

01/18/2022 NLRCC Presentation Notes to TFAD

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NVCaregivingRelief.org

Vision: Adequate Respite Care for All

Mission: The mission of the Nevada Lifespan Respite Care Coalition is to support caregivers in our community by promoting awareness and access to, as well as coordination and advocacy for, respite services in Nevada throughout the lifespan.

Nevada Lifespan Respite Care Coalition (NLRCC) will be working on issues surrounding caregiving and caregiver supports, such as respite. Respite is the number one request family caregivers make for themselves. Respite means a short-term, temporary break from providing care, meant to be used for the self-care of the caregiver. Respite provides family caregivers the freedom to enjoy interests & activities, receive support & encouragement in giving care, and maintain connection with friends, family & colleagues outside of caregiving.

The Nevada Lifespan Respite Care Coalition (NLRCC) represents family caregivers who are typically providing uncompensated care for someone else for 20 hours or more per week. Family care includes kinship and grand families (those extended family members providing care) but can also refer to unrelated individuals, such as friends and neighbors. Providing this level of care can negatively impact family caregivers' physical, emotional, and financial well-being. 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.

According to the **most recent data** from the AARP, an estimated 41.8 million people, or 16.8% of the population, currently provides care for an adult over 50. That's up significantly from 34.2 million (14.3 percent) in 2015.

Of those caregivers, 28% have stopped saving, 23% have taken on more debt, 22% have used up their personal short-term savings, and 11% reported being unable to cover basic needs, including food. The average age of someone providing care for an adult is 49, but 23% are millennials and 6% are Gen Z. Sixty-one percent are women, but male caregivers trends are up, and 40% provide that care within their own homes, up from 34% in 2015.

Only three in 10 caregivers have additional paid help, and 27% struggle to hire affordable care in their area. One in four caregivers find it difficult to take care of their own health, and the same percentage report that their health has deteriorated because of caregiving.

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. Family caregivers without support will eventually reach a level of burnout that causes exhaustion, collapse, or failure in their caregiving role. Having protective and emergency supports available and accessible to these caregivers, including regular respite breaks, is imperative for the health of the entire Long-Term Services and Support (LTSS) system.

In a recent study by Mental Health America (2020), only one-quarter of respondents (24 percent) reported that they were asked about their own personal needs as the caregiver. Doctors rely on caregivers to follow through on care and treatment plans but don't routinely check or assess the caregiver's need for support in that role.

Many family caregivers have known limitations for providing care, yet what they provide is invaluable. 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 and 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. However, 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. It is not quick, and it is not easy to get supports in place. Caregivers give up before they get very far. 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 care services, 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, often 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.

The lack of affordable or even available assistance means more “coerced” caregiving by family members who feel they have no other choice; according to the [AARP](#), this accounted for 53% of caregivers in 2020. In addition, finding replacement caregivers and then coordinating their hours is one of the most mentally taxing components of familial caregiving, a task that only gets harder when labor is in short supply.

Family caregivers may view diagnosis and treatment as assurance 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, once diagnosed, 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) 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.

I have reviewed the TFAD 2021 State Plan from the Nevada Aging & Disability Services Division website and noted several recommendations that address caregivers/care partners. I would love to see the data collection measures or instruments to be used to collect data on caregivers. It will be important to our work too.

NLRCC has been charged with finding out what Nevada knows about our caregivers across the lifespan, what Nevada caregivers need, and how well we, as a state, are doing in providing supports for those needs. I hope you have some information on your family caregivers and their needs.

Unfortunately, our LTSS programs have been focused on the challenges of providing service to the individual and may have made assumptions on the strength of the primary caregivers to provide care indefinitely, without ever asking what caregivers need themselves. This is a blind-spot we hope to correct.

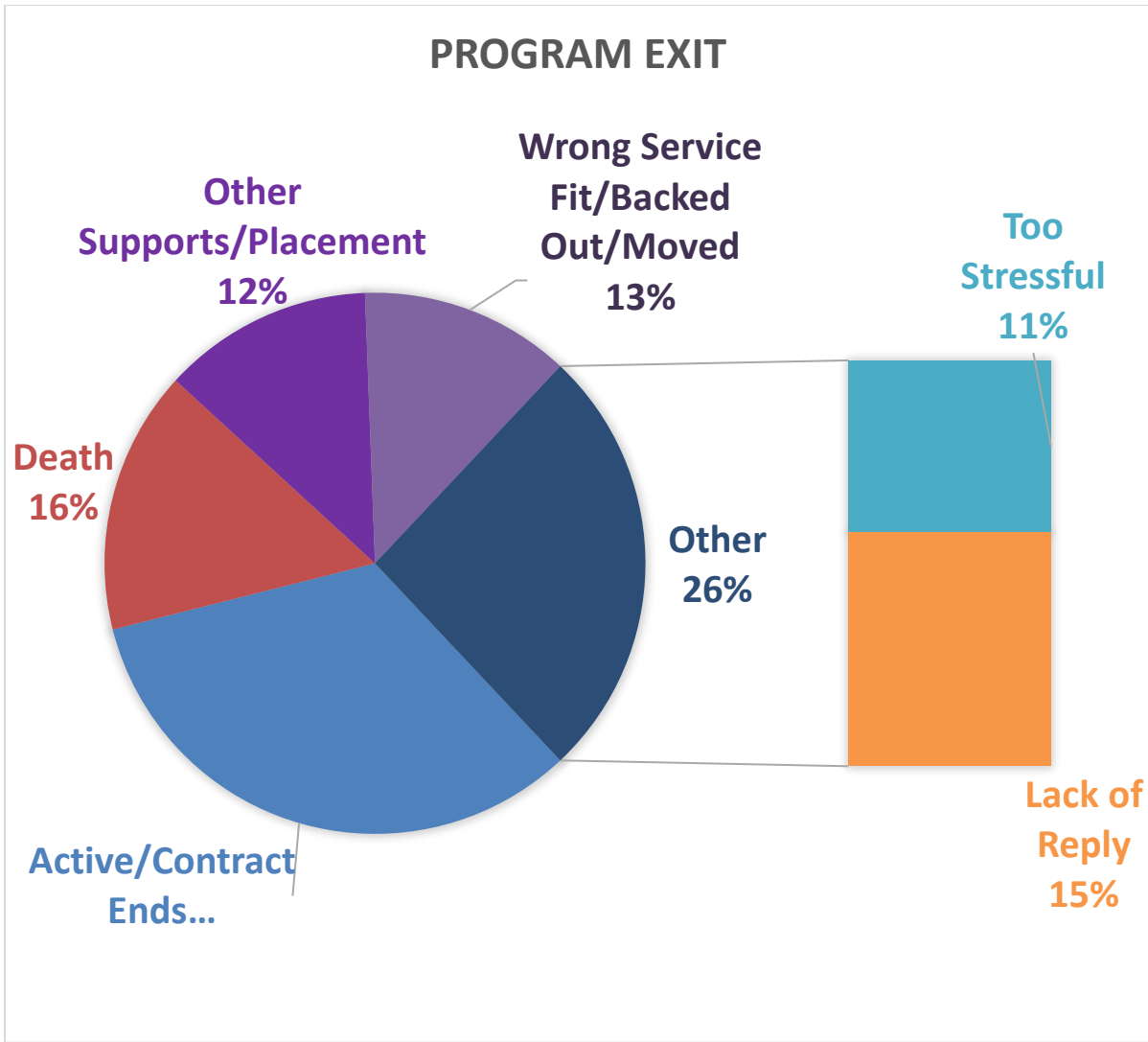
How does the systems and services that the TFAD oversees address the following?

- Helping family caregivers assess their abilities and circumstances. (Do they have the skills & knowledge they need to provide care? Do they have the time & strength to do so? How do we know?)
- Helping caregivers to become aware of trade-offs/sacrifices that they are making to provide care. (They cannot just add responsibilities to provide care/support interventions without letting go of other things – hopefully not ones that will preserve and protect them in their caregiving role! How do we help them make good decisions about those trade-offs?)
- Encouraging family caregivers to seek the help of respite services? (Do we see any of the strain that comes from caregiving in our families? Have we given them any “safety valve” to reduce the pressure they feel?)
- Providing suggestions to make respite most effective? (Respite isn’t the clean-the-house, do-the-necessary-shopping relief that caregivers need; it’s having time to call their own.)

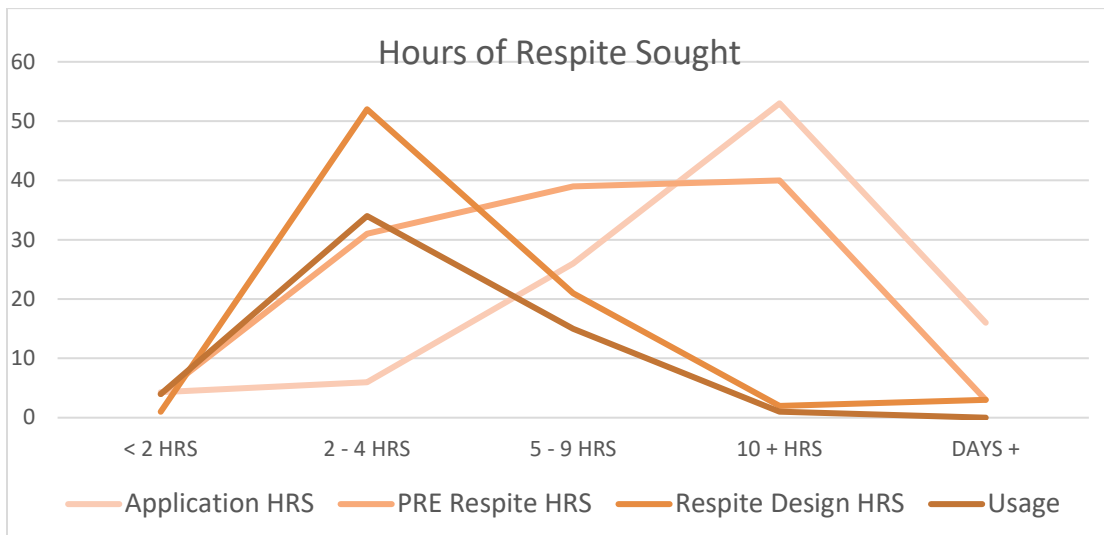
How can NLRCC help you in getting more information on your family caregivers? Would you support the dissemination of surveys or sharing of data?

Responses to TFAD Questions:

Drop-Off Rate –



Respite Usage -



At the time of application, most caregivers requested 9-12 hours on a weekly basis.

In a pre-respite survey, the results leveled out significantly. The “10+ hours” still got the majority again, but the average fell from 14.7 hours to 6.6 hours here per week.

After engaging the caregiver in a person-centered respite design planning process to figure out how respite would “fit” into their lives, the requested hours fell significantly again. Now, the majority fell in the 3-4 hours block of time and the average fell to 4.4 hours per week.

Given that the planned respite was designed for them individually, did they use it? For most, the answer is Yes. However, the average hours used on a weekly basis fell to 2.99 hours. We hit our target of providing 2-4 hours of respite per week, not because it was imposed but because that’s all they could fit in and benefit from.

[Respite RX report \(nv.gov\)](https://www.nv.gov)