education.