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# Caregiving In Nevada



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## Executive Summary

Family caregivers, who often don't recognize themselves as caregivers, provide countless hours of in-home emotional, physical, and financial care and support to individuals across the lifespan. The number of people providing care has expanded exponentially over recent years. The role of a caregiver, and the complexities of issues faced by caregivers are not widely understood by the public. Caregiving is a mixed and complex experience filled with both benefits and rewards. Caregivers must balance the demands of their own daily lives with those they care for, which can lead to stress and burnout. Numerous studies have cited the physical, emotional, and cognitive impacts that caregivers face.

The Nevada Aging and Disability Services Division (ADSD) under the Department of Health and Human Services (DHHS) is the state's single State Unit on Aging and Disability Services. ADSD's primary focus is to provide services to older adults, people with disabilities, and family caregivers that supports their long-term care needs. DHHS recognizes the integral role that family caregivers have in providing care to the populations served, as well as the sacrifices often made by caregivers. This annual report will document the systemic efforts driven through the Lifespan Respite Care Act of 2006 to provide support to family caregivers by providing an overview of the caregiving picture in Nevada, relevant caregiver data collected, challenges faced, and steps ADSD will be taking to advance caregiver supportive services.

## Introduction

The Nevada Aging and Disability Services Division (ADSD) is the state's single State Unit on Aging and Disability Services and is one of five divisions of the Nevada Department of Health and Human Services. ADSD's primary focus is to provide services to older adults, people with disabilities, and family caregivers that supports their long-term care needs. Much of the work of ADSD is also done in partnership with other DHHS divisions including: Child and Family Services, Public and Behavioral Health, Health Care Financing and Policy, and Welfare and Supportive Services. Collectively, the DHHS Division's offer a network of services to meet the long-term support needs of older adults and people with disabilities. DHHS recognizes family caregivers are an integral part of the long-term support network and our efforts include targeted support programs to help family caregivers maintain their informal caregiving role while protecting their health and well-being.

This report is being published annually to document systemic efforts to increase Nevada's efforts to support family caregivers, with an emphasis on ensuring the availability of respite services throughout Nevada for all populations. This work is being driven by the Lifespan Respite Care Act of 2006 and ADSD has led projects under this funding since 2009. Up until now, efforts have focused on increasing awareness of respite among family caregivers, helping caregivers recognize themselves as caregivers, and incorporating caregiver support within the Nevada Care Connection network (Nevada's No Wrong Door system). The Nevada Care Connection links people to services through an integrative system that provides person-centered planning, resource navigation, and case management.

The Nevada's Lifespan Respite Care Coalition (NLRCC), serves as a partner to these efforts, elevating the family caregiver voice in policy recommendations and program development. They are a leading partner in our state's efforts under the Lifespan Respite Care Act. The NLRCC promotes the needs of family caregivers through increased awareness of respite services, the value of providing respite, and advocacy to increase access in non-traditional models of respite.

Nevada's family caregivers are an integral part of the long-term services and supports system, yet the focus is often placed on the individual needing care (care recipient). Family caregivers provide countless hours of in-home emotional, physical, and financial care and support for older adults, adults with disabilities, and children across the lifespan.

This annual report will highlight Nevada's caregivers and system efforts, as well as next steps to move forward in addressing needs and challenges Nevada Caregivers face every day. As ADSD and partners build a comprehensive system of support, integrated into our long-term support system, for family caregivers, this report will shed light on key data and topics pertinent to caregivers in Nevada.

## Definitions

The following are common terms and definitions used throughout this report and in general, in caregiver support conversations:

- **Caregiver:** is a relative or other individual who has a “significant relationship with,” and who cares for an individual with a “chronic or other health condition, disability, or functional limitation.”
  - **Compound Caregiver-** Caring for more than one person who is an adult and/or child with special needs.

- **Family Caregiver** – Individuals who are members of the care recipient’s family of origin, or member from their family of choice.
- **Informal Caregiver**- A relative or a friend who may or may not live in the same household as the person they are caring for.
- **Sandwich Caregiver**: A person who is caring for an older adult and a younger person at the same time. This is commonly a person caring for an older adult parent while also caring for their own minor children.
- **Formal caregivers** -Caregivers who are paid and have received training to provide personal, medical, or respite care such as a nurse, home health aide, personal care aid, and certified nursing assistant.
- **Care Recipient**: An individual with a “chronic or other health condition, disability, or functional limitation who receives respite or other needed care.
- **Care Partner of Choice**: Can range from a non-profit organization, for-profit organization, a licensed individual that provides care, or someone the caregiver trusts to provide the adequate care the care recipient needs.
- **Activities of Daily Living (ADLs)**: ADLs are considered basic activities of daily living: eating, bathing, grooming, dressing, mobility, transferring (such as going from bed to wheelchair) and using the toilet.
- **Instrumental Activities of Daily Living (IADLs)**: IADLs can be viewed as more complex self-care tasks, or the next step to living independently. These include meal preparation, housekeeping, shopping, laundry, transportation, handling finances, managing medications, and using a phone.
- **Respite**: Pronounced “ress-pit”, is a break, or time away for a caregiver that can be short or long. It might just be a few hours so the caregiver can go shopping, visit friends, or see a movie. It might be a day or two, so the caregiver can tend to personal business or get away for a weekend. It could also be a week or two, so the caregiver can take a vacation and “recharge their batteries.”
- **Emergency Respite**: Unplanned or urgent breaks that allow the caregiver time away to attend to other needs such as their own health care, family obligations, work responsibilities, etc.

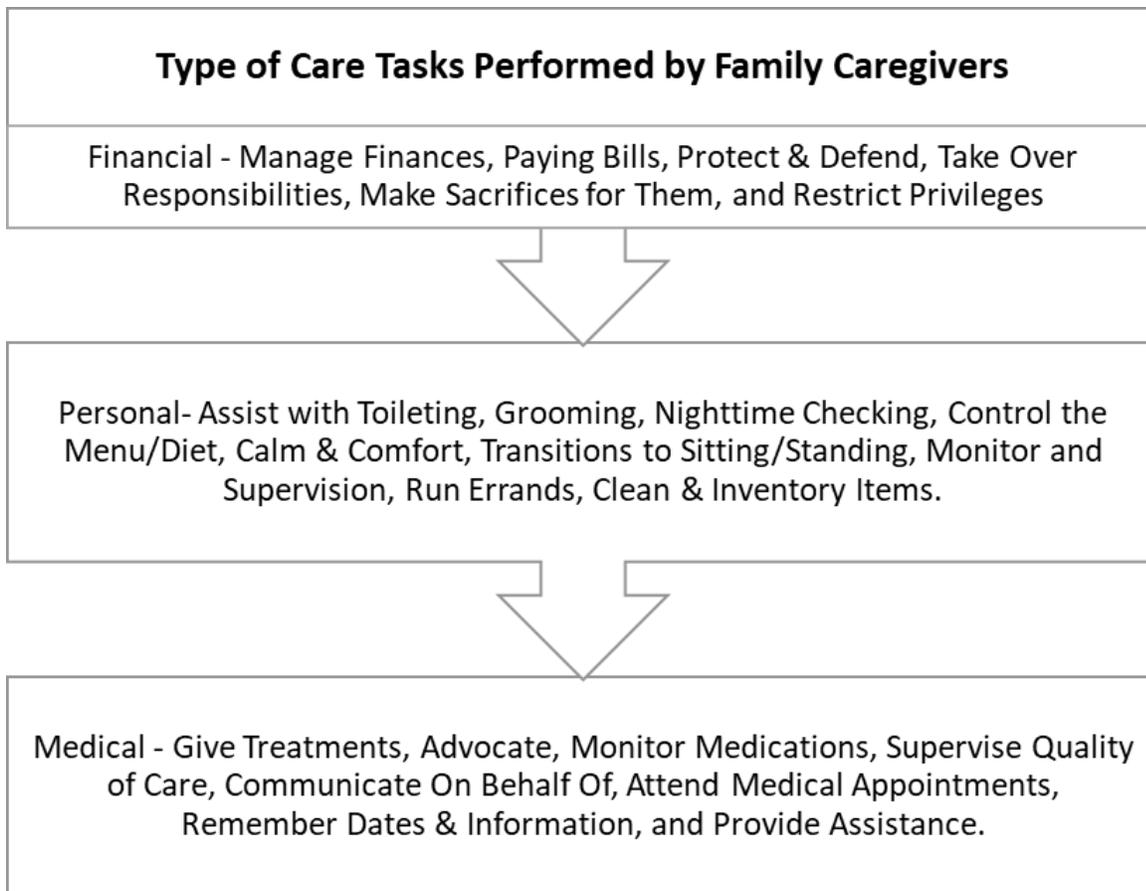
- **Respite Worker:** A paid or unpaid person who is trained to provide respite care to a caregiver who needs a break.

## Caregiver Support – An Overview

Family caregivers are an extension of health care systems and critical to the success of long-term services and support systems. As such, caregiver efforts must be recognized and supported throughout both health and social systems. This section of the report will provide an overview of the types of care family caregivers provide, the impact of caregiving on family caregivers, and the benefits of caregiver support services, namely respite services.

### Types of Care

Family caregivers operate as extensions of health care systems performing complex medical and social tasks by assisting care recipients with activities of daily living (ADLs) and ensuring their loved ones follow their medical and/or therapeutic treatments. Family caregivers function as home-based “care coordinators” and individual supporters on behalf of their loved ones. Below is an example of the many tasks that caregivers do, but this is not a comprehensive list.



Dr. Dale Lund's (2009) Continuity Theory of Life Course Aging states, "those who are able to maintain or continue engaging in their preferred and most meaningful activities (and values, beliefs, and preferences) or minimize the most disruption to them will have more positive adjustments to aging". This theory further concludes that helping caregivers find out what activities they have discontinued because of caregiving and encouraging them to use respite to restore these activities (or find substitutes), is the most beneficial purpose of respite.

Caregiving has always been vitally important to families, friends, and communities, but the depth of this role is not widely understood to the public. The COVID-19 pandemic highlighted the need to look more closely at how caregivers are being supported. This includes expanding the

definition of caregiving, and how a caregiver's life is impacted through this role. The pandemic has expanded the focus on the vast quantity of stressors caregivers experience, as well as the many rewards. Research into this topic shows that caregiving is a complex and mixed experience which requires more understanding, focus, and intentional support from the community and systems at large. Balancing caregiving, with the demands of daily life such as caring for children, maintaining employment, and maintaining social circles, takes a toll on family caregivers.

## Impact of Caregiving

Numerous studies emphasize the stress and burnout caregiving can cause on an individual or family. It can indeed be exhausting for the caregiver—physically, emotionally, and cognitively—because of a lack of time, connection, boundaries, or the emotional toll of caring. Often caregivers step into the role of caring for another without adequate support, training, or understanding of how that role will impact their life. Many suffer from impacts to their own health, finances, jobs, and overall wellbeing. Some research has even shown that long term effects of caregiving can lead to a higher mortality rate. When a person becomes a caregiver, that person must balance the care recipient needs with the existing demands of their daily life, which often creates a dramatic change which requires adjustment. This includes many areas of life such as: schedules, family roles and responsibilities, restructuring their employment or overcome the loss of work, financial hardship, how and when to get a break, pursuing hobbies, and how to meet the care needs of the person they are caring for, to name a few.

During the pandemic, caregivers in need of support and people who acquired additional care have expanded exponentially. Nevada recognizes family caregivers, and the demands of their

daily life were compounded during the pandemic as they maintained their caregiving role without relief from traditional roles such as parenting while childcare facilities and schools closed or reduced capacity due to the pandemic. Vulnerable adults also relied on any family or informal caregivers they could find, as many could not get the necessities such as food and medication, without caregiver support. Certainly, the pandemic is one factor, however, as people live longer, the “sandwich generation” in which people care for multiple generations becomes more and more of a reality for many.

## Benefits of Respite

EVERY person providing ongoing care to a loved one needs a break. How often those breaks occur, and how long they last, depends on each person’s situation. Regular relief can become a lifesaver! Respite services provide the following benefits:

- Help sustain the health and wellbeing of the caregiver and care recipient
- Avoid or delay out of home placements
- Reduces the likelihood of abuse and neglect
- Helps maintain their own health as a caregiver
- Gives the caregiver frequent breaks before they become overwhelmed and burnt out
- Re-energizes caregivers and allows them to continue caring for their loved one.

Respite services are available both inside and outside of the home. Traditional examples of respite care include but are not limited to:

- *Family, friends, and neighbors:* These natural supports provide a significant source of affordable and easily accessible respite. These people act as familiar supports for the caregiver to request breaks, or to help recognize and offer breaks when they see the caregiver may need one.
- *Homemaker services:* Private homemaker services offer support with meal preparation, shopping, and light housekeeping. Receiving help with homemaking services frees up

some time or lessens the burdens on a caregiver so they can take a break or focus on other needs.

- *Volunteer or paid companionship:* There are faith-based organizations and non-profit organizations that train and assist with connecting care recipients to a volunteer respite provider who can provide companionship while the main caregiver is away.
- *Personal care or home health agencies:* Personal care agencies can assist your loved one with daily living skills such as bathing, feeding and toileting. Home health agencies can address more specialized medical needs if your loved one requires it. This assistance provides a break from daily care to allow the caregiver time to focus on other needs while ensuring the care recipient's personal care and medical needs are met.

All these services provide a good foundation of support, but there is much work to be done to continue to build on these efforts. Expansion of respite through the 'creation' of respite in non-traditional ways will expand access to and utilization of respite throughout Nevada.

Ideally, respite care in Nevada should evaluate and incorporate the principles of **Freedom, Support, and Connection** to make respite care most impactful. National studies see caregiver benefits from respite aligning with one or more of these three categories:

1. **Freedom** is defined as the state of not being imprisoned or enslaved, released from something unpleasant, and the ability to move or act as desired.
2. **Support** related to respite is defined as bearing all or part of the weight of caregiving, holding up caregivers in their role, giving assistance to caregivers, enabling caregivers to function or act, strengthening their ability to endure or tolerate the situation, and providing a source of comfort or encouragement while they care for others.
3. **Connection** refers to a relationship in which a person is linked or associated with, those emotional bonds and interactions, strengthened by mutual experiences, and people with whom one has social or professional contact, or to whom one is related.

## Respite Survey - Results

ADSD has worked with state and community partners to launch a standard Respite Satisfaction survey to capture data related to **Freedom, Support, and Connection** to better understand how those qualitative measures in respite services benefit caregivers, as well as barriers that still need to be addressed. This survey launched in July of 2021, and while collection has been limited, the results to date highlight the value of respite for family caregivers (N = 43). These results are from surveys collected through ADSD and partners including: the Community Based Care unit, Systems of Care, Lifespan Respite Emergency Funds, Regional Centers, and Nevada Pep. As you'll see in the "Looking Forward" section (page 18), much more coordination and outreach is needed to increase utilization and dissemination of this survey.

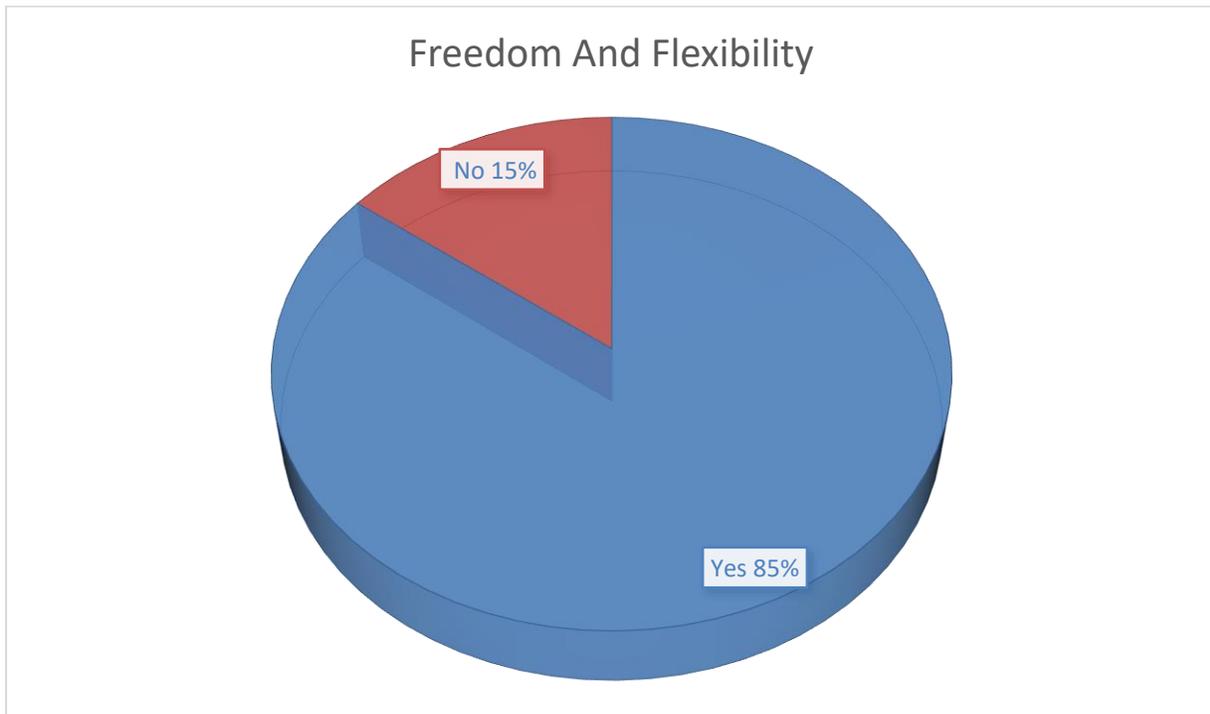
**Figure 1** indicates satisfaction results related to freedom for the caregiver to have the flexibility to choose when they wanted a break, and the majority answered yes<sup>1</sup>. For the 15% of caregivers who answered no; it was followed up with the question "If using the respite service was NOT flexible or DID NOT give you enough choice/control, what would you suggest for improving it?" Suggestions included:

- More formal and reliable caregivers/ respite workers
- Formal caregivers - COVID related concerns such as not wanting outside people to enter their home and higher health risk of care recipients in general
- Help with navigation of services and making informed decisions

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<sup>1</sup> Figure 1 – "Did you have flexibility to get a respite break when you could most benefit from it?"

Figure 1



**Figure 2** also relates to freedom and indicates that 51% of those surveyed felt they did get to do something they enjoyed at least occasionally, with 12% indicating they did something they enjoyed frequently<sup>2</sup>. Those who frequently/occasionally did something they enjoyed indicated that they: rested, took time for themselves, or took time away from home. Out of home activities included going out to eat, movies, outdoor activities, or having a date night with their significant other. For caregivers who indicated they rarely did something they enjoy responded that they instead did the following:

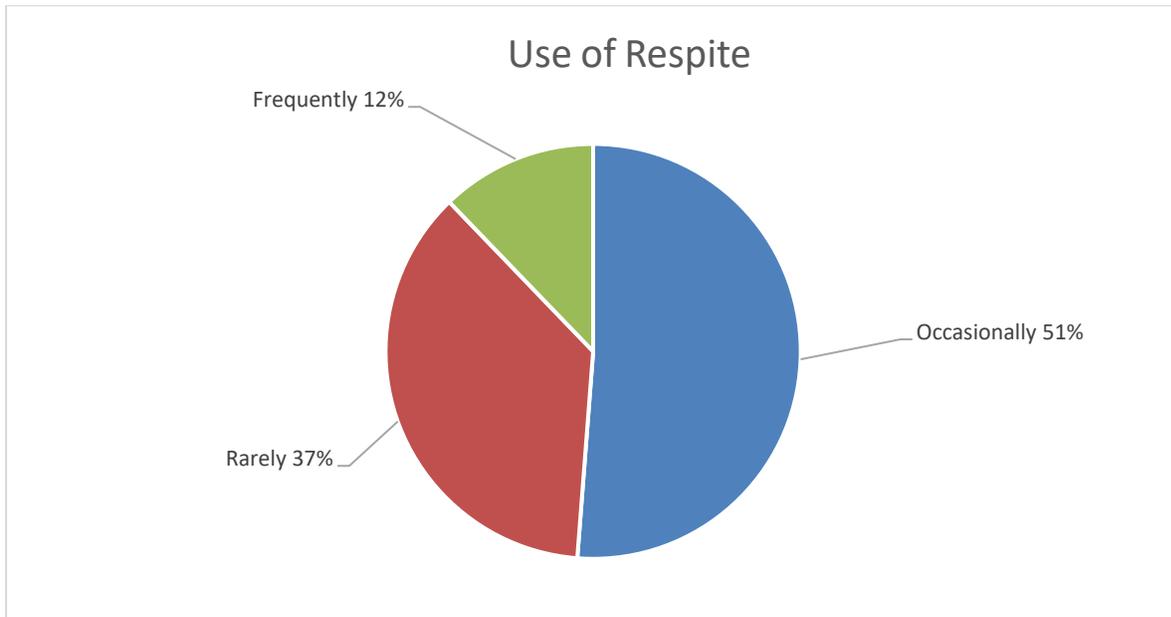
- Shifted their focus from caring for one loved one to another (e.g. caring for spouse to caring for grandchildren)
- Used their respite time to work or do household tasks

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<sup>2</sup> Figure 2 – “During your respite breaks, how often did you do something that you really enjoyed?”

- Completed errands or went to much needed doctor’s appointments for themselves

Figure 2

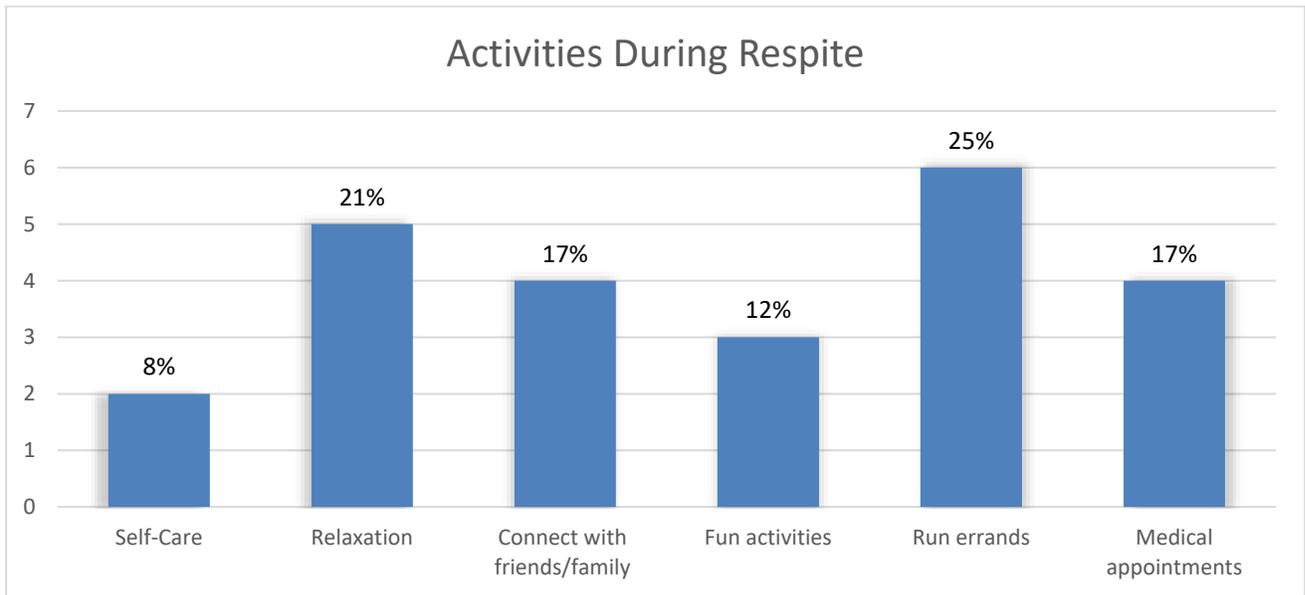


Caregivers often experience loneliness, isolation, and disconnection from their previous routines and lifestyle. Social isolation can be a factor of high levels of caregiver burnout. **Figure 3** measures a level of connection felt through various activities to paint a picture of how caregivers are currently connecting to their environments<sup>3</sup>.

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<sup>3</sup> Figure 3 – “What did you do for yourself during your respite breaks?”

Figure 3



Many times, caregivers prioritize other important life activities such as running errands and attending personal medical appointments over social connections and self-care. This data indicates a mix of both self-care, social, and daily life activities being completed as part of their day-to-day social interactions. More utilization of respite care could improve the amount of self-care and social type connections by allowing more time to focus on those areas of their lives.

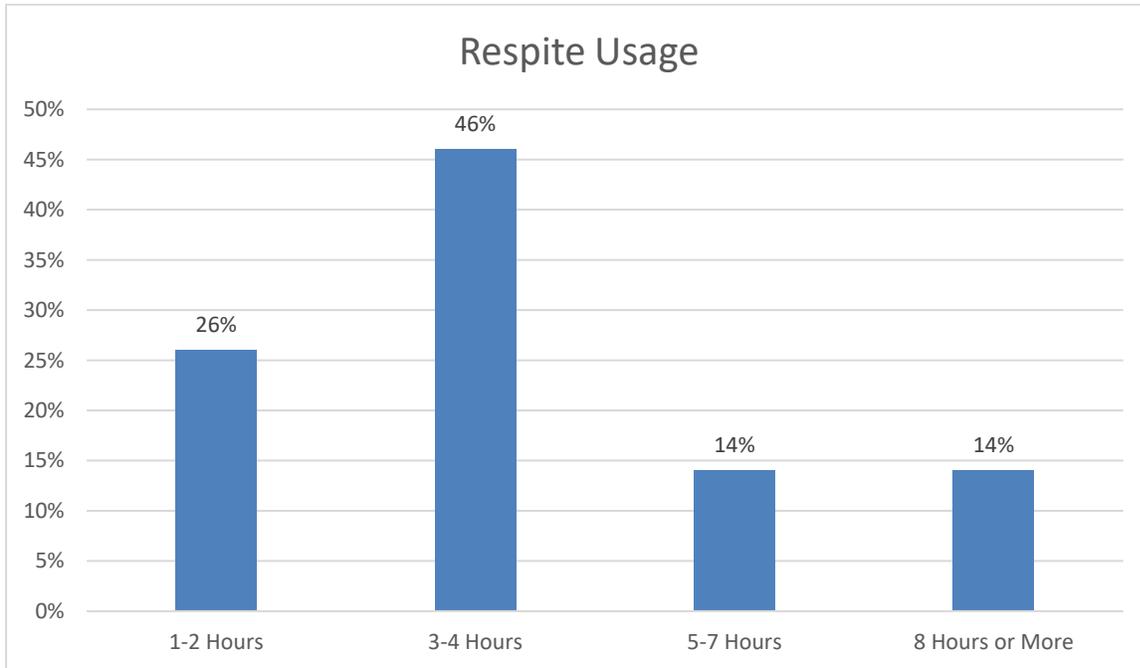
**Figure 4** shows most caregivers receive about 3-4 hours per respite occurrence, while one-quarter of respondents only used about 1-2 hours<sup>4</sup>. In previous lifespan respite projects, Nevada piloted self-directed respite services that enabled caregivers to get a monthly allotment for respite services. This allotment could be used for both regular, ongoing respite breaks as well as saving for larger, one-time or emergency respite breaks. This pilot showed that regular, respite

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<sup>4</sup> Figure 4 – “What amount of time did you most often use to take a respite break?”

breaks led to increased usage of respite for self-care and connection activities, which improves the benefits of respite breaks.

Figure 4

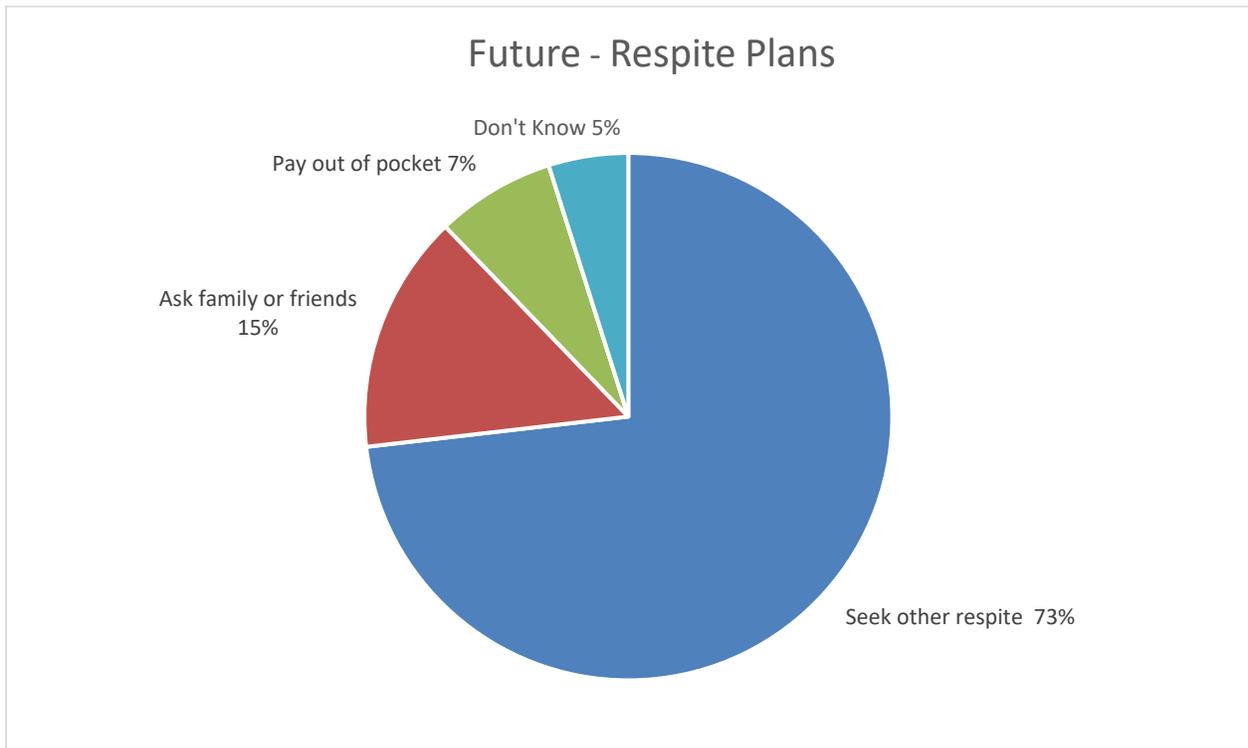


For many of the respondents in this data, they were receiving a one-time allotment of respite services. However, **Figure 5** measures caregiver future respite plans, capturing responses related to planning for additional respite after services had been rendered<sup>5</sup>.

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<sup>5</sup> Figure 5 – “Now that you have completed your Respite program, what plans do you have to continue receiving some form of respite break for yourself?”

Figure 5



The majority indicated that they would be reapplying for respite care assistance through respite programs in the future with very low utilization of respite from other avenues. This indicates there may be a lack of knowledge or access to other sources of respite care available. Each respite program also has differing policies as to how often someone can reapply for the same respite program, so it is possible people are utilizing the same programs repeatedly if they are able to meet their respite care needs.

## State Programs

In Nevada, there are several grassroots and organizational efforts to help support caregivers through public programming, community services, and volunteering. Nevada partners, both public and private, provide a multitude of caregiving services. These services include voucher and in-home coordinated respite, adult day care centers, evidence-based programs such as

Powerful Tools for Caregivers, grandparent respite to support grandparents in caring for minor children, family support programs, support groups, and various caregiver education series.

Funding for publicly funded caregiver support services come from a variety of sources including federal funding, state general funds, and Funds for Healthy Nevadans. Nevada caregivers are also supported by the Nevada Care Connection's No Wrong Door (NWD) system to assess and link individuals to services through case management and statewide connection. This network provides for a one-stop access point where people can be linked to a multitude of services throughout the state regardless of the provider or pay source.

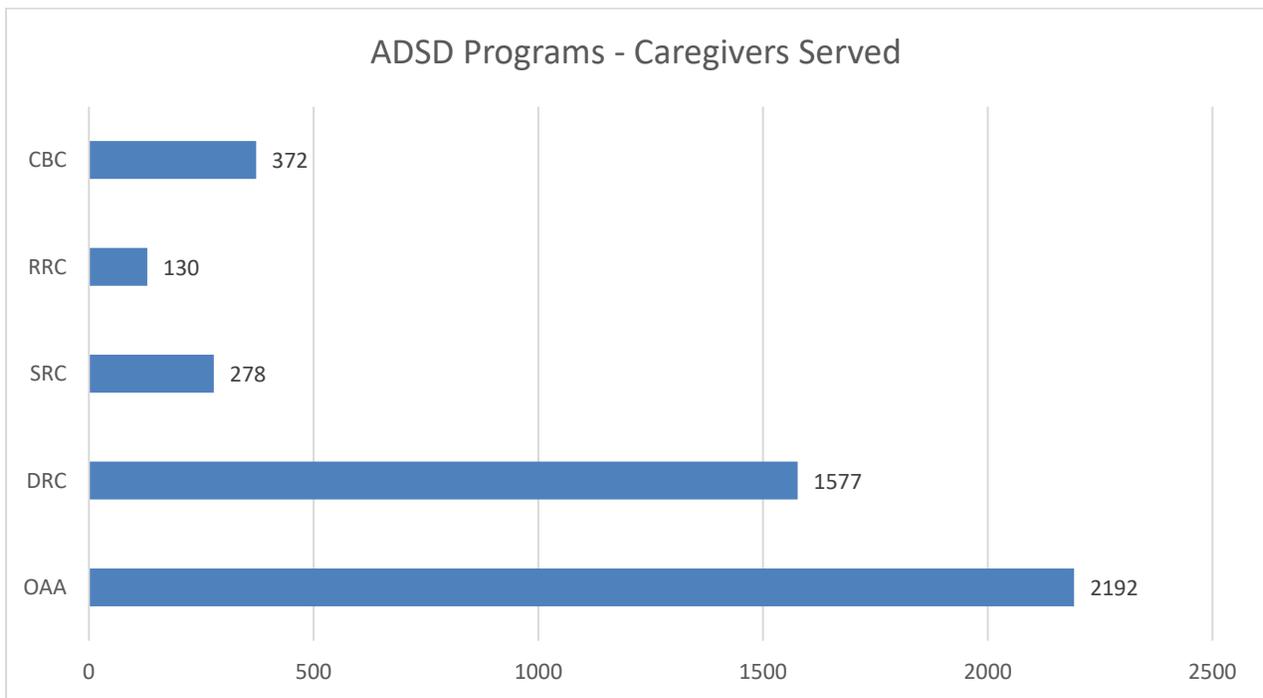
This section captures data for State Fiscal Year 2022 (July 1, 2021 – June 30, 2022) received from ADSD programs that provided any type of caregiver services throughout the state. This data serves as a baseline, starting with the overall picture of the quantity of caregiving services being utilized. The next Caregiving in Nevada report will include data from other state agencies as well as additional data points that focus on caregivers.

**Figure 6** highlights the number of caregivers served, mainly through respite programs by Aging and Disability Services Division (ADSD) programs in state fiscal year 2022<sup>6</sup>. This data is a total number of recipients receiving various caregiver supportive services including respite, adult day care, caregiver support groups/education, and caregiver information and referrals. This information will be used to help assess growth in service delivery over the next year.

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<sup>6</sup> CBC = Community Based Care, RRC = Rural Regional Center, SRC = Sierra Regional Center, DRC = Desert Regional Center, OAA = Older Americans Act programs

Figure 3



## Opportunities

Nevada has several opportunities to better support family caregivers. Some of the current challenges caregivers face in accessing support include:

- Limited/Insufficient Respite options for family caregivers, gaps for families of children with dual-diagnosis, and people with disabilities under 60 years of age.
- Lack of training and opportunities for family support within existing provider networks.
- Coordination of programming among public programs to facilitate access regardless of where a caregiver connects.
- Workforce shortages for paid and an unpaid respite workers.
- No comprehensive data regarding family caregivers in Nevada.

Under the Lifespan Respite Act, Nevada partners have opportunities to address these challenges in more systemic ways. These include providing adequate education of services available and needed, standardized data collection to obtain a clearer and more informed picture that includes

data on the caregivers, encouraging self-direction and flexibility with services, coordinating a framework for accessing services, and retaining a trained workforce that can provide caregiver services.

## Looking Forward

ADSD is leading efforts to strengthen support for family caregivers to address the opportunities identified. The major objectives we are working towards include: (1) to build a coordinated framework of respite access across the state that emphasizes self-direction and flexibility; (2) Promote awareness of respite and caregiver supportive services through advocacy, outreach, and education; (3) Enhance respite services in Nevada by creating opportunities for training and workforce retention.

To accomplish these objectives Nevada ADSD will be leading the following efforts in state fiscal year 2023:

- Outreach and awareness events across Nevada to promote the benefits of respite and education on how to access respite services.
- Build educational opportunities, training, and a respite database geared towards increasing access and connection to respite care workers and a trained respite care workforce.
- Standardized data collection across state agencies and ADSD funded partners that reports on strengths-based outcomes related to caregivers.
- Increased collaboration among public programs to review policy and resource constraints to accessing services, and to identify family support within existing provider networks.
- Pilot innovative respite strategies for families of children with dual diagnosis that focus on addressing the stigma of disability and mental health.

ADSD projects will continue to include coordination with state agencies and local partners to engage with family caregivers earlier by continuing with outreach across Nevada. This outreach includes underserved populations and those in rural communities to educate on respite and services available. Self-direction and flexibility will be encouraged during outreach to support the need for more individualized services and recipient choice. In the future, ADSD will continue to look towards efforts to further improve and streamline caregiving services in Nevada as more input is gathered and needs assessed.