2022

Caregiving In Nevada Report

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Executive Summary

The Nevada Aging and Disability Services Division (ADSD) is the state's single State Unit on Aging and Disability Services. ADSD is one of five divisions of Nevada Department of Health and Human Services, including Child and Family Services, Public and Behavioral Health, Health Care Financing and Policy, and Welfare and Supportive Services. The primary focus of ADSD is to provide statewide outreach and services for Nevada's adults and persons diagnosed with a disability across the lifespan, and their caregivers. Nevada strives to improve the system of support through coordination and expansion of services for older adults, people with disabilities, and their family caregivers.

The ADSD has facilitated and led projects under the Lifespan Respite Care Act since 2009 and has been able to increase awareness of respite among family caregivers, as well as incorporate caregiver support within the Nevada Care Connection network (Nevada's No Wrong Door system). The Nevada's Lifespan Respite Care Coalition a public advisory body to the state is also a leading partner in these efforts. The NLRCC helps to promote 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.

As we continue our efforts alongside our state partners, there is a vision and passion to give Nevada caregivers a voice through a comprehensive report that can provide a clearer picture on caregivers in Nevada. Nevada's family caregivers are an integral part of the long-term services and supports system. They provide countless hours of in home emotional, physical, and financial care and support for older adults, adults with disabilities, and children across the lifespan.

The 2022 report will contain Nevada's road map and summary of system efforts to date as well as next steps to move forward in addressing needs, challenges, and barriers Nevada Caregivers face every day. The ADSD and partners will strive to continue enhancing this report year after year to ensure we capture key data points and topics pertinent to caregivers in Nevada. In the future, this report will also contain policy recommendations to improve supportive services for caregivers.

Definitions

For the purposes of this report the following terms will be used and may be used interchangeably:

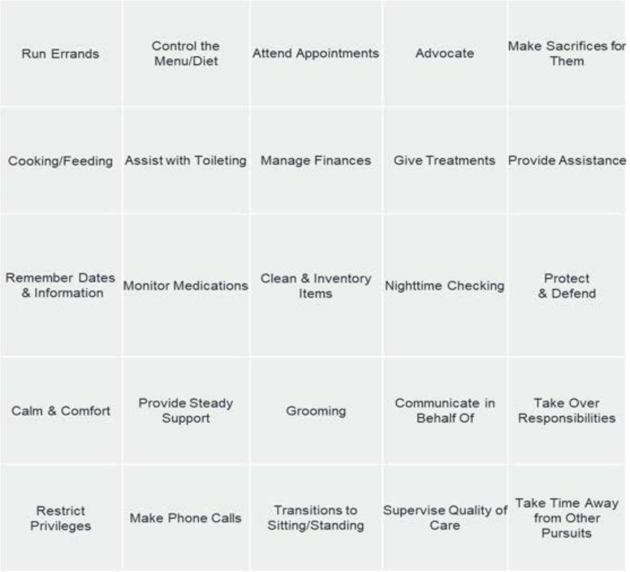
“Caregiver, family caregiver, informal caregiver, and compound caregiver”.

- **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 caregivers** – individuals who are members of their family of origin or to those who care for their family of choice.
    - **Informal caregivers-** is a relative or a friend who may live or may not live in the same household as the person they are caring for.
- **Formal caregivers -**are caregivers who are paid and have received training to care for a patient 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.
- **Provider of choice:** can range from a non-profit, for-profit organizations, or 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 considered as basic activities of daily living are: feeding oneself, bathing & grooming, dressing, mobility (such as transferring from bed to chair) and using the toilet.
- **Instrumental Activities of Daily Living (IADLs):** IADLs can be viewed as higher level of activity or the next step to living independently. For example, eating is step one. Meal preparation is step two. Other IADLs are housekeeping, shopping, laundry, transportation, handling finances, managing medications, and using a phone.

- **Respite:** Pronounced “ress-pit”, are breaks 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. Or it might be a week or two, so the caregiver can take a vacation and “recharge their batteries.”

Type of care family caregivers provide

Family caregivers operate as extensions of health care systems performing complex medical and social tasks by assisting them with ADLs/IADLs, 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 what caregivers do, but it is not a comprehensive list.



Run Errands	Control the Menu/Diet	Attend Appointments	Advocate	Make Sacrifices for Them
Cooking/Feeding	Assist with Toileting	Manage Finances	Give Treatments	Provide Assistance
Remember Dates & Information	Monitor Medications	Clean & Inventory Items	Nighttime Checking	Protect & Defend
Calm & Comfort	Provide Steady Support	Grooming	Communicate in Behalf Of	Take Over Responsibilities
Restrict Privileges	Make Phone Calls	Transitions to Sitting/Standing	Supervise Quality of Care	Take Time Away from Other Pursuits

Supporting Caregivers

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”. Dr. Lund, et al. (2009) 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. The COVID-19 pandemic highlighted the need to look more closely on how caregivers are being supported. The definition of caregiving has expanded and its impact on life has increased. All of this puts new stressors on caregivers as well as new rewards. In other words, caregiving is a complex and mixed experience which requires understanding, focus, and intentional support.

In Nevada, there are a number of grassroot and organizational efforts to help support caregivers through public programming, community services, and volunteering. Nevada is partnered with many statewide entities to 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, support groups, and various caregiver education series. Many of these services are funded through subawards under federal grant funding to ADSD by the Administration for Community Living (ACL) under the Older Americans Act (OAA) Title III funding. Emergency self-directed respite care is also provided through a Lifespan Respite Grant managed through ADSD. Nevada is also supported by the Nevada Care Connection's No Wrong Door (NWD) system to assess and link individuals and their caregivers to these services through case management and statewide connection.

Respite services are a main component to caregiver support. They are available both inside and outside of the home. Examples of this 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.
- *Homemaker services:* Private homemaker services offer support with meal preparation, shopping, and light housekeeping.
- *Volunteer or paid companionship:* There are faith-based organizations and non-profit organizations that train and can assist with connecting care recipients to a volunteer respite provider. Paid companions are usually trained staff that can assist with short-term breaks.

- *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.

All these services provide a good foundation of support, but there is much work to be done to continue to expand on these efforts. This report will begin to set the foundation of what Nevada has historically done, what we have done to improve our supportive efforts, and lessons learned.

Impacts on Caregivers

Studies over the years 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. Caregivers have stepped into the role of caring for another without adequate support, training, or understanding of how that role would impact their life. Many suffer from impacts to their own health, finances, and overall wellbeing. Some research has even shown that long term effects of caregiving can lead to a higher mortality rate.

During the pandemic, caregivers in need of support and people who acquired additional care have expanded exponentially. Parents/grandparents had to step up in their caregiving roles that included childcare and learning help—particularly as 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 resources, they needed without caregiver support. Certainly, the pandemic is one factor, however, as humans live longer, the “sandwich generation” in which people care for their children, parents—and sometimes grandparents—becomes more and more of a reality for many.

What support looks like

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:

- 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 your 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.

National studies see caregiver benefits from respite aligning with one or more of these 3 categories: **Freedom, Support, and Connection**.

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, or 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.

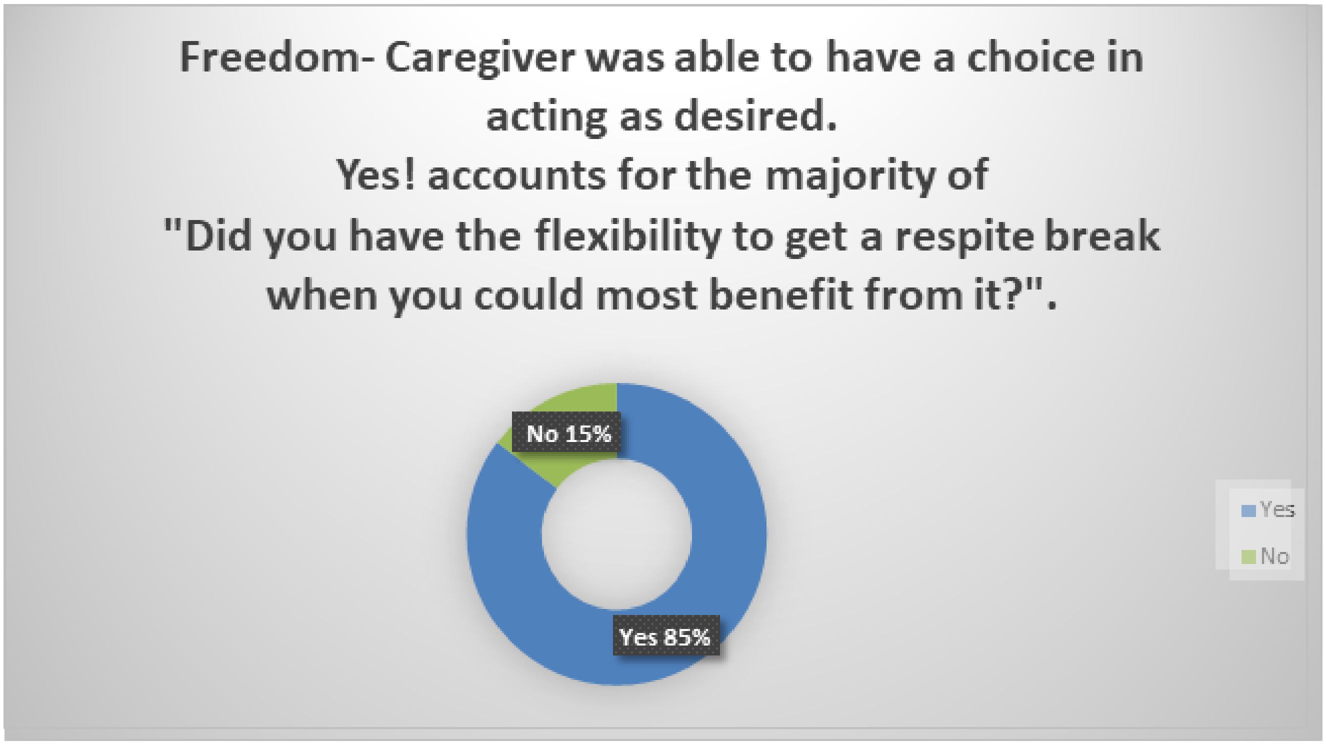
3. **Connection** refers to a relationship in which a person is linked or associated with, those emotional bonds and interactions, strengthened by mutual experiences, and people with who one has social or professional contact or to whom one is related.

In this report we will be sharing these qualitative data points through our caregiver satisfaction survey section.

Respite Survey Satisfaction

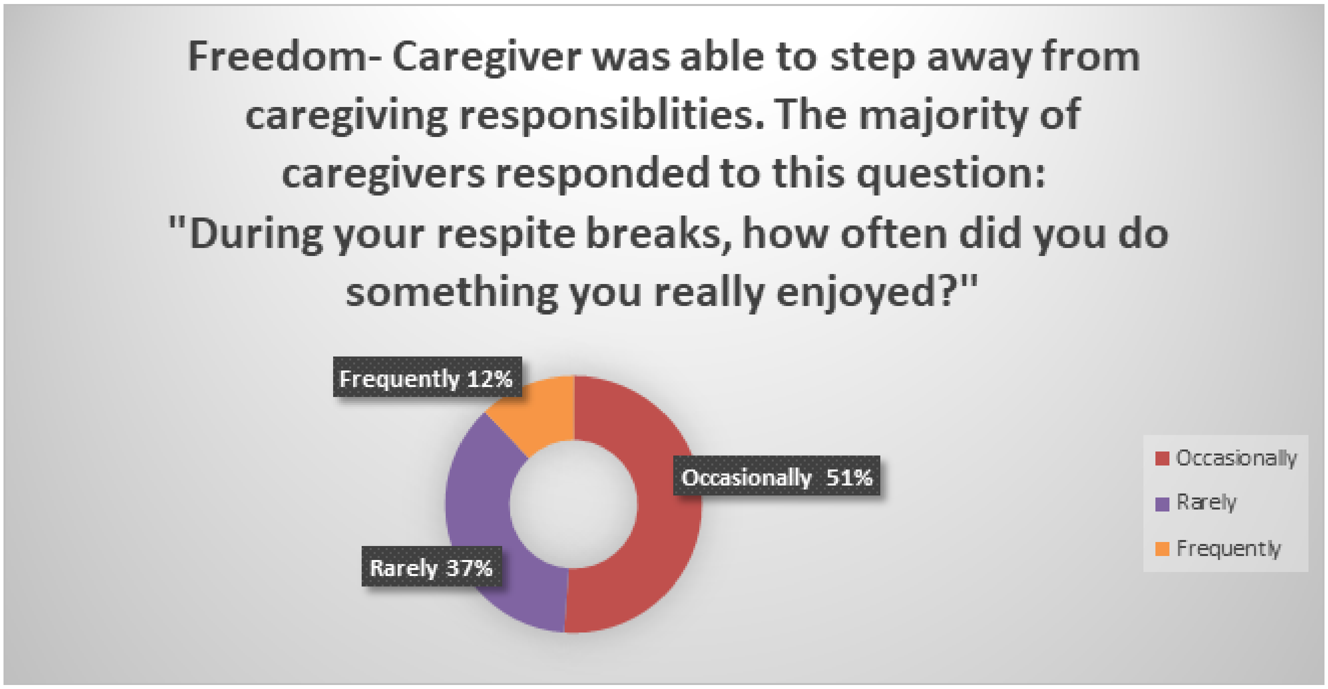
ADSD has worked with state and community partners to launch a standard Respite Satisfaction survey in Nevada to capture data related to **Freedom, Support, and Connection**. Currently data is collected from

Community Based Care unit, Systems of Care, Lifespan Respite Emergency Funds, Regional Centers, and Nevada Pep. Results show that….



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 improving it?” The 15% of caregivers that answered no, suggested the need for:

- More formal and reliable caregivers/ respite workers
- COVID related concerns
- Help with navigation of services and making informed decision



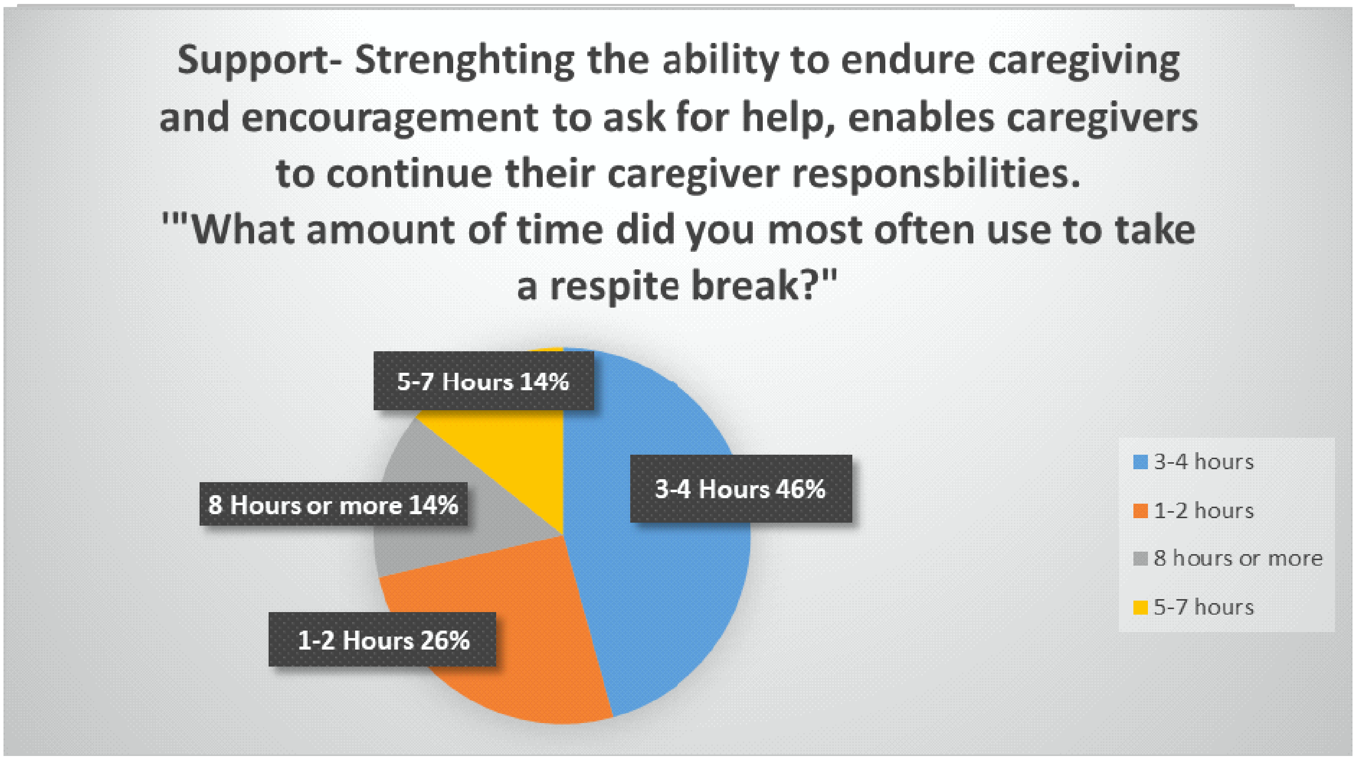
For the caregivers who answered the question on the scale of Frequently, occasionally, and rarely answered with a follow up short answer.

In general, for those who frequently/occasionally did something they enjoyed indicated they:

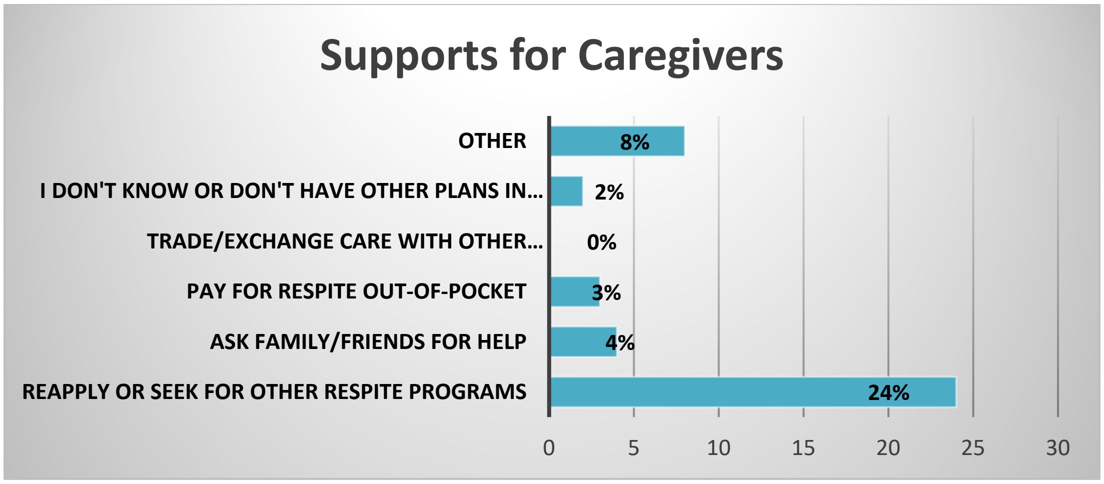
- Rested
- Took time for themselves
- Spent time away from home by going out to eat, sleep, going to the movies, spent time at the beach, went on hikes and fishing, and having a date night with their significant other.

For caregivers who rarely did something they enjoyed indicated in general they:

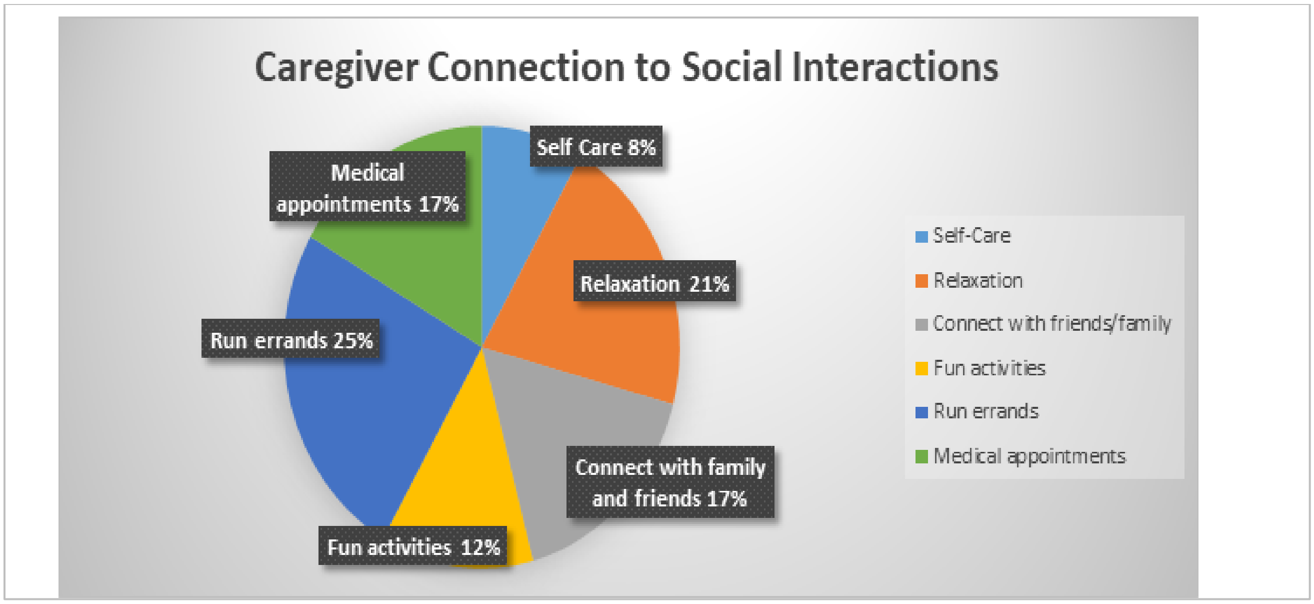
- Shifted their focus from caring for one loved one to another (e.g. caring for spouse to caring for grandchildren) or to work
- Scheduled much needed doctor's appointments for themselves
- Errands



As respite services come to end due to utilizing their voucher, hours, and/ or programming. It is important to capture information on caregiver's plan to continue respite in one way or another.



In the graph above, it captured data on support and/or planning for support after respite services had been rendered. "Now that you have completed your Respite program, what plans do you have to continue receiving some form of respite break for yourself?"



Caregivers often times experience loneliness, isolation, and disconnection from their previous routines and lifestyle. Social isolation can be a factor into higher levels of caregiver burnout that leads to a daily struggle. Asking caregivers “What did you do for yourself during a respite break?” provides an opportunity for a caregiver to be open and be connected to social connection and interaction by being in touch with person-to-person interaction.

- 17% of caregivers reported to connecting with family and friends.

Many times, caregivers prioritize other important life factors such as running errands, attending personal medical appointments which are all important but leave those social connections and self-care aspects of life as a lower or last priority. Self-care and/or respite is important for one to reenergize and continue efforts in caregiving responsibilities.

Nevada’s goal is for wider dissemination of this survey to expand to other ADSD sub-recipients that offer caregiver supportive services, to local and faith-based communities who offer volunteer respite companions, and other entities that are yet to be identified that offer caregiver supportive services.

Caregiver Support in Numbers

This report captures data for State Fiscal Year 2022 (July 1, 2021 – June 30, 2022).

<Pending data from state partners>

Opportunities

Nevada has many opportunities to better support Nevada Caregivers. Some of the current challenges we have faced include:

a. Streamlining application processes and building mechanisms to coordinate access to respite and other caregiver supports. ADSD has faced challenges due to resource shortages, various database systems, and individual funding stream requirements.
b. Limited respite care options for family caregivers due to funding stream and eligibility criteria that is based on care-recipients.
c. Educational training and creating opportunities for self-directed programming with provider networks.

Statewide initiatives and collaboration will continue to provide opportunities to reassess current and past practices to ensure support options are more meaningful and strengths based, processes become more streamlined, and barriers are addressed so caregivers can receive the crucial support needed.

Looking Forward

ADSD is leading efforts to strengthen support for family caregivers to address the opportunities identified. Our projects include coordination with state agencies and local partners to engage with family caregivers earlier, standardize data collection efforts, and increase the network of support for family caregivers. 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.