

Caregiver Respite Self-Directed Pilot



State of Nevada Aging and Disability Services Division

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Contents

- Report Highlights 3
- Self-Directed Respite 5
 - Nevada’s Overview 5
- Building Partnerships 5
 - Partner Roles & Functions 5
- Respite Rx Pilot 7
 - Nevada’s Methodology 7
 - Data Collection from Start to Finish..... 8
 - Conclusion and Recommendations Include:..... 8
 - Comparison with Research & Study Related to Respite 9
 - Internal & External Barriers 15
 - COVID 18
 - Lessons Learned from Caregiver Data 19
 - Findings & Implications for Policy..... 20
 - Conclusion..... 21
- References 22
- Appendices..... 23

Report Highlights

Building partnerships was instrumental in the efforts to serve caregivers statewide on the Respite Rx pilot. Collaboration between the partners who were able to bring expertise and knowledge provided leverage to develop a comprehensive self-directed program for these family caregivers across the lifespan was key to Nevada's success.

>See pages 6-8 for more information

Nevada's methodology driving force was empowering caregivers to view respite as a benefit for themselves in thinking of ways to give them time to refuel. It was critical to caregivers to have autonomy of their individualized respite programs. Program staff were there for support, guidance, and collaborative efforts with caregivers to overcome barriers and challenges that may have prevented a caregiver from utilizing respite.

> See pages 8-9 for more information

Comparing research and study related to Respite allowed Nevada to view and incorporate best practices and philosophies that would essentially have a positive impact on caregivers receiving respite. The LifeCourse Respite Portfolio was utilized with each caregiver to understand their caregiving responsibilities, help them understand this program is designed for their needs, identify how respite can benefit them on a regular basis and what needs to be in place for the caregiver to take this break without stress or worry.

> See pages 9-18 for more information

Nevada's goal was to remove as many internal & external barriers for caregivers to receive respite services. This resulted in continuous changes to the original policies of the programming to ensure caregivers in Nevada were given an opportunity to benefit from this program. Program staff worked with these entities to educate and inform them on the Respite Rx program intention and the value in acknowledging the caregiver as the recipient of the service, not only for them but for their care recipient. COVID really brought social isolation issues, decreases in internal supports and why respite is crucial for caregivers to the forefront.

> See pages 18-22 for more information

Nevada learned that the more caregiver burden increased, the less confidence caregivers felt in their caregiving abilities and ultimately lead to feelings of loneliness. Nevada learned that one of the primary challenges faced by caregivers was recruiting respite workers and the program needed to dedicate time to strategize how to overcome unique challenges. Also, learning and understanding why participants exited the program early was another informational piece to reflect on how we can better serve our caregivers.

>See pages 22-23 for more information

Building strong continuous communication mechanisms between all partners and caregivers was important to ensure collaboration kept moving forward. Research methodologies and data collection was also important to evaluate internal infrastructures and barriers that may cause caregivers not to

apply for respite. This is vital information to know when building a respite model. Taking opportunities to make changes to ensure caregivers get the respite they deserve and need to keep going is also essential in building a successful respite program.

> See pages 23-25 for more information

This is not the end, but only the beginning, as we reflect on the self-directed pilot program and the importance in partnerships and developing common goals to the caregivers we serve across the lifespan. The importance on continuing to provide choice, flexibility, and access components as demonstrated by this pilot program offers a strong model to address a myriad of internal and external changes that may occur within a caregiver's world. Respite makes a real and significant difference when supports and resources are in place to support the caregivers in their caregiving journey.

> See pages 25-26 for more information

Self-Directed Respite

Nevada's Overview

As defined by the ARCH National Respite Network (2015), respite is “planned or emergency services that provides a caregiver of a child or adult with a special need some time away from caregiver responsibilities for that child or adult, and which results in some measurable improvement in the well-being of the caregiver, care receiver, and/or family system”. In keeping with this definition, efforts were made to incorporate what was already known about making respite effective into the design of a new respite voucher program.

Nevada designed a self-directed respite option that included a person-centered philosophy model into the service delivery of respite, with the focus on the caregivers instead of the care recipients. Care recipients were still an important factor of the program but not the primary focus. The design of the new pilot program took a year of preparation, working to remove as many known barriers to caregiver participation as possible.

As outlined in the Lifespan Respite grant, the self-directed program was targeted to fill certain “gaps” in the social service delivery system, specifically rural communities and caregivers caring for individuals aged 18-59. Eligible caregivers for Respite Rx also included those unable to qualify for other respite programs due to limited eligibility criteria, waitlists, or program reach that did not deliver care after-hours, weekends, overnights, etc. Nevada was able to see higher usage in the self-directed program when caregivers were empowered to decide who, what, when, where, and how they could use respite to best fit their respite goals.

“One of the most researchable questions about respite is whether to take into account the needs of all family members when determining eligibility or designing and delivering services.” – ARCH Respite Network (2015)

Building Partnerships

Partner Roles & Functions

The Nevada Aging and Disability Services Division (ADSD) is the state's single State Unit on Aging and Disability Services. It is also one of five divisions within the Nevada Department of Health and Human Services (DHHS), including Child and Family Services, Public and Behavioral Health, Health Care Financing and Policy (Nevada's Medicaid Office), and Welfare and Supportive Services. Community partnerships included Nevada Care Connection Resource Centers (NVCC), Nevada Lifespan Respite Care Coalition (NLRCC), a Fiscal Management Service (FMS) Agency, and various programs and agencies that were instrumental in the efforts to serve caregivers selected for the pilot program.

Aging and Disability Services Division provides Nevada with a unique opportunity to combine the skills and knowledge of people who have experience working with persons who have an intellectual disability with the experience of those specialized in working with older persons.

This diversity in populations served through Nevada provides a great opportunity to develop a comprehensive program for family caregivers across the lifespan. The roles, functions, and communication between partners was critical to achieving successful outcomes.

The Nevada Care Connection Resource Centers, Nevada's single point of entry into long term services and support systems (LTSS), helps individuals and their caregivers explore options available to meet their goals and needs. [Nevada Care Connection](#) provides coverage to all counties (urban, rural, and frontier) which was critical in getting referrals to Respite Rx, a feat that would have been difficult to achieve with project staff alone. The intake protocols for this pilot program were built on existing No Wrong Door (NWD) service systems and created a process for identifying caregivers who needed respite and supportive services.

The Nevada Lifespan Respite Care Coalition supported plans to direct caregivers to the Nevada Care Connection sites for referral to respite. A pass-along card with the appropriate information was prepared by NLRCC to assist caregivers in making that connection, with a tagline "Respite Refuels Caregivers" promoting the Coalition and awareness of respite. While members of the coalition were still engaged in their own organizational recruitment and awareness activities, they shared pass-along cards with those who were not eligible for their respite programs, to help direct people to connect with NVCC and explore alternative options in their area.

The Nevada Caregivers Coalition was another partner in dissemination of information on respite and the pilot program, Respite Rx. While professional caregivers (in day programs, in-home services, assisted living, and nursing homes) are the primary focus of the Coalition, family caregivers and caregiver support groups are also engaged in their activities.

ADSD Community Advocates provide advocacy and assistance to older adults (age 60 and older), people with disabilities and their family members. Services include information and referral, emergency assistance, and outreach. The Community Advocates program was engaged in addressing emergency respite needs for caregivers outside of the Respite Rx program. Funding for emergency respite also came from the Lifespan Respite grant. The application and criteria were geared to quickly assess the emergency need and processes were developed to distribute funds as directed. Limitations on funds were established and applications were accepted for one-time use. These caregivers were referred by Respite Rx staff, the Nevada Care Connection sites, and partner agencies and organizations.

The FMS agency, PALCO, is an existing state contractor. ADSD was able to quickly amend the contract in place to include the Lifespan Respite self-directed pilot program to be added for this grant period. The FMS had already met the readiness criteria needed to implement this program to enrolled caregiver program participants as employers-of-record into their payroll system.

ADSD's sister agencies were engaged to work collaboratively by utilizing the pre- and post-surveys within their own respite programs to help gather information on the benefits caregiver received system wide to have a better understanding where the caregivers stand with the service delivery and how the state can work collaboratively to address the gaps and streamline data gathering to reduce programmatic "silos" and work together in strengthen caregiver support.

Program staff provided a series of trainings prior to launching the pilot program to the Nevada Care Connection Resource Centers, with information regarding respite, who this program was targeting, how they could identify caregivers, and how to begin the referral process into the Respite Rx program. Program staff also provided outreach and education to advertise the new pilot program throughout Nevada, specifically in the rural/frontier areas.

Respite Rx Pilot

Nevada's Methodology

The Respite Rx pilot program is a self-directed program that was designed to empower caregivers to have autonomy over their own respite services. The caregivers on the Respite Rx program were given a full year to utilize it. They were provided a monthly budget of \$308 or \$3,696 for the year. After determining a maximum amount of respite funding, Nevada committed to serve 60 families through the self-directed program on a "first-come, first-served" basis. As barriers were found throughout the program's life cycle, several refinements to the model were made to ensure caregivers were given the opportunity to utilize the program to their advantage.

Starting in December 2018, for unserved/underserved caregivers in Nevada, Respite Rx was the new respite prescription; 2 to 4 hours of respite per week (on average) was the recommended dosage. This weekly respite goal was based on Dr. Dale Lund's work on best practices for effective respite. According to Dr. Lund (n.d.), effective respite starts early in the "caregiving career," is used regularly, in sufficient amounts, and tied to other services, such as skill development, education, emotional and social supports, counseling, transportation, nutrition, and leisure activities.

Nevada Care Connection was able to refer one hundred and sixty-five caregivers into this pilot program that included intake of basic demographics, a caregiver burden questionnaire, and other responses that have added to the data and information collected during this pilot program. The program staff maintained open communication with NVCC on each applicant, so that they were aware of the status of all referrals to Respite Rx. Notifications of Respite Rx acceptances, denials, and withdrawals were sent to the referring program, so that records and follow-up contact could be maintained. Nevada's transient population makes maintaining contact with families difficult, so Respite Rx feedback was appreciated. Nevada Care Connection

staff also assisted with language translation and interpretation services during Respite Rx contacts with caregivers.

Each caregiver accepted into the program received the same monthly allotment of funding, which covered the cost of the respite service and any employer-paid payroll taxes under their spending plan. The program coordinator would also work hand in hand with each of the caregivers through a five-step process to set up services and utilization of the program.

Data Collection from Start to Finish

Throughout the grant period, the Respite Rx program would gather data on caregivers (and care recipients) from applications, pre- and post-respite surveys, information collected during respite design sessions, quarterly program reviews, and voucher usage data.

Gathering current information on caregivers and comparing to baseline data from 2012 (Appendix A) was also an objective of the pilot program. In addition, information and data results from Respite Rx will be compared to emerging research and study on caregivers, respite, and other caregiver supports and services. Highlights on these findings are also included in the report.

Conclusion and Recommendations Include:

A holistic planning approach to working with caregivers (and care recipients) results in better usage of respite, as it is tailored to specific needs and situations. Self-direction and person-centered practices work effectively in meeting the needs of diverse unserved and underserved populations.

Understanding caregiver motivation behind the demand for respite needs to be used to develop awareness and outreach activities, training, and educational supports, and incorporated into respite service delivery, caregiver resources and materials aimed at reducing barriers to respite.

Case management services are needed to support a successful voucher program, much more than typically provided. This is essential in recognizing barriers to respite and addressing them expeditiously (in partnership with the caregivers served).

Barriers continue to prevent caregiver access to respite, in finding and recruiting respite workers, overcoming caregiver isolation, and mitigating health risks from respite workers coming into the home (such as during the COVID-19 pandemic). Efforts to remove these barriers will continue to be evaluated and addressed.

Respite Rx data highlights new findings that will add to the collected knowledge on respite and caregivers, potentially changing the way respite is delivered in Nevada and elsewhere. These findings need to be shared broadly with state and local leaders, respite providers, and caregivers themselves.

Comparison with Research & Study Related to Respite

The Nevada Lifespan Respite Program has made concerted effort to engage the best practices and philosophies for respite. Studies on aging, children with special healthcare needs, caregiving, and loneliness are highlighted here. The following research and/or studies have provided some basis for the Respite Rx self-directed model:

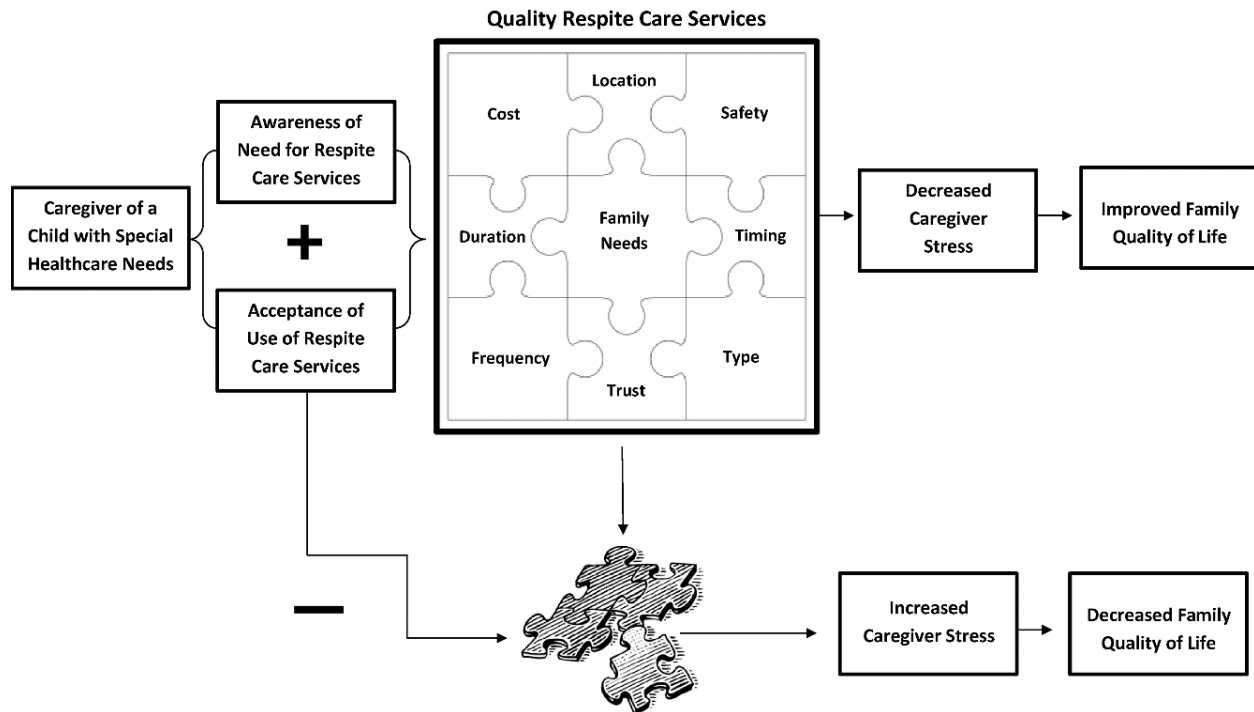
Dr. Dale Lund's (2009) Continuity Theory of Life Course Aging states that "those who are able to maintain or continue engaging in their preferred and most meaningful activities (and values, beliefs, and preferences) or minimize the most disruption to them will have more positive adjustments to aging". 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.

Respite Rx considered how to assist caregivers in this process and utilized the LifeCourse Respite Portfolio, developed by the UMKC-Institute for Human Development, UCEDD, in partnership with the Missouri Family-to-Family program.

The core beliefs behind the Charting the LifeCourse (CtLC) framework is that "all people and their families have the right to live, love, work, play, learn, and pursue their life aspirations in their community" (Charting the LifeCourse Nexus, 2020). Using the LifeCourse Respite tool causes people to think differently about respite, to think about the "ALL", about stretching respite resources, and how to incorporate short breaks into everyday life as not everyone gets respite funding. The LifeCourse Respite Portfolio (Appendix B) was designed to create a successful plan for the use of respite.

Respite Rx used the tool during the Respite Design session with each caregiver to provide a "snapshot" of the caregivers' current situation and help them identify the benefits of taking a break. It also helps caregivers identify what is going on in their lives, how a short break from care would help them and the person they care for, and what needs to be in place to make a short break happen. From this plan, caregivers could use the self-directed program funding to secure the workers they needed to meet their unique respite needs.

The Concept of Respite Care



The concept of respite care developed by Kim Whitmore (2016) on decreasing caregiver stress and improving quality of life suggests that there are several quality measures that need to be evident in respite programming for positive outcomes to be experienced. Failure to deliver all these components will result in a breakdown of respite service delivery and negative outcomes for caregivers.

In reviewing these components needed for successful respite, Respite Rx attempted to emulate the following measures:

Awareness & Acceptance of Respite: An area of strength, Respite Rx benefited from caregiver protocols implemented at the Nevada Care Connection sites, and awareness of respite was increased each time a caregiver was identified at intake. The concept of respite was introduced to identified caregivers and referrals to respite made when caregivers were willing to give respite a try. The Nevada Lifespan Respite Care Coalition also helped increase awareness and access to respite through products and activities aimed at caregiver education and referral. Although outreach and other awareness activities were useful in promoting respite and the Respite Rx program, having a single point of entry, and getting caregivers connected from the start was crucial.

Cost: Respite Rx provided funding for most costs associated with respite services (including employer-paid taxes, background checks, and payroll services), up to the monthly allotment and maximum limits established (Appendix C). All income levels were considered eligible, and no co-pays or cost sharing fees were charged. Out-of-pocket and participation costs for caregivers might have included expenses related to placing job ads,

printing/faxing/scanning/ mailing forms and documents, and/or transportation costs, as well as any supplies associated with these expenses.

Location: As part of a self-directed, person-centered design of respite, caregivers determined the preferred location for respite, primarily selecting in-home or community-based programs. Respite Rx funding was accepted by most, but not all, vendors of in-home or community-based services as it was difficult to recognize this was not a Medicaid funded program and therefore did not require Medicaid approval. Caregivers were able to find acceptable alternatives for providers in those cases.

Safety: Respite Rx allowed caregivers to hire trusted friends and family or select a provider of their choice. Caregivers were able to terminate contracts at will with workers as needed for various reasons. Respite Rx funding paid for background checks on workers and provided safety guidance on screening, interviewing, and meeting applicants.

Safety measures were also engaged with the FMS agency as the agency conducted federal backgrounds on respite workers, if requested by caregivers. All caregivers were encouraged to do background checks, but it did delay the start date of respite to wait for results so caregivers could review risks before starting respite sessions. Caregivers were given the opportunity to decide to move forward with any “flagged” respite worker and signed release paperwork filed with the FMS to do so. Only one background was flagged during the project. Program staff and the caregiver reviewed and assessed the risks, discussed options together, and the caregiver determined to continue working with this respite worker.

Duration: Caregivers were given the flexibility to set hours, schedules, and duration of respite sessions, up to the maximum hours and availability of funds. While the goal was to provide 2-4 hours of respite on average to caregivers each week, as recommended by Dr. Dale Lund’s (n.d.) studies on effective respite, these hours could be grouped each month as needed. Some caregivers combined their allotment of hours so that the duration of a respite session could cover weekend vacations or day trips.

All Respite Rx spending plans (Appendix D) were reviewed by program staff, approved, and submitted to FMS for their records. This planning process of the spending plans achieved the minimum goal (or better) despite varying costs per hour. The respite contracts were 12 months long, giving caregivers the time needed to adjust to the experience of respite and see the benefits from respite during their time on the program.

Family Needs: Family routines and schedules were discussed in the person-centered Respite Design session with caregivers. The support needs of the care recipient and caregiver motivation for use of respite was also discovered. Respite worker duties could include light housekeeping chores but were primarily directed at activities and interaction with care recipient. Training needs for respite workers was also discussed. Caregivers tended to schedule respite sessions during times when care recipient needs were minimal (Appendix E). While some caregivers were looking for respite workers with specific skills, training resources offered

were universally rejected in favor of caregiver-led instruction (one of the duties caregivers/employers could assume under self-direction).

Timing: Under a self-direction model, caregivers were given choice and control to best judge for themselves when to set hours and schedules for respite, up to the maximum hours funded each month. Caregivers tended to schedule respite sessions during times when care recipient needs were minimal. With ADSD authorization, caregivers could also “save” hours toward future known needs or push more hours to some months and use less in other months. When this occurred a Respite Rx Risk Assessment (Appendix G) was conducted for these requests. This encouraged them to plan out respite time that would best serve the caregiver’s respite needs, at times finding that the flexibility in scheduling as needed allowed for a better result.

Caregivers could schedule respite during mornings, afternoons, evenings, nights, after work, overnight, weekends, and vary the timing of respite from session to session as it suited their needs and interests. The only limit would be the availability of the respite worker, so attention was given during Respite Design sessions to draft the job description to represent the scheduling flexibility the caregiver needed.

Frequency: While the program intent was to give caregivers a weekly dosage of respite, caregivers were given control over how frequently they used respite. Some caregivers used the monthly allotment up in one week each month or grouped the hours to cover one longer get-away. Some used fewer hours per session so they could participate in classes or exercise regularly multiple times per week. Initially, the self-directed program ran on a “use it or lose it” philosophy, so if they did not use all the hours allotted each month, they could not “roll” hours into the next month. This encouraged the regular use of respite, at a rate that would hopefully generate positive outcomes.

When the pandemic began in 2020, program staff found that although a monthly allotment of funds was given to encourage regular use, the goal was to also ensure that all participants had the opportunity to utilize the maximum yearly funds available to them within their 12-month respite program. At that time, adjustments to the model were made to accommodate this new philosophy for those who had been impacted by the pandemic.

Trust: In the self-directed model, caregivers could hire family and friends, a service provider they already trusted, or they could hire someone new. Trust takes time to develop, so caregivers were encouraged to use “respite trials” – introductory or shorter respite visits – to determine if a respite worker would be satisfactory. Caregivers were also encouraged to secure a second or backup respite worker under the Respite Rx contract, and guidance was provided to help caregivers interview and select applicants who would be competent and reliable.

Caregivers who care for someone with mental health needs had more difficulty finding respite workers, particularly due to stigma. It was found that most CNA/Nursing programs do not train on how to work with individuals with mental health needs and finding alternative respite workers was difficult. Families said they would discuss care needs with any “willing to try”

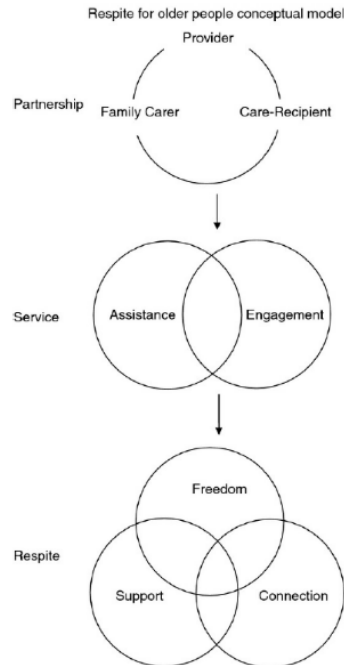
applicants and provide their own training – tailored to the specific care needs of the individual. Mental health respite looked different from in-home care; it might start at home, but it was geared more towards getting the care recipient out into the community with care beside them, around positive people, and exploring interests and activities outside of home. Caregivers, respite workers and care recipients needed to have trust in each other to make that happen.

Type: All respite types were available to caregivers, including faith-based or volunteer respite services. In-home care was the most popular type of respite service requested but in-home providers were short in supply. Rural communities had to rely almost exclusively on hiring individual respite workers, so type availability was severely limited in some areas of the state. Respite Rx focused on ways to help caregivers recruit workers, by drafting job announcements (Appendix H) and disseminating them through various channels of communication. Not all caregivers wanted in-home respite, especially for younger aged care recipients and for those who had mental health needs.

Emerging research on the “essential ingredients” of respite, focused on caregiver motivation, has also been used to assess the Respite Rx model. As cited in studies by Gaugler & Kane (2017), the challenges of categorizing respite alongside other service types (non-pharmacological interventions) results in an over reliance on deficit-oriented outcomes, rather than strength-based measures, such as resilience, successful aging, goal attainment, and social health.

Respite Rx looked to find evidence in the Respite Design sessions of the motivations expressed by caregivers seeking respite. Using Freedom, Support, and Connection as the outcomes sought through respite, participating caregivers showed the greatest desire for a combination of Freedom & Connection, as opposed to Support. Eighty-six percent of caregivers expressed a desire for Freedom; 71% sought Connection, and 56% needed Support.

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.



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, enable caregivers to function or act, strengthening their ability to endure or tolerate the situation, and provide a source of comfort or encouragement while they care for others.

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

Still, Respite Rx utilized too many deficit-oriented measures in tracking outcomes and the results made it difficult to report any significant improvements due to respite. Deficit measures will still largely exist for caregivers, despite access to respite, so future movement towards tracking strength-based outcome measures may show more positive outcomes. Unfortunately, these measures were not incorporated into the self-directed model in time to generate any comparison on results.

Research studies on loneliness indicated from Holt-Lunstand, et al. (2015) found that certain “relationship impacts” to physical health were so profound that chronic loneliness and isolation can be as dangerous as a pack-a-day smoking habit. The loneliness study reveals that “social disconnection” turned out to be worse for health than problems like obesity, alcoholism and pollution or factors like high blood pressure or high cholesterol levels.

The relationship impacts of caregiving are well known but understanding loneliness has only been recently introduced by other Lifespan Respite grantees in the ARCH Lifespan Respite Network as a potential area of caregiver study and program review. Loneliness can shorten

lifespan by about five years. Interestingly, caregiving long-term is known to do the same. People who do not have strong social support systems – such as a caregiver’s need for trusted friends and family members to provide respite – persistently experience poorer outcomes. Unfortunately, loneliness is nearly a universal experience that crosses borders and cultures and can affect people as easily when they are in a crowd as when they are alone.

However, Respite Rx had the opportunity to explore some findings on loneliness during the COVID-19 pandemic. For the first time in a long time, caregivers feeling stuck at home had something in common with their peers who were not necessarily caregivers but now were equally “stuck at home.” Everyone had to figure out how to do things when one could not leave one’s home without jumping through many hoops of prevention and precaution.

While loneliness is not a mental health condition, those who already grapple with depression or anxiety are at a significantly greater risk for experiencing loneliness. In turn, loneliness and isolation can exacerbate existing mental-health challenges and form a vicious cycle. COVID-19 impacts on mental health has been a top news story in 2020.

Interestingly, loneliness is a perception, and not everyone who is isolated or even lives alone “feels” lonely. But in times of uncertainty, people are more likely to crave the reassurance of connection. When there is not someone close to offer support, loneliness enters. Because of stigma or shame, discussing loneliness is uncomfortable – no one wants to become an object of pity.

Nevertheless, loneliness is a simple biological imperative, like hunger. Hunger is the body’s way of saying, “It is time to eat.” Similarly, loneliness is the body and mind’s way of saying “You need to be around people.” Most caregivers feel a hunger for social connection, as loneliness & social isolation was a standard experience well before social distancing and sheltering-in-place aggravated the problem. But, even after COVID-19 is controlled, loneliness will be the shadow pandemic that remains. Hopefully, the silver lining of the COVID-19 crisis might be highlighting just how devastating social isolation really is and how respite can be an important solution.

Internal & External Barriers

In attempting to find and overcome barriers to respite inherent in voucher models, Respite Rx encountered both internal and external challenges. As a result, the model for Respite Rx has been continually refined throughout this grant period. Nevada Care Connection was the single point of entry into the Respite Rx pilot program. NVCC Resource Navigators help in navigating resources and programs available to individuals contacting them for help that included caregivers. Resource Navigators were given a new caregiver protocol that was developed and conducted in an intake with caregivers who were identified and interested in Respite (Appendix F).

It was a challenge to convince caregivers that **they** were the participants in our program! Most respite programming is based on the eligibility of the care recipient and little attention is given to the needs of the caregiver. While participating in the Respite Rx program, caregivers would express surprise when asked about what was important in their own lives, what a caregiving break would mean to them, and what they would consider doing if they had a break on a regular basis. The responses of “I get it now – this service is for me” or the “Wow, I haven’t had time to think about me before” comments were very common.

Various respite programs throughout the state would refer caregivers who had challenges such as not meeting eligibility criteria or already exhausted their one-time voucher for the year, simply due to the focus and flexibility of the program. However, Medicaid-based services for the care recipient, who offer options for respite in lieu of other service options, threatened the loss of services for the care recipient if respite was received through another program. Convincing program officials that caregivers in Respite Rx qualified on their own, without regard for the Medicaid status of the care recipient, was difficult to convey. It will require continued work and effort to coordinate all state respite programming and eligibility, based on these differences.

Originally Respite Rx required verification of caregiving relationship to avoid a potential fraudulent usage of the program. But it was quickly determined that NVCC staff were able to adequately verify the caregiving relationship and a separate verification process was no longer necessary. Initially, the Respite Rx pilot also determined that people who lived with the care recipient were ineligible as respite workers, to avoid supplanting natural supports to care recipients. That decision was revoked. Caregivers were reluctant to ask other family members for respite support unless they could pay them. Also, family members would move out of the home to qualify as respite workers – causing unnecessary hardships and delays when “family-only” support arrangements were the only acceptable option for respite. During the COVID-19 pandemic, these respite support arrangements held up best when other respite services were shut down or faced restrictions.

Dissemination of the funds was done through the FMS. This was the safest route for caregivers as they did not receive any funding directly, which avoids tax consequences for the caregiver. The Fiscal Management Service (FMS) agency was contracted to handle employer tax responsibilities and payroll for workers.

One challenge was coming into agreement with the FMS about who our participant was and who was the Employer of Record. In the Veterans Choice program, another program administered by ADSD, served by the same FMS, the veteran needing care was the participant and the employer of record. The caregiver hired through this program was considered the employee. However, in the Respite Rx design, the **caregiver** was categorized as both the program participant and the Employer of Record, and the respite worker was the employee. Since other program eligibility is typically built around a care recipient’s needs, this was a definite change – and a communication challenge for both the FMS and the caregivers.

Unfortunately, the FMS set-up process for the caregivers and their respite workers was a challenge and barrier that was not anticipated and required a lot of assistance by program staff to help get participants and their workers enrolled with the FMS. The amount of paperwork and information required by the FMS caused anxiety and confusion for most participants. It even caused some participants to withdraw from the program when FMS enrollment became an additional burden and consumed time the caregiver did not have. It was also found that, because Respite Rx was added to an existing state contract with the FMS, the program was supplied with old forms and information. Billing errors and other corrections had to be made when old FMS documents and instructions were relied upon. At times, documents that caregivers and respite workers provided were unreadable, missing, needed signatures, or were expired for use. The FMS information also confused caregivers and respite workers on where to send the timesheets for payment. Respite Rx staff were not alerted to these errors by the FMS, and problems were identified only when an issue arose or expected pay was not received.

As a preventative measure, Respite Rx staff began offering and conducting FMS paperwork reviews with caregivers (and respite workers) before submitting for enrollment. This was one of the case management services added to the program. It was determined important that the FMS fully understand the context of the programs they served as each one has unique eligibility or traits to them. Also, training by the FMS on how to fill out the required paperwork and to better understand their process is recommended so that caregivers and their respite workers have a clear understanding of time frames and what they can do to not delay processing.

Finding part-time employees for respite was challenging, and online employment boards, such as Care.com, were potentially considered a way to help caregivers and respite workers connect. Unfortunately, costs associated with these online venues was significant, and they were not effective in many situations, such as meeting needs in rural Nevada. Families used Facebook, Craigslist, Indeed.com, and other social media platforms to disseminate job announcements, as well as spreading by word-of-mouth. Respite Rx staff helped by sharing listings to CNA and nursing programs, adult education, workforce development, and employment centers. Sometimes these efforts were successful, but a stronger respite worker recruitment and dissemination plan needs to be created to support these efforts.

Another area for future study needs to be mental health. The characteristics of the respite need is very different from what is usually associated with disabilities & aging. Respite Rx's few cases exhibited a respite design geared toward more peer- and activity-based solutions, where the individual with special needs is encouraged to get out, make friends, and socialize. Hiring respite workers from the typical pool of talent for respite work was not very successful – the skill set is too different. Including mental health in a job description has also been tricky – in avoiding stigma and fears around working with this growing population.

Getting caregivers to respite required case management support, beyond what had initially been planned. To improve results and keep caregivers moving forward, Respite Rx staff conducted quarterly reviews, pre- and post-surveys by phone or through online survey links, drafted respite worker job announcements, and sought destinations where job announcements could be disseminated. Surveys conducted during the program period, specifically the quarterly program reviews and post-surveys, were challenging to complete with both past and present Respite Rx participants. Though these surveys and reviews were offered in different formats (online, via phone, or through mail), the extra requirement to complete these surveys added another burden to the caregivers' already heavy loads of responsibility.

COVID

As the COVID-19 pandemic quickly emerged, it created problems for respite programs statewide, when the state went under mandated social distancing directives and only essential services were able to continue services. Respite Rx staff began contacting all participants and holding conversations with them about where we were at as a state, providing additional information and resources relating to COVID, learning about the impact on accessing respite, and addressing next steps, as they could be foreseen. Program staff were able to connect with most participants at least once a month and by the third month, Respite Rx began conversation with each participant about how they would like to move forward and continue with the program. Since most of the caregivers were utilizing internal supports such as trusted family and friends, they opted to continue services as planned. For those negatively impacted during COVID restrictions who had to pause respite services, Respite Rx staff worked with each participant to develop plans to utilize their funds/hours remaining in their respite contract year. A few caregivers decided to wait a little longer before starting up respite services again, as they did not feel comfortable with having people coming in and out of the home and putting their loved one or family at risk.

In Nevada, there were over 450,000 older adults who were potentially homebound due to social distancing measures. Nevada's aging services network, including NVCC Resource Centers came together to do a rapid assessment of the population and workforce. Nevada defined three critical areas of need: access to food and prescription medication, social supports, and medical services, specifically telehealth options. The Resource Centers had increased their efforts to help provide care coordination of older adults, people with disabilities and caregivers who have multiple needs during the COVID-19 response. These efforts result in reduced barriers and duplication of efforts for individuals who needed to coordinate services with multiple providers and has resulted in increased social support being offered to individuals as part of the normal intake and assessment functions.

The NLRCC also gathered and shared information and resources that caregivers might need to care for their families and find the support that they needed. This list of resources was added to their website and shared with members. The NLRCC Facebook page featured many of these resources, in addition to messages prepared for its social media campaigns. During COVID-19

restrictions, participation in the social media platform grew and reached many more caregivers, even internationally.

The Caregivers Coalition members also saw an increase in demand for respite services and has been supportive of Respite Rx and other respite programs by directing family caregivers to the Nevada Care Connection sites. The Caregiver Coalition conducts an annual Caregiver Recognition event each year in November (for National Caregiver Awareness Month), and family caregivers are honored alongside professionals recognized during the event. Several Respite Rx caregivers were honored at this event (Appendix I) after they permitted the project coordinator to share their stories.

Lessons Learned from Caregiver Data

Highlights from the Respite Rx data are detailed more completely in the Appendices to this report. However, the findings are summarized here:

1. **Caregiver Burden** (Appendix J) – Demand for respite increased as care required greater sacrifices from caregivers, by taking more & more time away from self, time with family & friends, and time for enjoyable activities.
2. **Caregiver Commitment & Confidence** (Appendix K) – Caregivers have low confidence in the quality of their own care, feeling the need to do more or do better at delivering care. Not reflected as an increased demand for training and skill development, this may be a plea for supportive shared experience with other caregivers, with the secondary purpose of combating loneliness.
3. **Demand for Respite Hours** (Appendix L) – From program intake to respite usage, caregiver demand for respite fell from 10+ hours per week to a mere 3 hours per week. Fitting respite into their lives takes dedicated planning.
4. **Getting to Respite** (Appendix M)- Recruitment and selection of respite workers required an investment of time and effort and additional interventions. Strategies for quickly identifying and hiring respite workers need to be developed.
5. **Pre-Respite & Post-Respite Results** (Appendix N)- Caregivers reported having a better perception of health, relationship with their care recipient, and relationship with others after respite services were received. Interestingly, the number of caregivers who stated that their access to someone who could provide emergency respite decreased after the Respite Rx program time. Note: Pre-respite surveys were conducted for all Respite Rx applicants, including those who did not get approved for the program. Post-respite surveys only included surveys from Respite Rx participants. This could have skewed the results.
6. **Respite Benefits Sought** (Appendix O)- Caregivers who sought respite were motivated by the respite benefits of freedom and connection. Respite awareness messaging described respite as a supportive break from care but also needs to be directed at these other motivations.

7. **COVID Impact on Respite Rx** (Appendix P) - Respite Rx participants had lower interruption and cessation rates on services, owing primarily to the exclusivity inherent in hiring friends and family for respite services.
8. **Program Exit** (Appendix Q)– Knowing the reasons for program exits will help respite programs in developing messaging, resources, training, and case management services to support participation. This data report provides a baseline for measuring improvement.
9. **Caregiver & Care Recipient Demographics** (Appendix R)– Nevada caregivers are older than national averages; program diversity is difficult to achieve without targeted outreach.

Findings & Implications for Policy

Initially, Respite Rx staff had trouble getting caregivers into the program when referral was quickly followed by the death of the care recipient. This prevented several caregivers from getting any respite at all or cause them to retire their respite contract well before expiration. Programs that serve elderly populations may be able to justify shorter contracts, but the real need is to get caregivers to respite earlier in their caregiving career.

Planning for an FMS service needs careful consideration. The FMS provides more than payroll services, and good communication with program staff, caregivers, and respite workers is crucial. Without transparency and strong communication systems, caregivers were not sure when they could begin using their respite hours, and some lost respite workers to other jobs that started quicker.

Respite invoices from vendors and timesheets from respite workers need to be routed through (or copied to) ADSD for tracking purposes. Instead of being the last to find out about expended funds, ADSD should know what invoices are pending for FMS payment and that respite hours are being regularly used by participants. Errors in paperwork submissions could be caught earlier to prevent FMS payroll delays. During the grant, ADSD experienced significant delays in receiving FMS invoices with timesheet documentation. Being able to match reimbursement and fee invoices from the FMS with records that ADSD already knew were pending would allow for more accurate fiscal grant management and program projections.

To improve communication with ADSD and caregivers, the FMS agency should be required to send email confirmation about any change in status of a caregiver/employer, their vendors/workers, and include an effective date. This information would be valuable in improving program response time to caregiver and worker inquiries about their status.

When caregivers did not use up all their allotted funding each month, the unused portion was essentially placed into an emergency respite fund, and could be used for short, temporary emergencies for caregivers. Some caregivers were being referred with crisis needs and did not have the time necessary to go through the Respite Rx steps of getting to respite, so an emergency respite option proved to be a great way to utilizing Lifespan Respite grant funds and

meet the needs of more caregivers. Again, partnering with the community advocates helped to identify and distribute these funds.

Improving research methods and processes for data collection and analysis will always be important to being able to place respite appropriately in funding priorities. Consistent with the definition of respite as a service or support designed to benefit the family caregiver, the caregiver should be an important focus of any research study or evaluation of respite services. Any benefits accruing to the care recipient, the family unit, and to others are important, but the caregiver should be the focus of at least one independent variable/dependent variable relationship to improve research on respite outcomes.

Qualitative methods should be employed to capture contextual information. This information is critical to data interpretation. Qualitative Questions such as “What services do you consider to be respite services?” “How did you decide to use respite services?” “How satisfied were you with the service you planned for?” “What would you change about your respite services?” “What more would you like for me to know about you and your need for respite services?” are the type of questions that might explain why a caregiver uses a respite program or not.

The relationship between respite “dose” to outcomes has not been examined fully. Future research needs to be aimed at examining respite dosage (i.e., frequency, duration, and intensity of respite) and its relationship to caregiver burden, family well-being, and care recipient quality of life. Also, respite programming needs to examine the relationship of contextual factors to caregivers’ access to and desire for respite. Variables would include demographic characteristics, burden, family well-being, quality of life, dose frequency, duration of respite use, and intensity of respite care.

Conclusion

As Nevada considers the needs of the Long Term Supports & Services (LTSS) community, respite should be recognized as essential for caregivers and their loved ones. The partnership of support to care recipients that includes respite for all caregivers will allow for better in-home aging, delay out-of-home placements, and build resilient caregivers. While funding for respite may not soon see increases after COVID impacts, the self-direction model that includes choice, flexibility, and access components as demonstrated by this pilot program offers a strong model to address a myriad of internal and external changes that may occur within a caregiver’s world. It is highly recommended that self-direction becomes an important piece that should be incorporated into respite programming. Caregiver sacrifices are well-known, as they forfeit earnings, social ties, and leisure time to accommodate the needs of loved ones. Not every care recipient has the option to be cared by family or friends, but when family or friends step up to meet these LTSS needs, they deserve to have the resources and support they need to continue in their caregiving journey. Respite makes a real and significant difference when supports are in place.

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Appendices

Appendix A: Nevada Lifespan Respite Care Program Data on Caregivers 2012

Nevada Lifespan Respite Care Program Data on Caregivers 2012

Report by Cheryl Dinnell, Coordinator, Nevada Lifespan Respite Care Program

The Lifespan Respite Balancing Initiative (LRBI) was the second Lifespan Respite proposal from Nevada to receive Administration on Aging funding. It was also referred to as the LRBI Respite Expansion Grant, and ran from October 2011–August 2012. This grant ran concurrently with the original Lifespan Respite grant's final year, but had a service delivery component to it. Nevada's LRBI grant offered a voucher program with the goal of providing respite to 174 families in 11 months, with targets of 15% Hispanic families, 13% rural residents, and 40% between the ages of 18-64. The grant was to be promoted statewide, to all disabilities groups.

Through the service delivery of respite, the LRBI project would be able to:

- Test Assessment & Guidance Materials
- Collect Demographics on Caregivers
- Target Underserved Populations in Nevada
- Empower Families to identify resources and develop own support system
- Provide Resources for Respite that are flexible and applicable to a broad range of caregivers

Data on caregivers came from applications, assessments, pre- and post-respite surveys, and voucher claim forms. This information was collected and recorded by two voucher administrative programs:

- 1) GAB, Inc. – serving Clark County, and
- 2) RAVE Family Foundation- serving all other counties

This document was developed from the data reported by these two programs. The data contained within it represents the most comprehensive study of caregivers yet completed in Nevada. It will provide a basis for future studies, will be valuable in formulating strategies for serving and supporting more families statewide, and will provide insight into the complex process of providing respite to a diverse population of caregivers.

Note: GAB recorded information on all applicants; RAVE did not. While having data on more caregivers improved the sampling, the database did not always tie this information to voucher recipients. GAB has worked to add information that helps identify their voucher recipients; RAVE only provided information on voucher recipients – those on the waiting list were not captured.

DEMOGRAPHIC DATA

The demographic data collected represent geographic residence, ethnicity, age of both caregiver and care recipient, disabling condition, support needs, income levels, and the compounding of care.

Geographic Representation

This data comes from the LRBI application form. Charts are labeled from 1.1 to 1.13.

The Lifespan Respite Balancing Initiative (LRBI) received strong interest from caregivers around the state. Based on the data available, applicants to the LRBI program represent 8 of the 17 counties in Nevada. The breakdown is provided below:

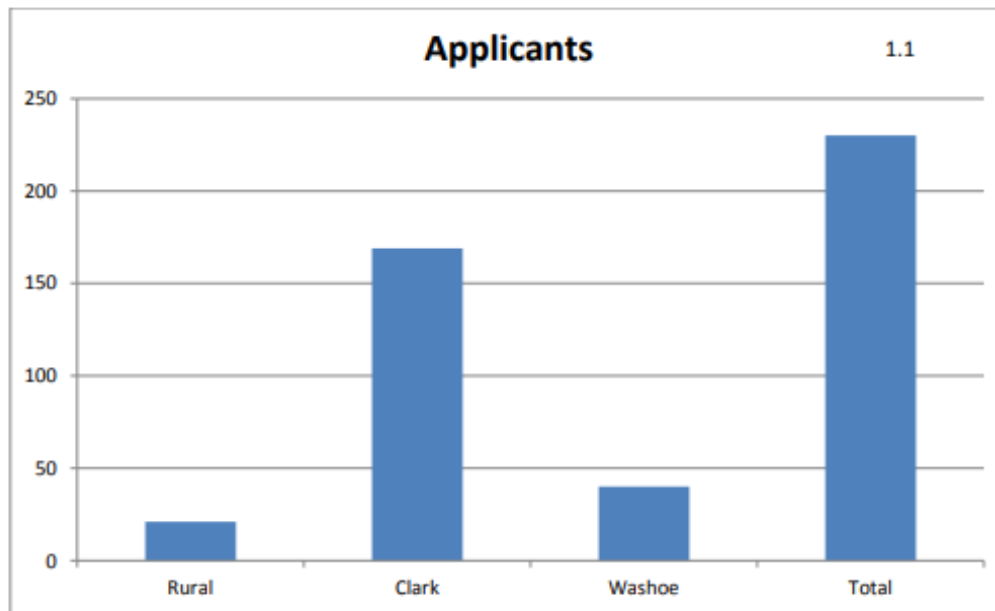
N=230

Rural Counties (Churchill-1, Carson City-3, Douglas-4, Lyon-5, Elko-4, Nye-4) =21

Clark County = 169

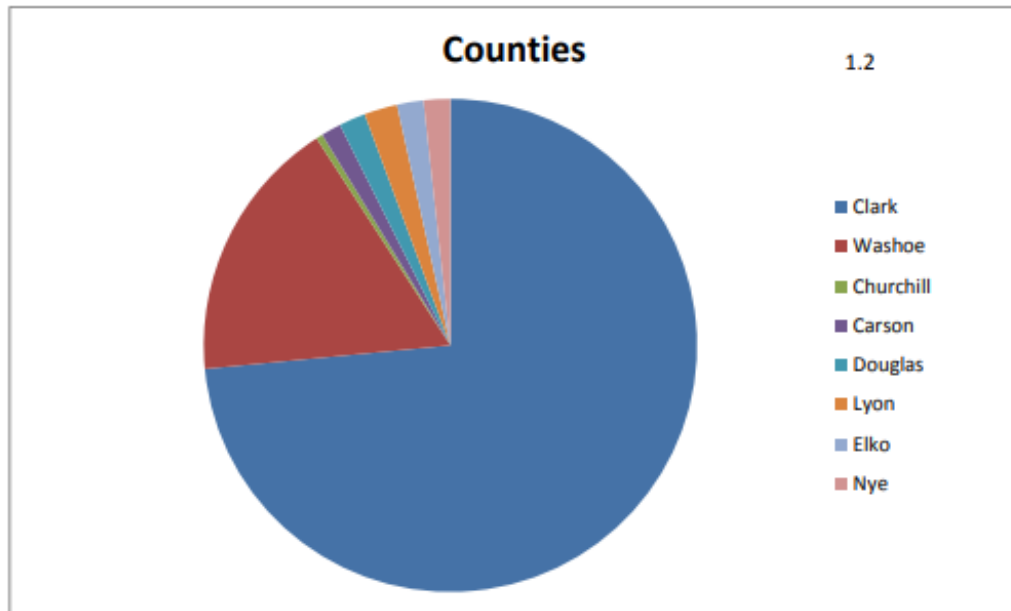
Washoe County = 40

Note: This data is based on the caregiver's residence. In six cases, the applicant did not live with the care recipient. In all of those cases, the caregiver and care recipient lived in the same county. So, the charts below accurately reflect the geographic location of the care recipients also.



The following chart also illustrates the applicant response from around the state. It also reflects that the LRBI program made significant efforts to reach caregivers around the state. The LRBI grant had a target of 13% rural representation of caregivers. The number of rural participants is 20 families, which represents 11.5% of all the caregivers in the program. However, only RAVE was charged with outreach

in rural counties. Of the 58 vouchers that RAVE awarded, these 20 families represent 34.5% of the voucher recipients.



Ethnicity

This data comes from the LRBI application form.

The LRBI grant also made significant effort in outreach in the Hispanic communities around the state. The LRBI grant had a target of 15% Hispanic families in the program. The LRBI program attracted a very strong 39% application rate from Hispanic families, as well as a diverse showing of other ethnic groups.

RAVE issued 20 of its 58 vouchers to Hispanic families = 34.5%. GAB also had good outreach to Hispanic families. Ninety-seven of the 230 applicants were Hispanic = 42%.

N= 250

Hispanic = 97 or 39%

Native American = 4 or 1.5%

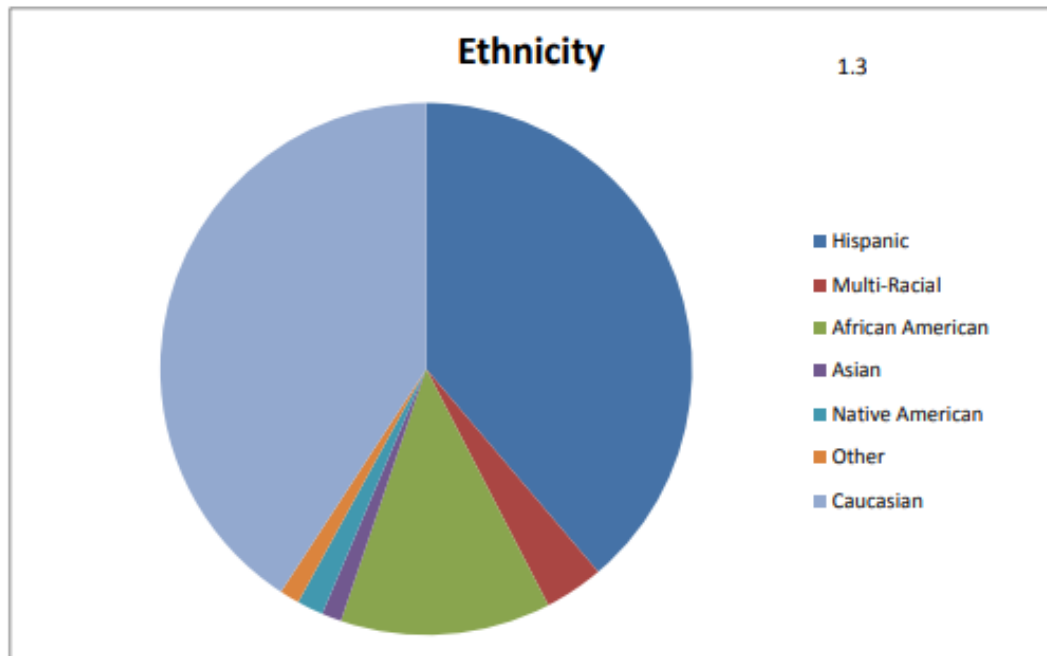
Multi-Racial = 9 or 3.5%

Other (Hawaiian-1, IndoEuropean-2) = 3 or 1%

African American = 32 or 13%

Caucasian = 102 or 41%

Asian = 3 or 1%



Household Income Levels

This data comes from the LRBI application form.

Note: There had been some concerns initially stated about not placing income limits on who received voucher awards. The LRBI grant proceeded without income limits. The data shows no evidence that the distribution of vouchers unfairly benefited those families with higher income. Based on the application data available, it could be surmised that either higher income families did not apply because they believed they would not be eligible for respite support, or they did not feel the need for the voucher resource that was offered.

N = 160

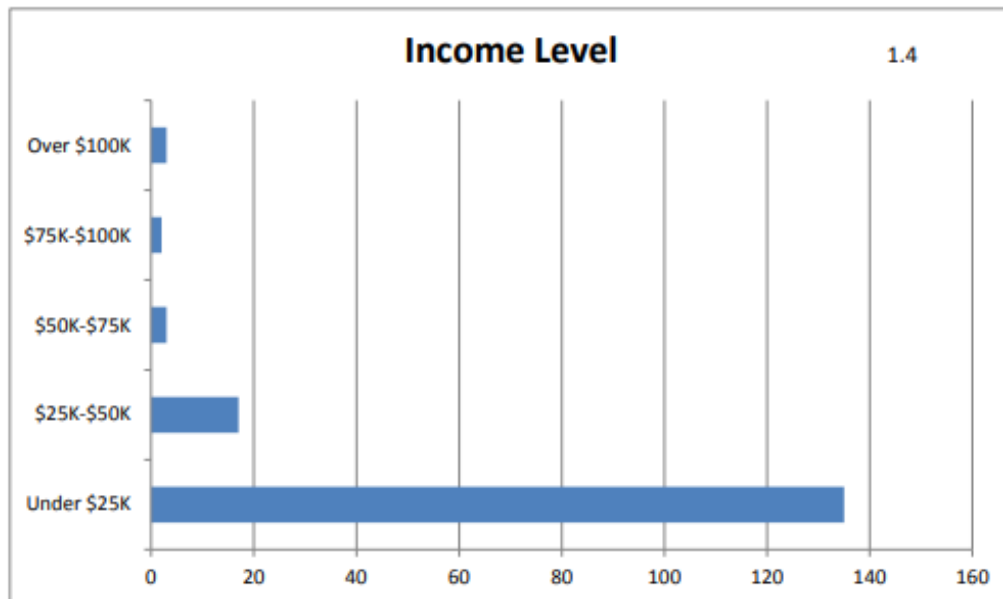
Under \$25K = 135

\$25K-\$50K = 17

\$50K-\$75K = 3

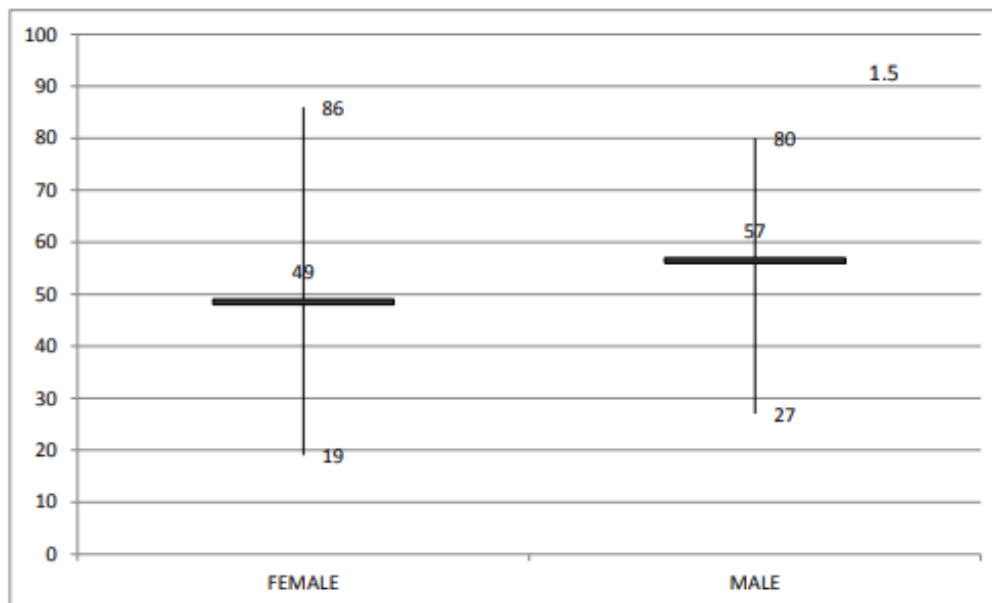
\$75K-\$100K = 2

Over \$100K = 3



Caregivers Data

This data comes from the LRBI application form.



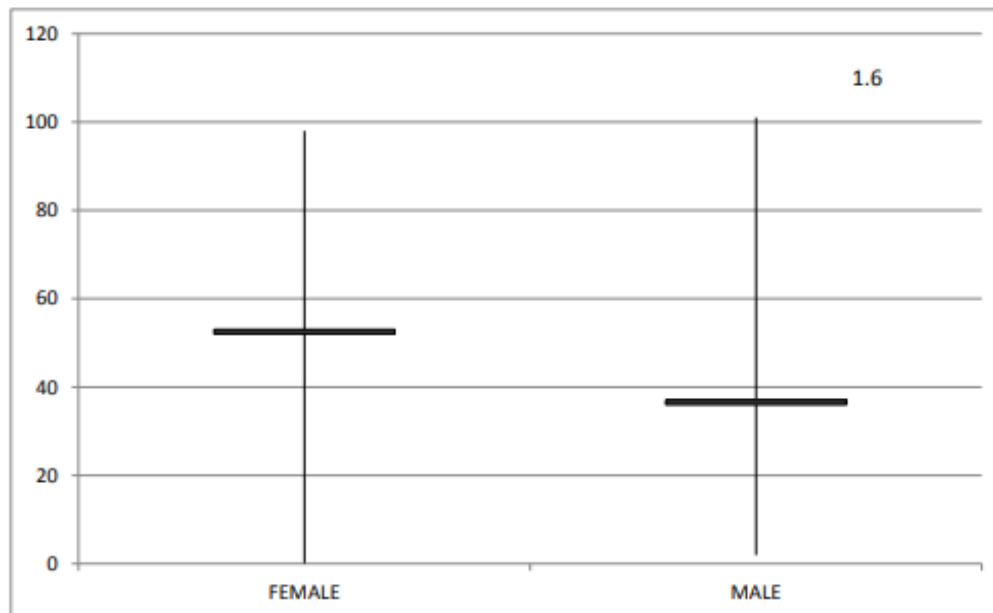
Female = 189 Female Avg. Age: 48.5 Female Age Range: 19-86 No Female Age Given= 10
 Male=40 Male Avg. Age: 56.7 Male Age Range: 27-80 No Male Age Given = 2
 No Response=1 Male/Female Combined Avg. Age: 50

Care Recipient Data

This data comes from the LRBI application form.

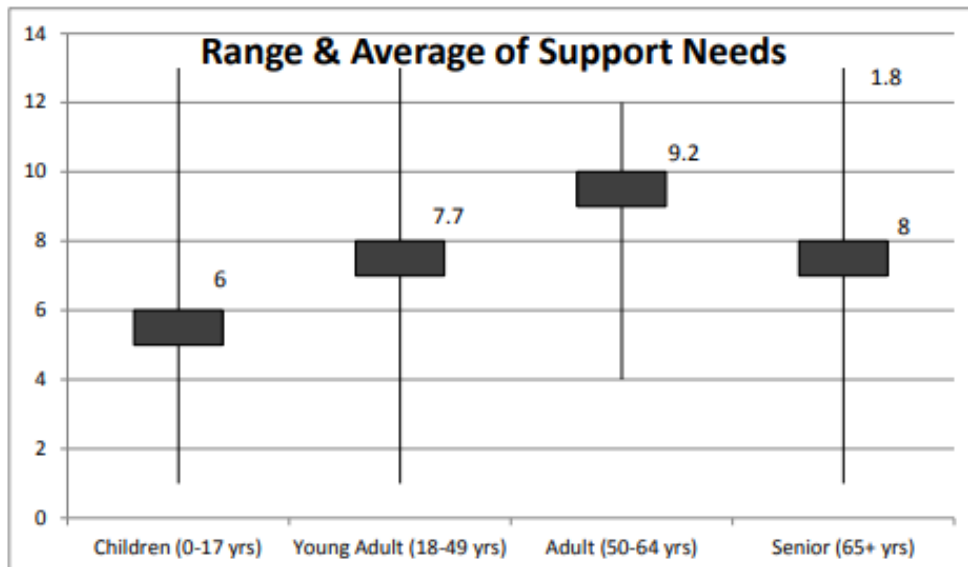
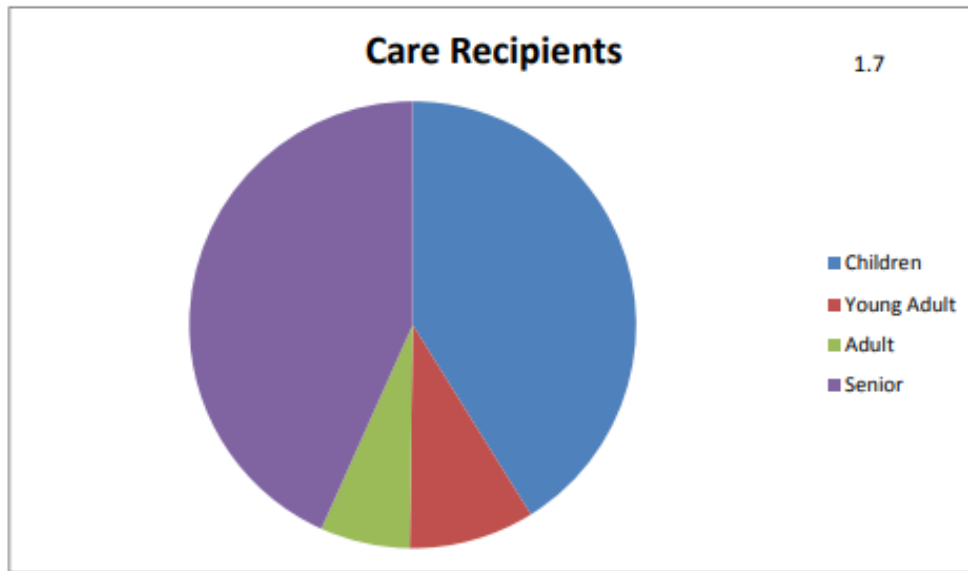
The following series of charts reflect the age, disability, and support needs of care recipient, as stated by their caregivers.

Female= 123 Avg. Age=53 Age Range=1mo-98years
 Male=108 Avg. Age=36.5 Age Range=2-101yrs
 Male/Female Combined Avg. Age = 45.2



The ages of care recipients were grouped into four categories. Minor children are eligible for different respite funding and resources, as are seniors. The adult population was split at age 50 to see changes in the identified disabling condition. Concerns that care recipients with early onset dementia or other age-related conditions are not old enough to qualify for respite programming that serves seniors. This data attempts to recognize those care recipients and conditions.

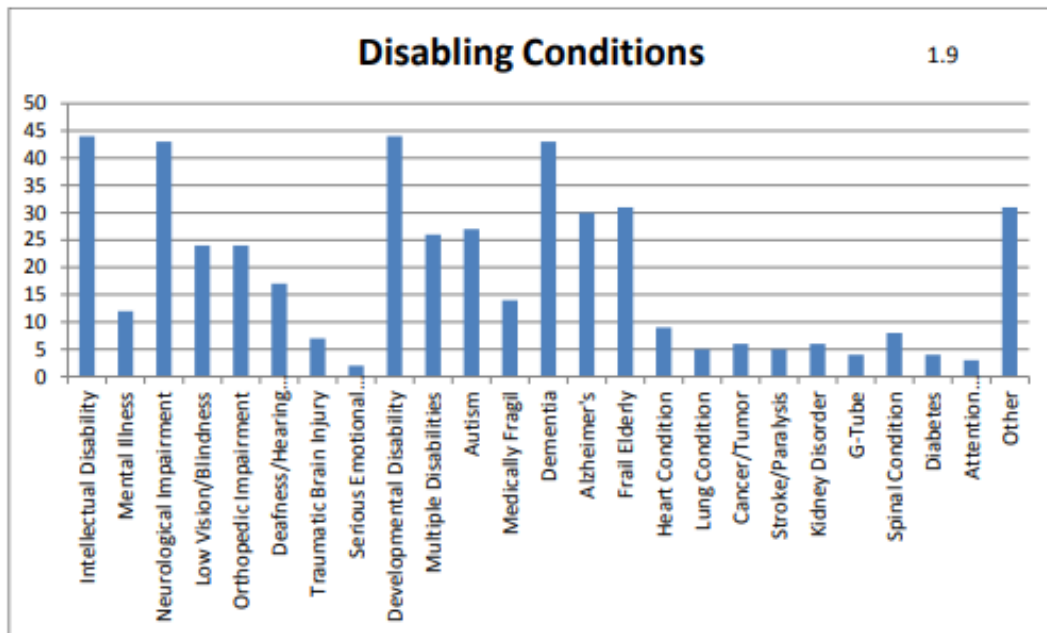
Child (0-17 yrs) = 95	Range of Supports Needed =1-13; Avg. = 6
Young Adult (18-49 yrs) = 21	Range of Supports Needed =1-13; Avg. = 7.7
Adult (50-64 yrs) = 15	Range of Supports Needed =4-12; Avg. = 9.2
Senior (65+ yrs) = 100	Range of Supports Needed =1-13; Avg. = 8



Note: Applicants were able to select more than one response on both disabling condition and the assistance and supervision needed. There were 16 choices of condition, and 13 choices for assistance and supervision.

Disability

Major Disabling Condition: 44=Intellectual Disability, 12=Mental Illness, 43=Neurological Impairment, 24=Low Vision/Blindness, 24=Orthopedic Impairment, 17=Deafness/Hearing Impairment, 7=Traumatic Brain Injury, 2=Serious Emotional Disturbance, 44=Developmental Disability, 26=Multiple Disabilities, 27=Autism, 14=Medically Fragile, 43=Dementia, 30=Alzheimer's, 31=Frail Elderly, Other (Please Specify) 9=Heart Condition, 5=Lung Condition, 6=Cancer/Tumor, 5=Stroke/Paralysis, 6=Kidney Disorder, 4=G-Tube, 8=Spinal condition, 4=Diabetes, 3=ADD/ADHD, 31=Other



Listed as: Intellectual Disorders, Mental Disorders, Neurologic Disorders, Developmental Disorders, Medical Disorders, Sensory Impairments, Orthopedic Impairments

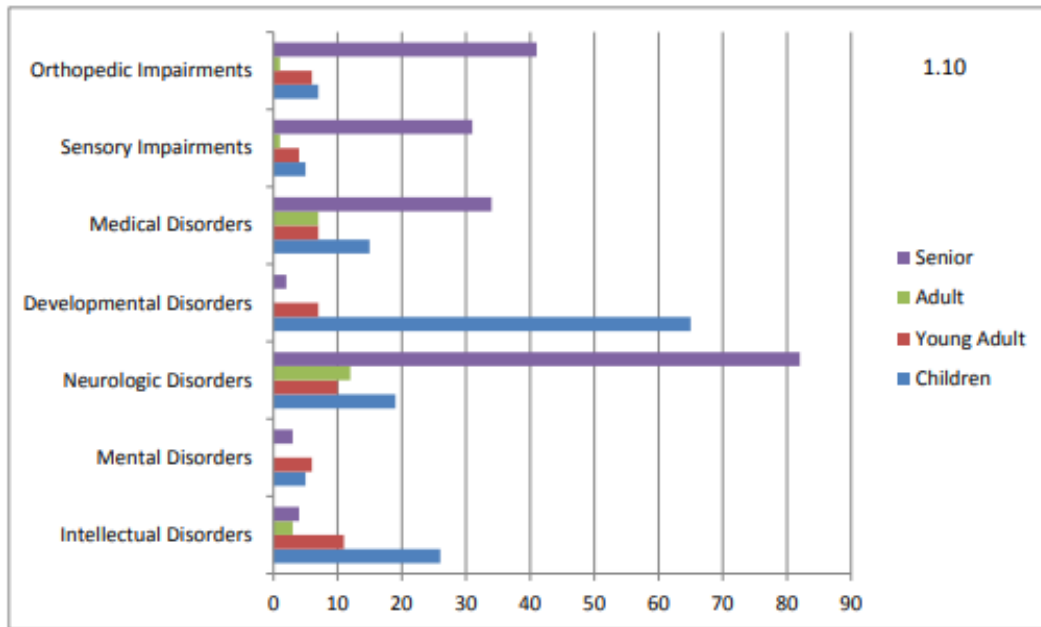
Groupings: Mental + SED = 12, Neuro+TBI+Dementia+Alzheimers= 123, DD+Autism+ADD=74, Medically Fragile+heart+lung+Cancer+Stroke+Kidney+G-Tube+Spinal+Diabetes=61, Vision+Hearing= 41, Ortho+Frail= 55

Children: Intell= 26, Mental=5, Neuro=19, DD=65, Medical=15, Sensory= 5, Ortho=7

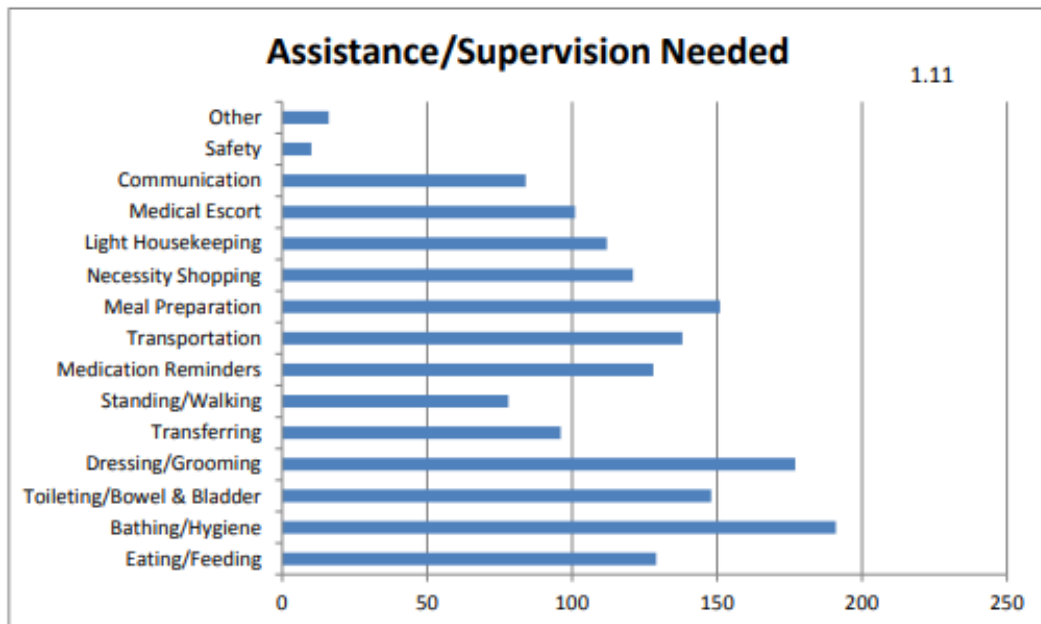
Young Adults: Intell=11, Mental= 6, Neuro= 10, DD= 7, Medical=7, Sensory= 4, Ortho=6

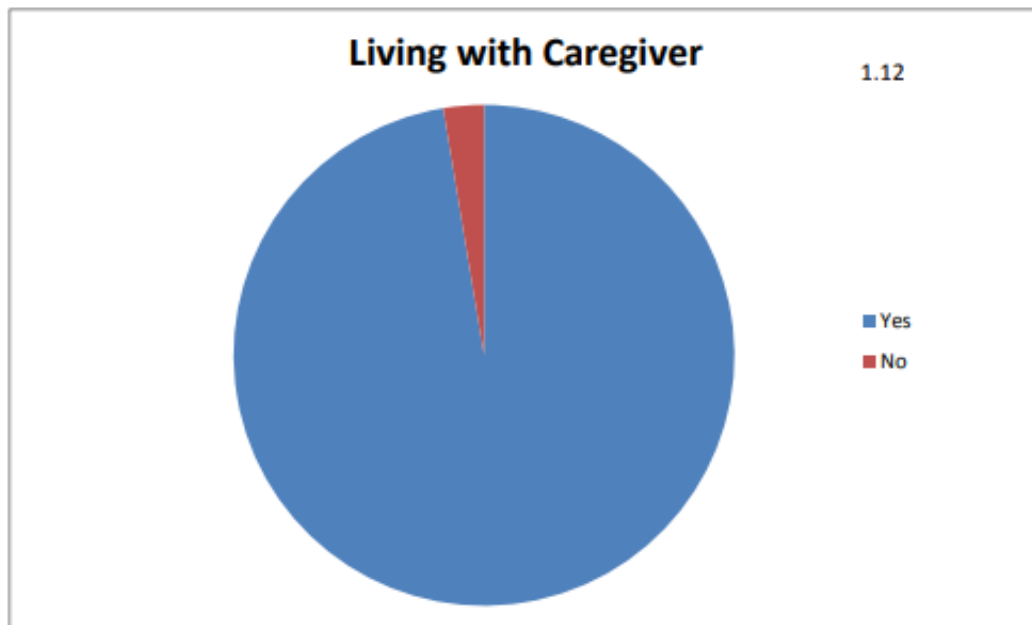
Adults: Intell=3, Mental= 0, Neuro=12, DD= 0, Medical= 7, Sensory=1, Ortho=1

Seniors: Intell= 4, Mental=3, Neuro= 82, DD=2, Medical= 34, Sensory= 31, Ortho=41



Assistance/Supervision Needed for: 129= eating/feeding , 191=bathing & hygiene , 148= toileting, bowel & bladder care, 177=dressing & grooming, 96=transferring, 78=standing & walking, 128=medication reminders, 138=transportation, 151=meal preparation, 121=necessity shopping, 112=light housekeeping, 101=medical escort, 84=communication, other (please specify) 10=Safety, 16=Other





Living with Caregiver? Y=224 N=6

Note: Other informal surveys of Nevada’s Parkinson’s Support Groups indicates that caregivers feel that the care recipients (60%) are most satisfied with the care arrangements that have been made for them. Only 40% of caregivers felt the same satisfaction with care arrangement.

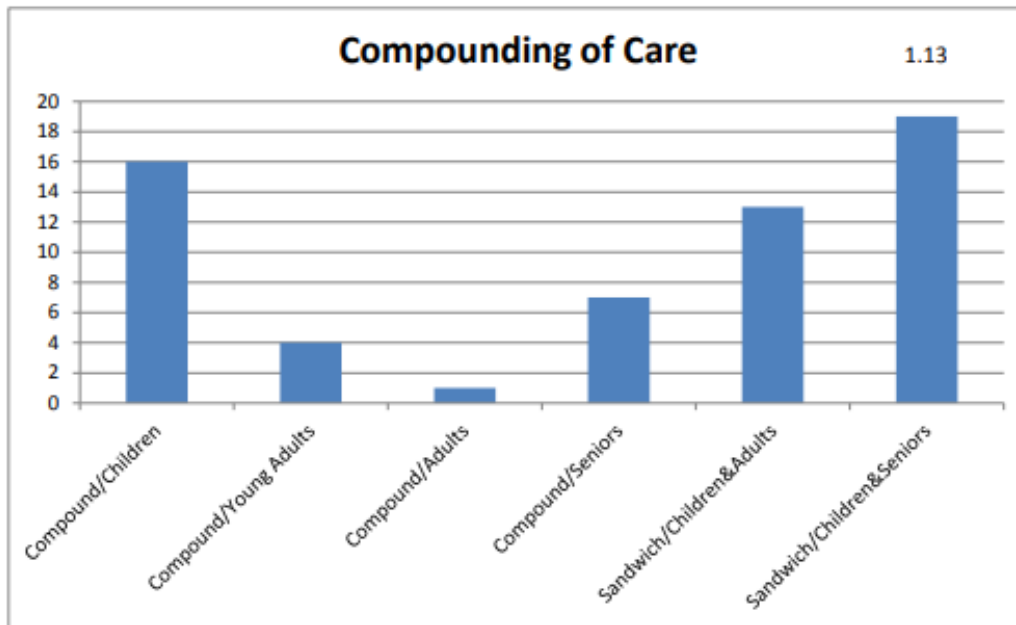
Compounding Care

If a caregiver cares for an older person and also has minor children at home, they are part of the “sandwich generation.” The demands of care and the related financial and employment-related challenges have been well documented. Nevada has 32 families with this situation, representing 18% of the LRBI participants.

But a newer finding of studies and research describes caregivers who are “compound caregivers” because they care for more than one person with special needs. Because people with disabilities are living longer, and seniors are living longer, compound caregivers are becoming much more common. They are also burning out at a much higher rate. Nevada’s sample shows compounding impacts 16% of the LRBI participants.

Compound Caregivers of Children=16, Compound Caregivers of Young Adults=4, Compound Caregivers of Adults=1, Compound Caregivers of Seniors =7

Sandwich of Children & Adults (18-64) =13, Sandwich of Children & Seniors=19



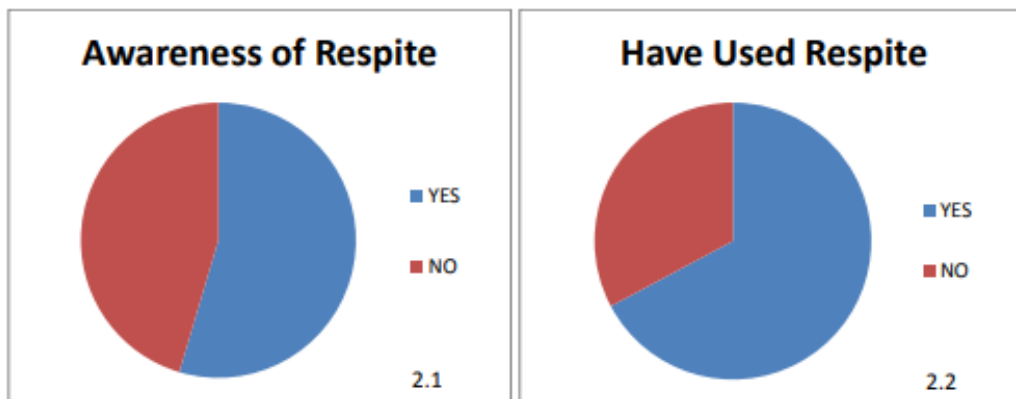
Pre-Respite Data

Families who applied for the LRBI voucher program were asked to complete a survey prior to receiving and using their voucher awards. The questions and responses are given below. The charts are labeled from 2.1 to 2.19.

Were you aware of respite or respite services prior to making this contact? YES NO

Aware of Respite? Yes=125 No=104 Inconclusive=2

If YES, have you received respite services in the past? YES NO

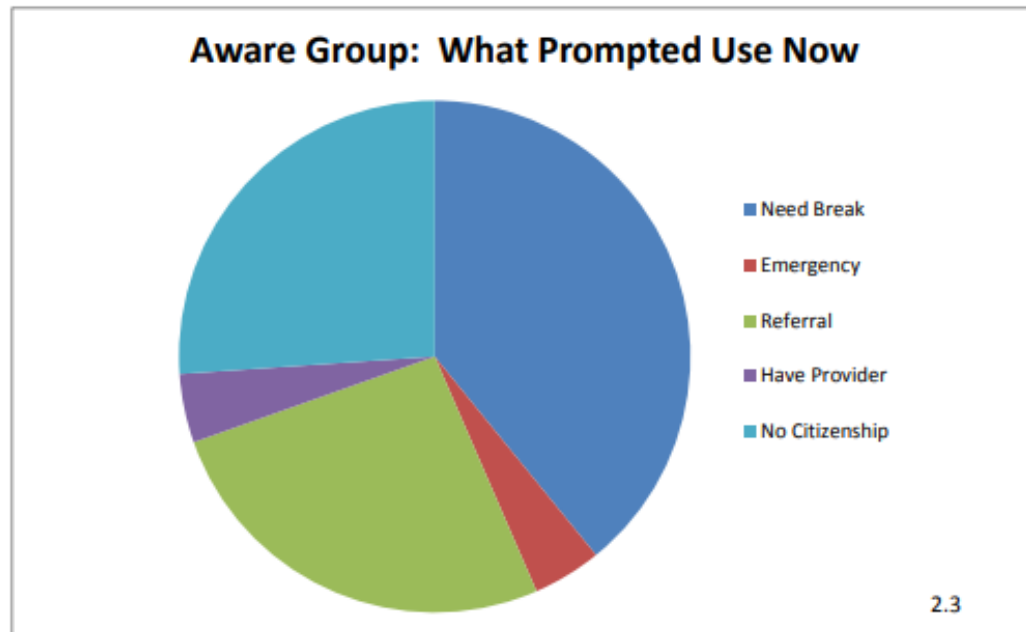


If Yes, Used Respite? Of the Aware group of 125, 84 had used respite previously=67%. Of the Aware group, 41 had not used respite before = 33%.

Of the Aware group who have previously used respite, some shared what had prompted their use of respite now (not required response), received (n=8) responses: Referral= 7, and Knew about Opportunity=1. Of Referral Sources: Provider/Service Orgs=6, Aware=1, Agency=1

New Users of Respite: Of Aware group, but no previous use, received (n=23) responses about what prompted use: Break Needed =9, Emergency=1, Referral=2+1+3=6, Easier to Find Provider=1, Not need US Citizenship=6

Of Aware group, but no previous use, Referrals (n=6) responses are: Agency=2, Provider=3, Friend=1

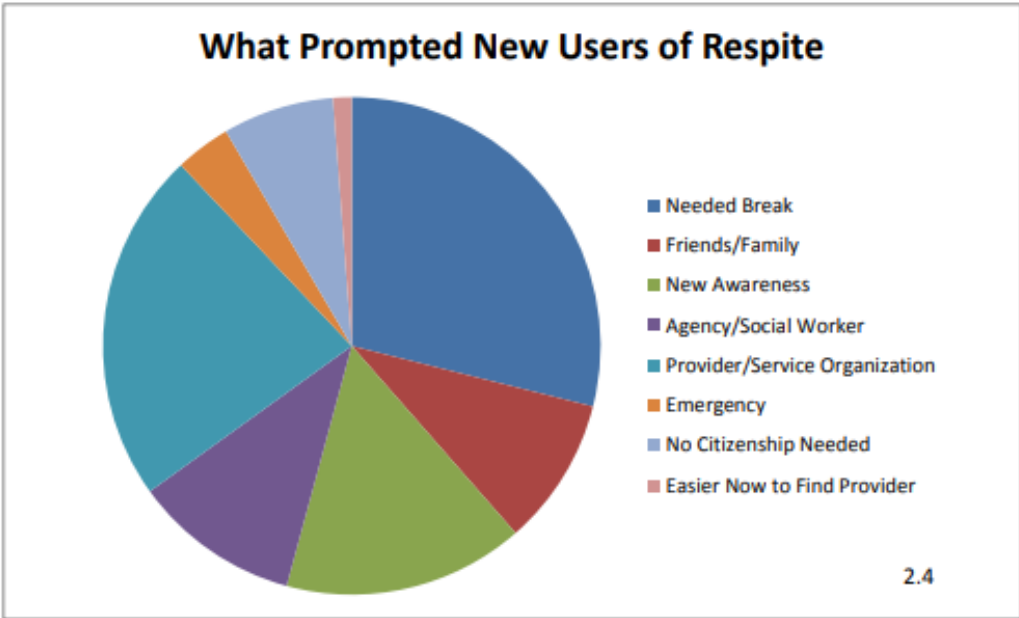


If NO, what prompted you to seek respite now? _____

If Not Aware, What Prompted Use? N=52 responses. Referral=5+7+11=23, Now Aware=4+4+3+1=12, Need Break=15, Emergency=2

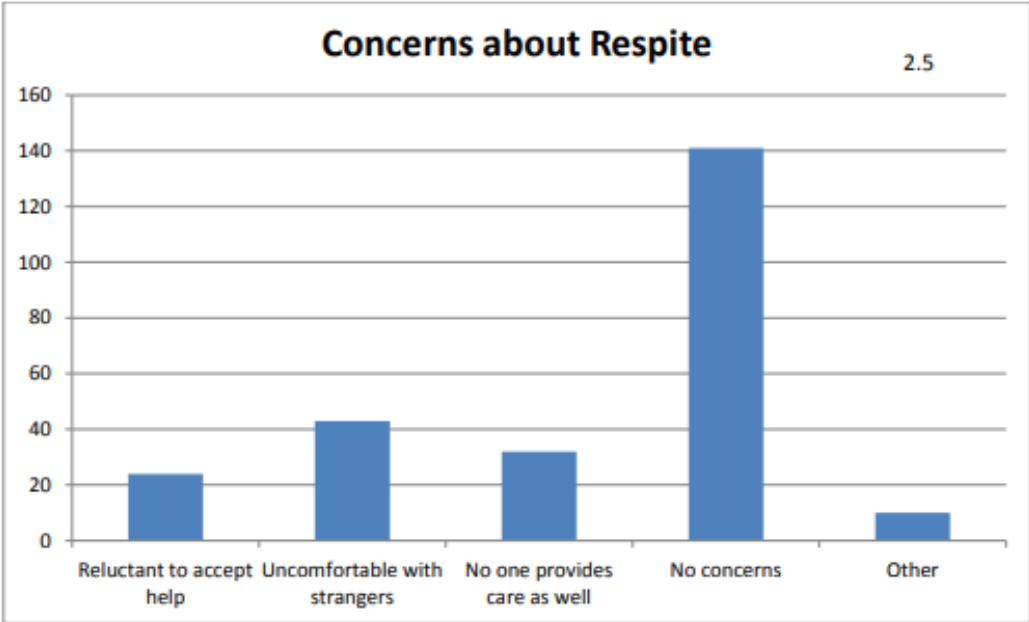
Of Not Aware Referrals (n=23), Agency/Social Worker=6, Provider/ServiceOrg=10, Friends/Family=7. For other sources of referral (n=12), responses are: TV=4, Print=4, Internet=1, Other =3. What Prompted Use (n=17), the responses were: Need Break=15, Emergency=2.

Of total (n= 83=23+52+8) Prompted Use responses: Break=9+15=24, Friend/Family=1+7=8, Aware =1+12=13, Agency/Social Worker=2+1+6=9, Provider/Service Org=3+6+10=19, Emergency= 1+2=3, No Citizenship=6, Easier to Find Provider=1.



All Referrals $N=6+7+23=36$ came from: Agency/social worker=2+1+6=9, Provider=3+6+10=19, Friend/Family=1+7= 8

2. Do you have concerns about receiving respite services? (Check all that apply)



24=Care recipient is reluctant to accept outside help

43=Uncomfortable with having people we do not know in the home

32=No one else can provide care as well as I do

10=Other -(Breakdown of Other is not available – Data Collection Tool neglected to capture)

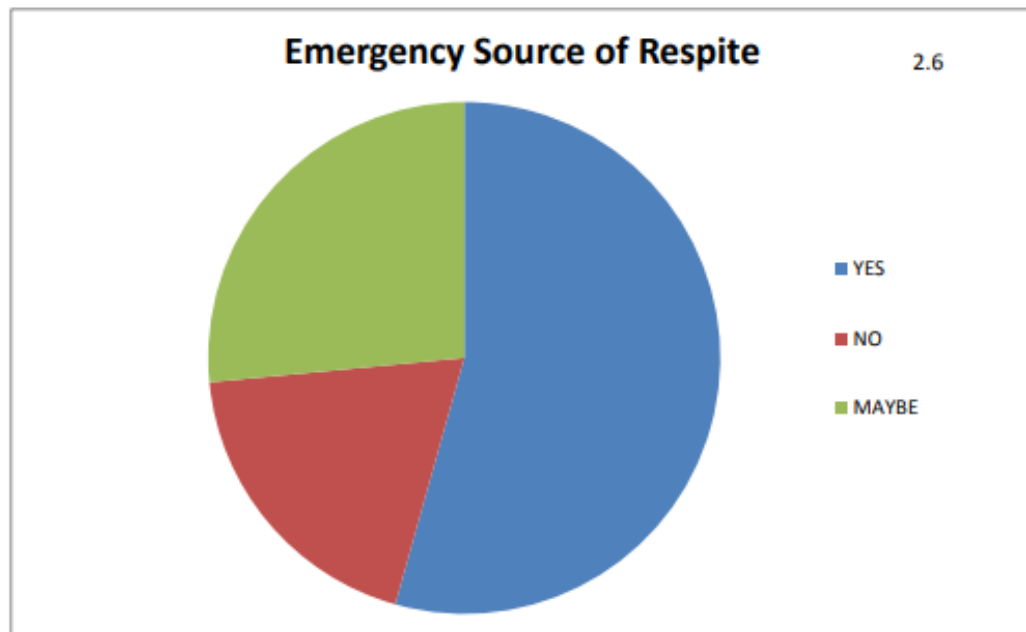
141=No concerns at this time

3. Is there anyone you can call on in an emergency to fill in for you as a caregiver?

Yes=125 or 54%

No=44 or 19%

Maybe=61 or 27%



4. If care recipient has a chronic disease or condition, how knowledgeable do you feel about this disease or condition?

VERY= 135 or 60%

SOMEWHAT= 75 or 33%

NOT AT ALL = 5 or 2%

NOT APPLICABLE= 12 or 5%

Note: This data reflects the experience and preparation that caregivers had prior to seeking respite through the LRBI program. When data was analyzed for differences in awareness of respite or prior use of respite, the results did not change the percentages significantly from the group as a whole.

5. Do you need information, education and/or training about any of the following? (Check all that apply)

83=In-home support services

80=Legal and financial issues, powers of attorney, living will

64=How to care for yourself while caring for others

63=How to get other family members to help

59=Support groups

50=Long-term care options (insurance and/or other benefits)

49=Home safety and/or home modifications, or equipment

45=Short-term respite care in a facility

38=More information about care recipient's disease/condition

34=Individual counseling options

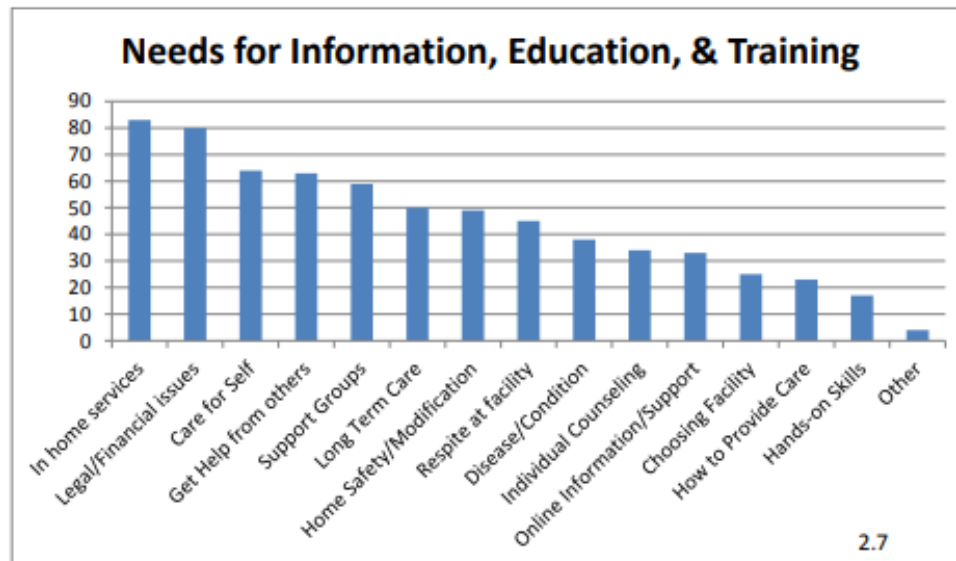
33=On-line information and supports

25=Choosing a long-term care facility

23=How to provide care to an aging individual or a person with a disability

17=Hands-on skill training for personal care tasks (bathing, grooming, toileting etc.)

4=Other (Please describe) - DNR Orders, Diabetes Class, Caregiver, None Given

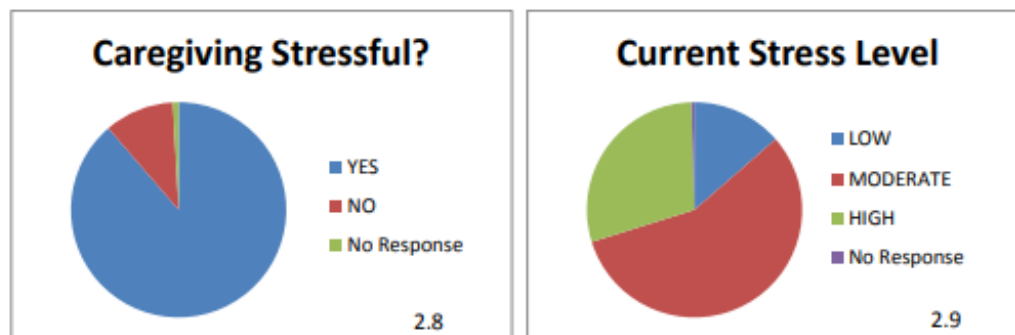


6. Do you find care-giving to be stressful? YES=204 or 90% NO=24 or 10% No Response=2

Rate your current stress level: LOW MODERATE HIGH

Of the YES group: Low=17 or 8%, M=121 or 59%, High=66 or 32%

Of the NO group: Low=14, M=8, High=1, No Response=1



7. Has your relationship with your spouse/partner/other family members been strained due to your care-giving responsibilities? YES NO MAYBE

Of Yes/High Stress: Yes=53, No=16, Maybe=2, No Response=1

Of Yes/Moderate Stress: Yes=62, No=23, Maybe=33

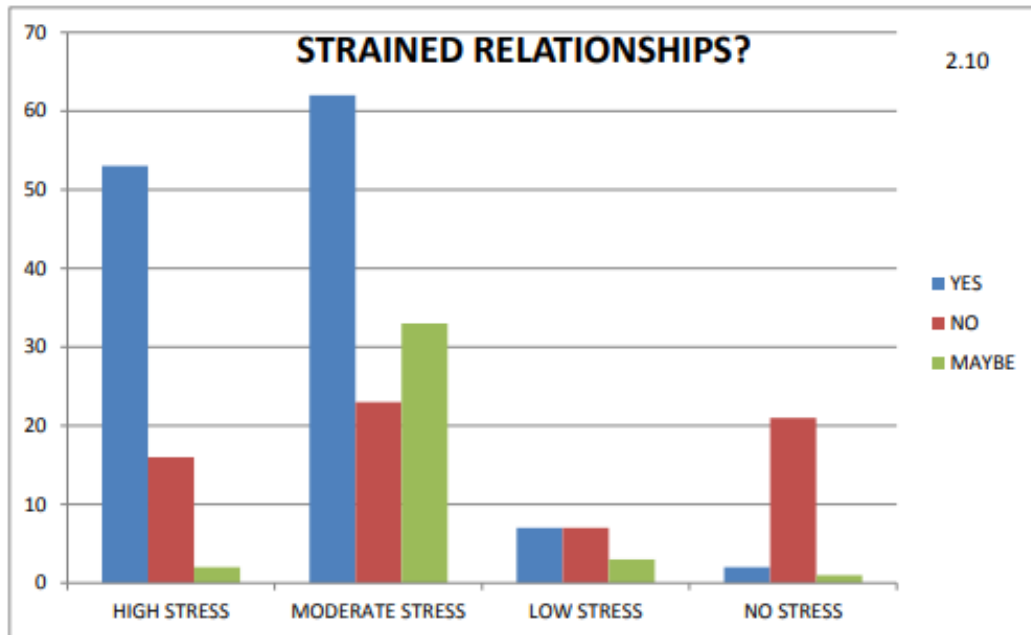
Of Yes/Low Stress: Yes=7, No=7, Maybe=3

Of No Stress Group: Yes=2, No=21, No Response=1

The data in this sampling shows the correlation between caregiving stress and its impact on other relationship. As stress levels increase, strain in other relationships increase as well.

Note: Caregiving studies have shown that as caregiving demands increase, caregiving can emerge as the primary role, forcing out other roles the caregiver might have held. Care demands might make it impossible for them to participate in social events, attend church, volunteer or work. It may also limit a caregiver's ability to be the spouse, parent, friend, or other relational roles they once held, both to the care recipient and to others they care about. Care duties may require time, abilities, skills, and knowledge beyond the caregiver's ability to provide. They may also prevent a caregiver from getting sleep, eating well, exercising, and otherwise taking care of themselves. They may take great care to make sure their loved one gets seen by medical professionals, but they sacrifice their own healthcare.

Burnout results when caregivers reach a point of exhaustion, when they no longer have the physical or emotional strength to continue. Damage has likely occurred within the family unit by then, with divorce, substance abuse, domestic violence, abuse & neglect reflecting the impact of un-relieved caregiving on these familial relationships.



Note: Questions 8 and 9 have been interchanged for the purposes of this report. The numbers are for reference to the document they were taken from.

9. Have you found yourself increasing the use of medication or drugs (including over-the-counter medications), smoking, or drinking alcohol to help you manage the stress of your care-giving and other responsibilities?

NEVER RARELY SOMETIMES FREQUENTLY NEARLY ALWAYS

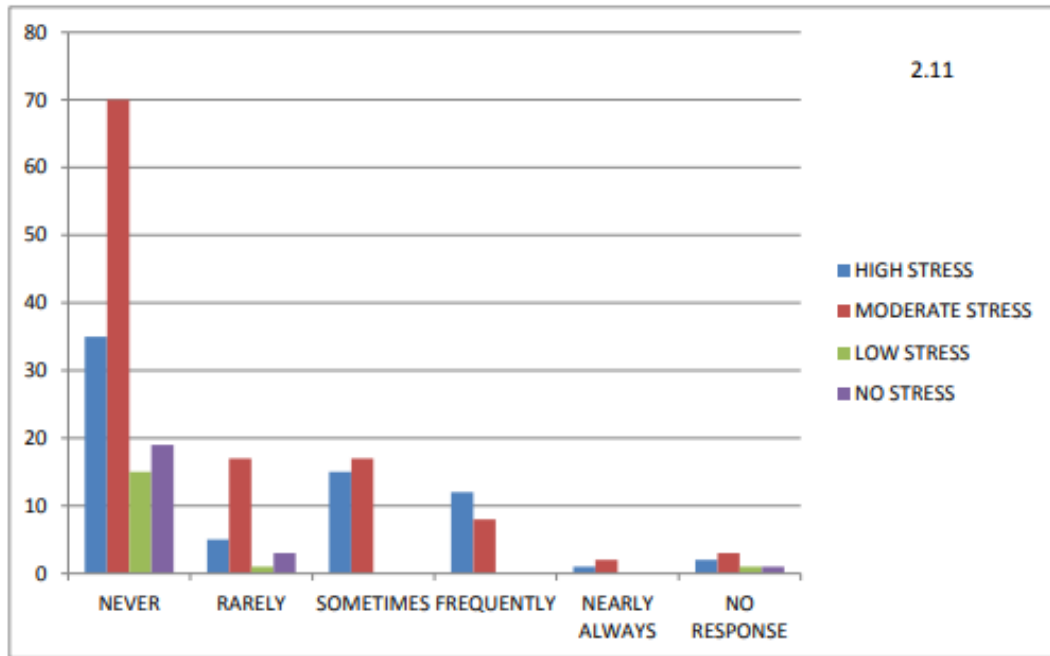
Of Yes/High Stress (n=70): Never=35, Rarely=5, Sometimes=15, Frequently=12, Nearly Always=1, No Response=2

Of Yes/Moderate Stress (n=117): Never=70, Rarely=17, Sometimes=17, Frequently=8, Nearly Always=2, No Response=3

Of Yes/Low Stress (n=17): Never=15, Rarely=1, No Response=1

Of No Stress Group: Never=19, Rarely=3, No Response=1, Write in of "Prescription Meds"=1

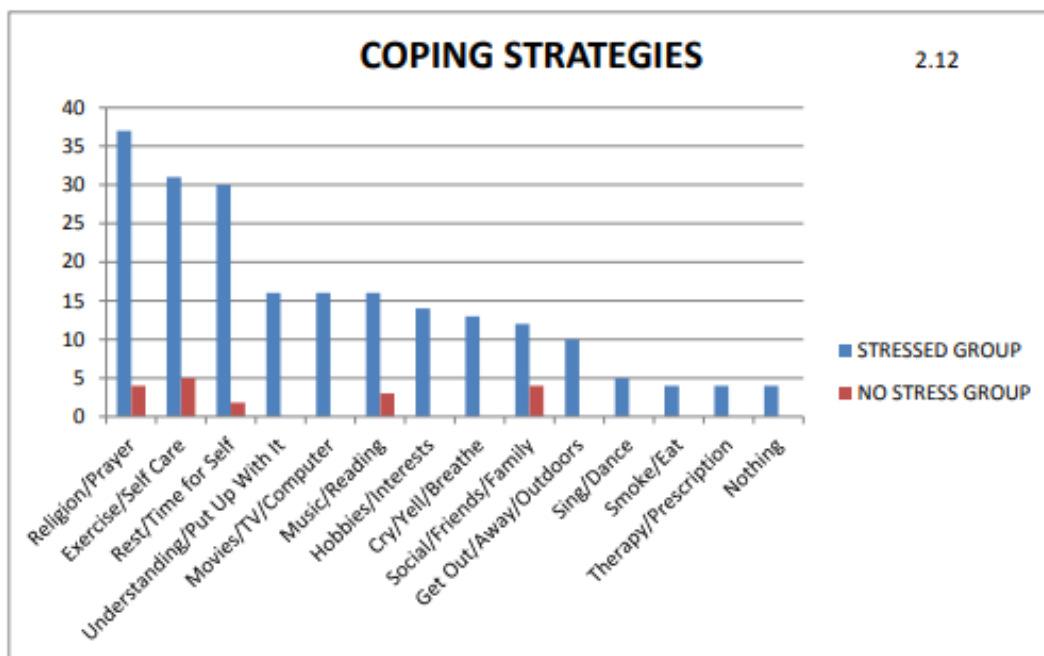
Note: Some funding of respite has been tied to at-risk behaviors. This data attempts to see whether caregiving stress leads to at-risk behavior.



8. What do you do to cope with the stress related to giving care? Please Describe _____

No Stress Group: Exercise/Self-Care=5, Prayer=4, Social/Activities=4, Music/Reading=3, Write in of "Hard to find time" =1

Yes Stress Group: Religion/Prayer=24+1+12=37, Exercise/Self-Care=20+1+9+1=31, Sleep/Rest/Relax/Time for Self=4+2+2+13+8+1=30, Be Understanding/Put Up With It=12+1+1+2=16, Movies/TV/Computer=3+6+7=16, Music/Reading=8+8=16, Hobbies/Interests=1+1+1+1+1+1+1+2+1+1+3=14, Cry/Yell/Breathe=10+2+1=13, Social/Friends/Family=11+1+1=12, Get Out/Get Away/Outdoors=3+3+3+1=10, Sing/Dance=4+1=5, Smoke/Eat=1+3=4, Therapy/Prescription=2+2=4, Nothing=1+1+1+1=4 (Write in: "Nothing, Not sure what to do, Don't know how, Having a hard time")



10. I feel (Check all that apply) n=230

Positives:

179 or 78%=A commitment to provide care as long as I am able

135 or 59%=Confident about providing care

129 or 56%=A sense of satisfaction in helping to provide care

Negatives:

161 or 70%=Care-giving is likely to continue indefinitely

141 or 61%=My finances are strained because I provide care

137 or 60%=A sense of obligation to provide care

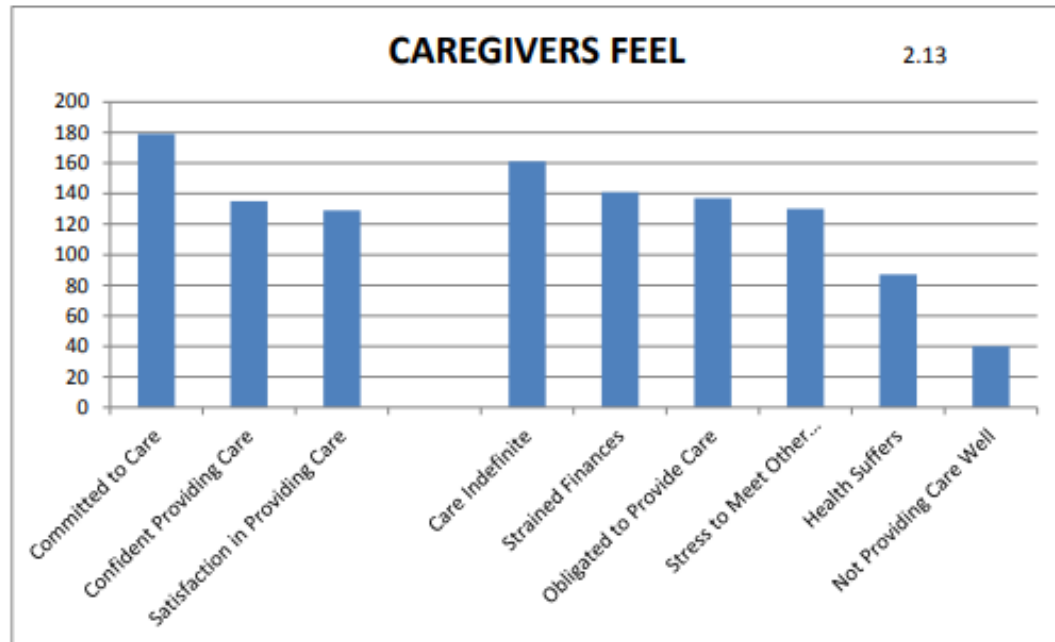
130 or 57% =Increased stress when giving care and while also trying meeting other responsibilities

87 or 38%=My health has suffered because of my involvement with providing care

40 or 17%=I am not providing care as well as I could or feel I should

Note: This question asks about the caregiver's commitment to care. Keeping caregivers committed to providing care is why respite has become a top priority for Nevada. Alternatives to care when the caregiver's commitment

to continuing care wanes (due to stress, health, finances, burnout, etc.) are expensive, and difficult to provide everywhere they are needed.



Comparisons Drawn: Confidence about care/care not well as should= 135 vs 40, Commitment/Care Indefinite= 179 vs 161, Satisfaction/Increased Stress= 129 vs 130. Finances/Health/Stress= all three =56 or 24%, two=66 or 29%, one=58 or 25%

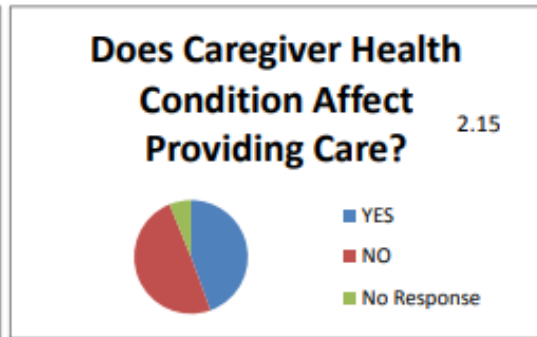
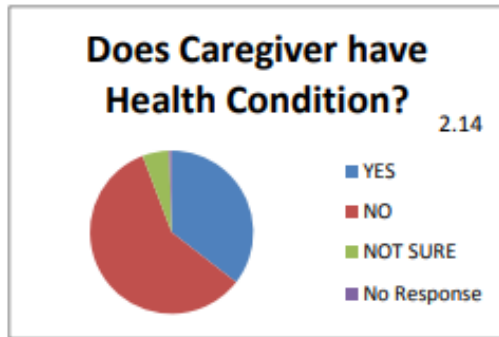
Note: Tipping points (such as Commitment to Care versus Care Continuing Indefinitely) may reflect how positive feelings offset negative feelings. In the comparison of Satisfaction in Providing Care versus Stress of Meeting Other Responsibilities, the negative feeling is slightly stronger. When other negative feelings are added in, the positive feelings regarding caregiving are at risk of being overwhelmed.

11. Do you have a chronic health condition or have you experienced a recent health crisis of your own?

YES = 81 or 35% NO=134 or 58% NOT SURE=12 or 5% No Response=4 or 2%

If YES, has your health condition affected your ability to provide care?

YES=36 NO=40 No Response=5



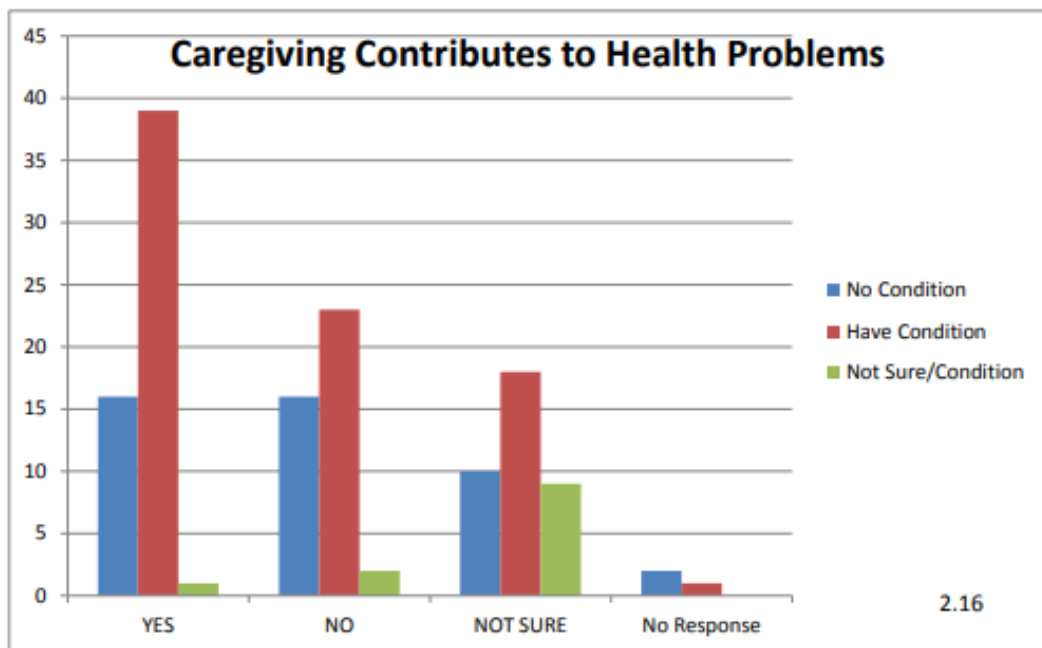
12. Have your care-giving responsibilities contributed to ANY health problems you may have?

YES NO NOT SURE

Of NO Health Condition Group, n=107+16+10+2=135, Yes=16, No=107, Not Sure=10, No Response=2

Of YES Health Condition Group, Yes=39, No=23, Not Sure=18, No Response=1

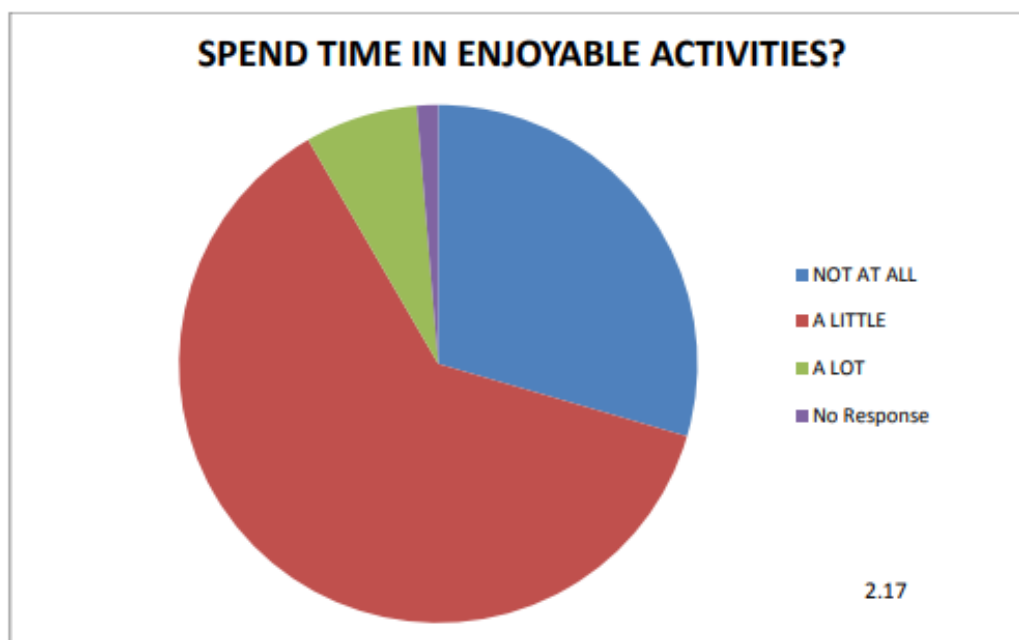
Of Not Sure Health Condition Group, Yes=1, No=2, Not Sure=9



Note: Interesting to see that caregivers who said they had no health problems indicated that caregiving contributed to health problems. Those caregivers who had health conditions strongly see that caregiving contributes to their health problems.

13. How often have you been able to spend time in the various activities that you enjoy (e.g., going to religious services, socializing with others, going out for a meal) or spending time on hobbies or activities you like to enjoy alone (e.g., reading or gardening)?

NOT AT ALL =67 or 29% A LITTLE =141 or 61% A LOT=16 or 7% No Response=3 or 1%



Note: The following questions attempt to gauge the caregiver readiness to access respite and their expectations of benefit. Caregivers who applied for the LRBI vouchers had high expectations. These responses should be compared to similar questions in the LRBI Post-Respite Survey, to see if these expectations were met. Since the Post-Respite data is not yet available, some of the data below is not illustrated.

14. Do you feel that if you are able to access respite, it would make a positive difference for you and your family? YES = 219 or 95% NO = 4 or 2% No Response=8 or 3%

15. How much do you think you will benefit from receiving respite services?

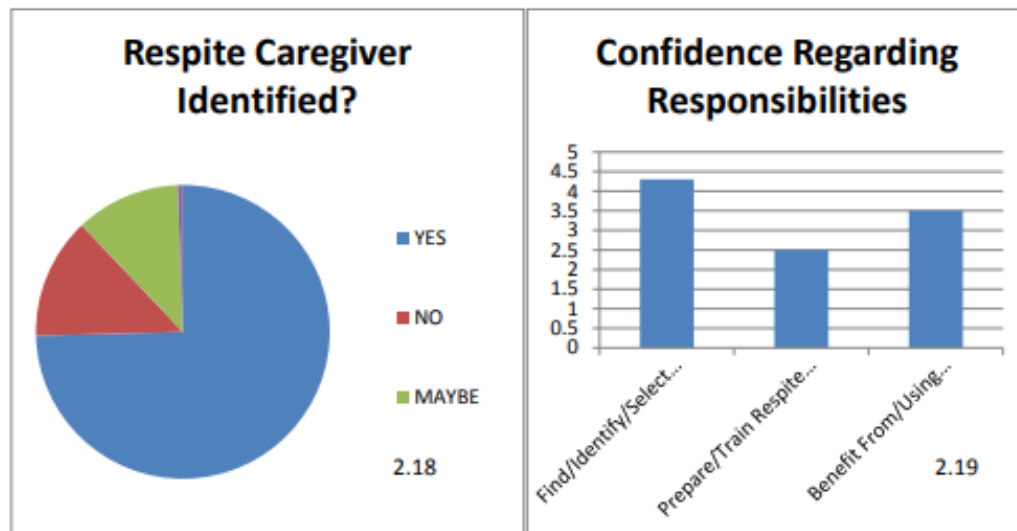
NOT AT ALL = 2 or 1% A LITTLE = 10 or 4.5% A LOT= 213 or 93%

No Response= 3 or 1.5%

16. As you need to identify your own respite provider for this program, do you have anyone in mind?

YES= 168 or 73% NO= 30 or 13% MAYBE= 26 or 11% No Response=7 or 3%

Note: Seventy-three percent of Caregivers who applied for the LRBI vouchers already had potential respite caregivers identified. This counters speculation that finding a respite caregiver is a barrier to respite. This data should be compared to LRBI Post-Respite Survey data about the ease/difficulty of finding respite caregivers.



17. I feel (Check all that apply)

198 or 86%=Confident about finding/identifying/selecting a respite provider

150 or 65%=Confident about preparing/training a respite provider to give care

200 or 87%=Confident about benefiting from respite and using respite breaks effectively

RX Diagnosis: Caregiver Assessment

This document was developed as a screening and assessment tool for caregivers, especially those who would not recognize themselves as caregivers or be looking for respite. It attempts to capture information on potential “talking points” for engaging a caregiver in a conversation about respite, and collect information on known barriers to respite. The LRBI grant used it in the application process and it was captured along with the other Pre-Respite data. The charts are labeled from 3.1 to 3.8.

Note: This document gathered information on relationship between caregivers and care recipients, length of time in caregiving, employment status of caregivers, language barriers, and other information that potentially has bearing on the access and use of respite services. The document also uses a modified Zarit Burden Interview in Question 7. Studies have demonstrated that the Zarit Burden Interview is a valid and reliable instrument for measuring the burden of caregivers.

1. A friend or family member may already depend on you for help or assistance, or to respond when needs arise. Please select the choice that best reflects your role.

220=Yes, I provide care regularly.

12=Yes, I provide assistance occasionally, or as requested.

2=No, I have not personally provided any assistance but I know he/she has a need for some support.

1=No, I have not personally provided any assistance, but I have an increasing concern about his/her ability to manage things without help.

0=No, I currently do not provide any type of direct care, support, or assistance.

Note: Since this was used in the LRBI respite program, the caregivers had already identified their caregiving role. The results of Question 1 are not surprising. No illustration was prepared for this question.

2. What is the relationship between you and the friend/family member you identified above? For example, are YOU the parent/spouse/sibling/child?

37=a=Spouse/Significant Other

6=e=Grandchild(ren)

108=b=Parent/Step-Parent/In-Law

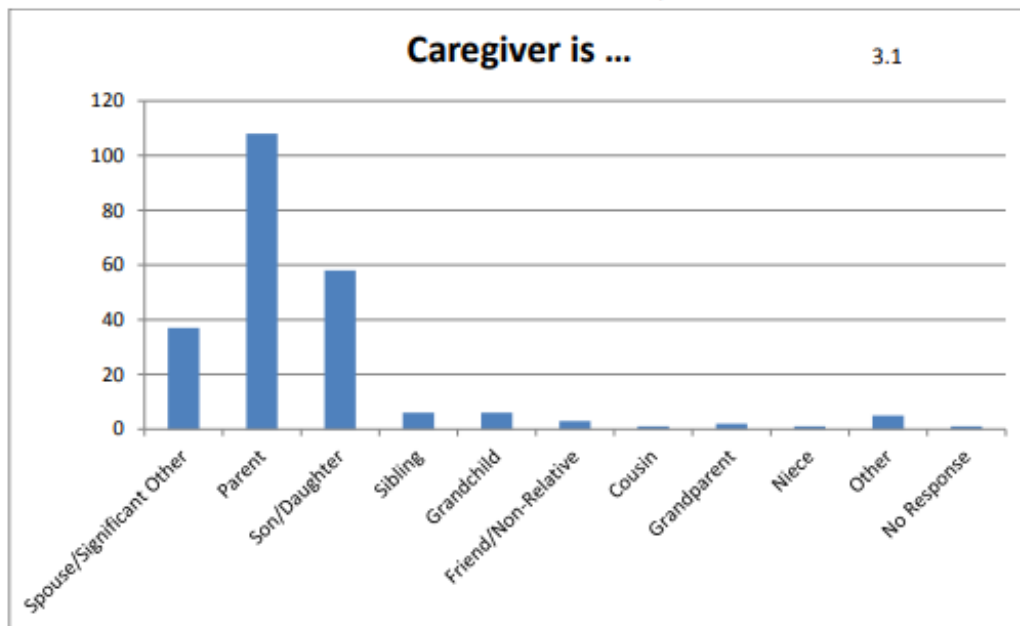
3=f=Friend/Non-Relative

58=c=Son/Daughter/Step/In-Law

9=g=Other (please specify): Cousin -1, Grandparent-2, Niece -1, None Given-5,

6=d=Brother/Sister/Step/In-Law

1= No Response



3. How long have you been giving extra care and assistance to the person identified above? Give an approximate length of time.

6 or 3%=a=One month or less

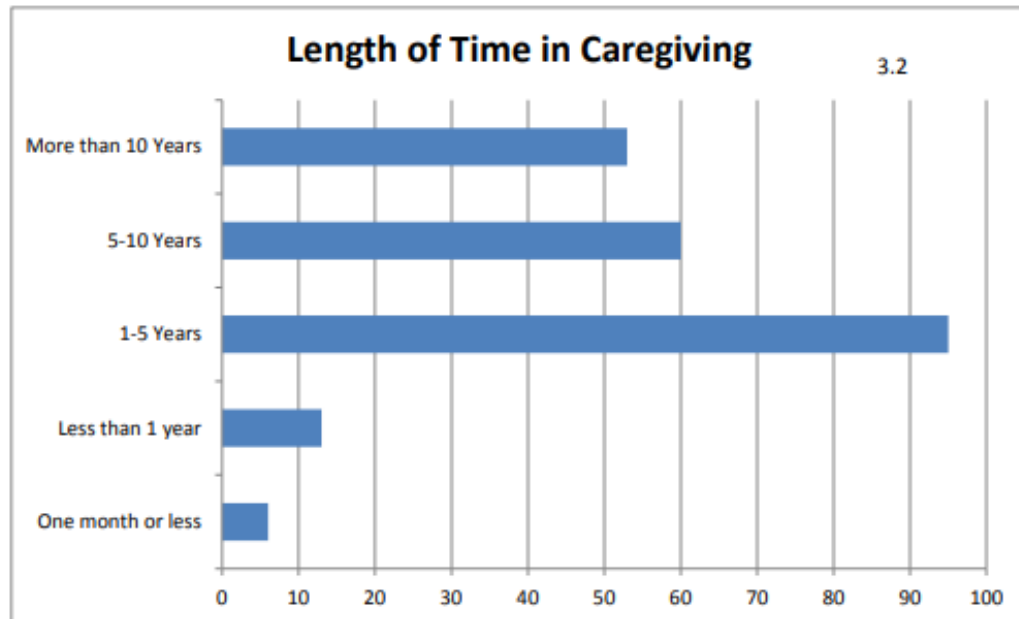
60 or 26%=d=5-10 years

13 or 6%=b=Less than 1 year

53 or 23%=e=More than 10 years

95 or 41%=c=1-5 years

No Response=2 or 1%



Note: Studies have shown a risk to caregivers who provide care for 5 years of more. They lose 10 years off of their life expectancy. This data shows that the LRBI Respite Expansion grant, aimed at new users of respite in un-served and underserved populations, picked up a significant number of caregivers who been providing care for 5, 10, or more years.

Note: Question 4 also attempts to capture the age of the care recipient and identify the compounding of care. This supplements data from the LRBI application form. The age breakdown is different, to isolate young adults transitioning from home and school, early onset of age related conditions, and to help identify whether LRBI grant hit its target in serving adults between ages 18-64. Compare to data from the LRBI Application form.

4. Give the ages of all the persons who need your care. Include the person identified above, if appropriate.

110=ages 17 or younger

6=ages 22-35

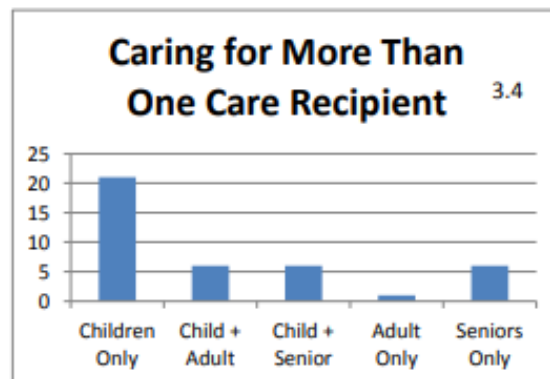
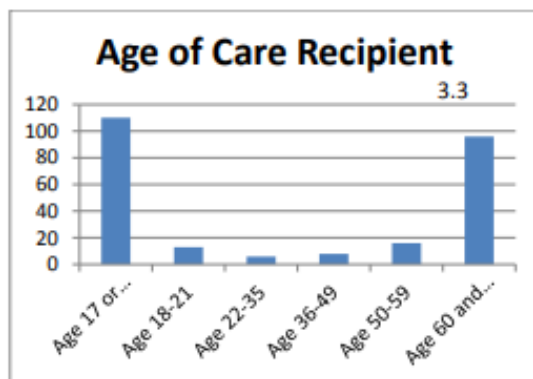
13=ages 18-21

8=ages 36-49

16=ages 50-59

No response=1

96=ages 60 or older



Compound Caregivers: n=40 or 17%, Children Only=21, Seniors Only=6, Child+Adult=6, Sandwich Child+Senior=6, Adult Only=1

Total Number of Care Recipients: 283 (or equivalent to 1.24 persons per caregiver)

5. Which of the following categories best describes your employment status?

38=a=Employed, working 1-39 hours per week, including one write in "own self issues"

29=b=Employed, working 40 or more hours per week, including one write in "self-employed"

66=c=Not employed, homemaker, including Write in 1=Not employed, 1=unable to work, 1=Caring 24/7

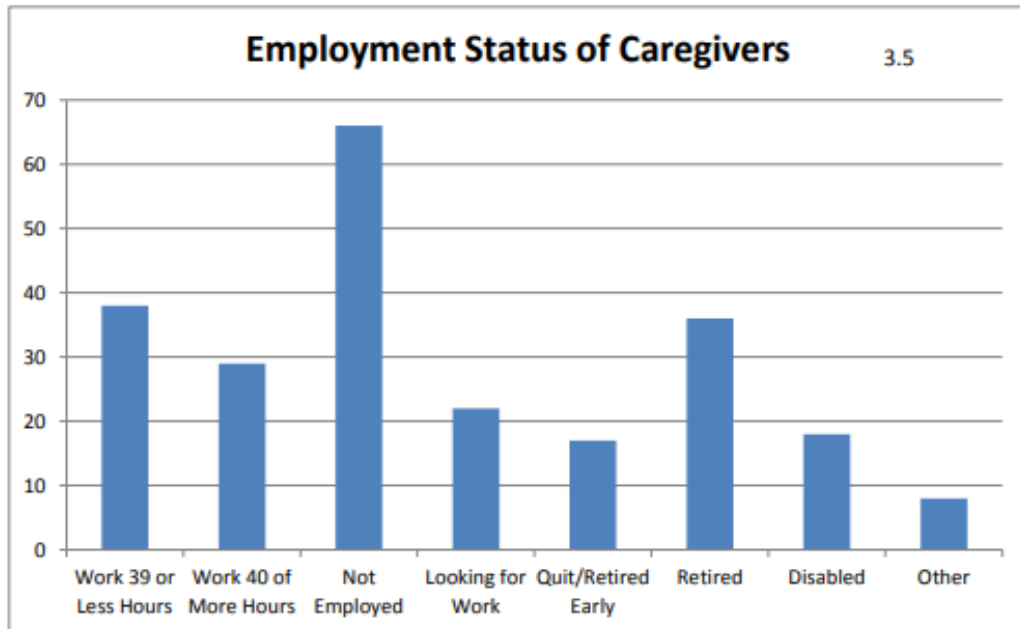
22=d=Not employed, looking for work full- or part-time, including Write in 1=Airforce, 1=Excessive demands, also combinations of 1=looking for employment but quit job/retired early, and 1=looking for employment but also retired

17=e=Not employed, quit job or retired early, including Write in of 1=terminated

36=f=Retired, including Write in combination of 1=retired and disabled/not able to work

18=g=Disabled or not able to work, including Write in of 1=Volunteer

None of the Above= 8, with Reasons Given: Student=1, Can't make enough money to pay someone else to stay with Mom=1, Unspecified "unable to work"=1, Terminated=1, None Given=4)



6. Please read each statement and indicate if any apply to you.

141=The care recipient is now living in my home so I can provide care.

29=I now live in the care recipient's home so I can provide care.

10=I often or regularly go to the care recipient's home to provide care, as I do not live with the care recipient.

2=I provide support at a distance, as I am not able to be physically present to provide assistance.

74=I am Hispanic, and English may be a secondary language for me.

9=I am Non-Hispanic, but English is not the primary language for me.

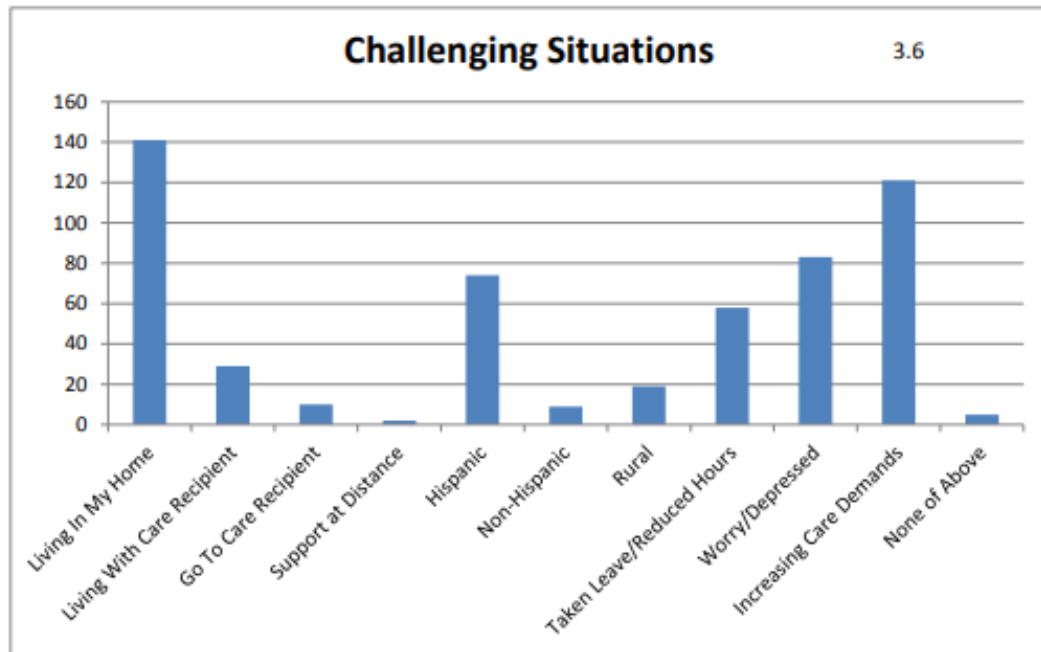
19=I live in rural or frontier areas of Nevada.

58=I have taken leave from work or reduced hours at work to provide care.

83=I have felt worried, anxious or depressed since I began to provide care or support.

121=The demands of care giving are increasing, and I am struggling to meet them.

5=None of the above



Note: Question 7 below is the modified Zarit Burden Interview. This information is not captured in any other tool used by the LRBI Respite Expansion grant. Compare to Question 10 in the Pre-Respite Survey.

7. Since becoming a caregiver, do you feel ...?

- 19=That you are asked to give more care than is really needed.
- 162=That time spent in care giving leaves little time for yourself.
- 110=Stretched between demands as a caregiver and demands from work and family.
- 31=Embarrassed/scared by behavior from person you provide care to.
- 33=Sometimes angry when you have to provide care.
- 54=Care giving for one person is negatively affecting your relationship with others.
- 139=Afraid of what the future will be like for the person you provide care for.
- 163=That the person you provide care for is dependent upon you.
- 39=Strained in your relationship with the person you provide care for.
- 34=Uncomfortable about having other people over when you are care giving.
- 89=Like you are expected to provide care because no one else can be depended on.

163=That there is not enough money for the extra care needed.

36=Unsure about your ability to continue to provide care much longer.

63=A loss of control over your life.

36=Wishful about leaving care giving in someone else's hands.

24=Uncertain about knowing what to do for the person needing care.

30=You should be doing more.

31=You could do a better job of care giving.

85=Burdened by care giving.

104=Your own health has suffered because of the demands of care giving.

95=A loss of privacy because of care giving.

163=A loss of a social life because of care giving.

6=None of the above.



Note: The results above may also be important to awareness campaigns and marketing of respite. Helping caregivers recognize the sacrifices they make in providing care is an important part of getting them to accept respite.

8. Thinking of your own needs as a caregiver, what would help you the most?

112=Good information about resources and services available.

52=Advice from other caregivers, gathered from their experiences.

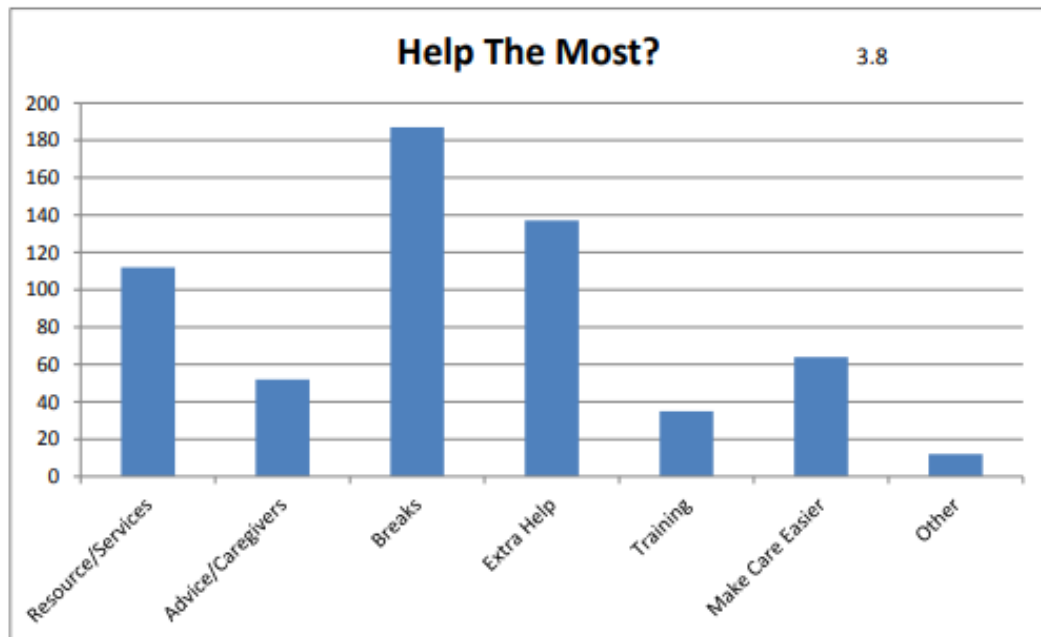
187=Regular or temporary breaks from care giving role.

137=Extra assistance or help so you can provide the care needed.

35=Training so you can provide better care.

64=Strategies to make your care giving easier.

12=Other (please specify) 1=Money, 10=Unspecified, 1=Time



Note: Compare the results of Question 8 above with data from Question 5 of the LRBI Pre-Respite Survey.

Note: Question 9 can be compared to Question 14 & 15 of the LRBI Pre-Respite Survey, and supplements the results given for those questions. For that reason, the data in Question 9 has not been illustrated.

9. How likely would you be to use Respite?

184=Extremely likely

25=Very likely

8=Moderately likely

7=Slightly likely

5=Not at all likely

If not, why not? _____

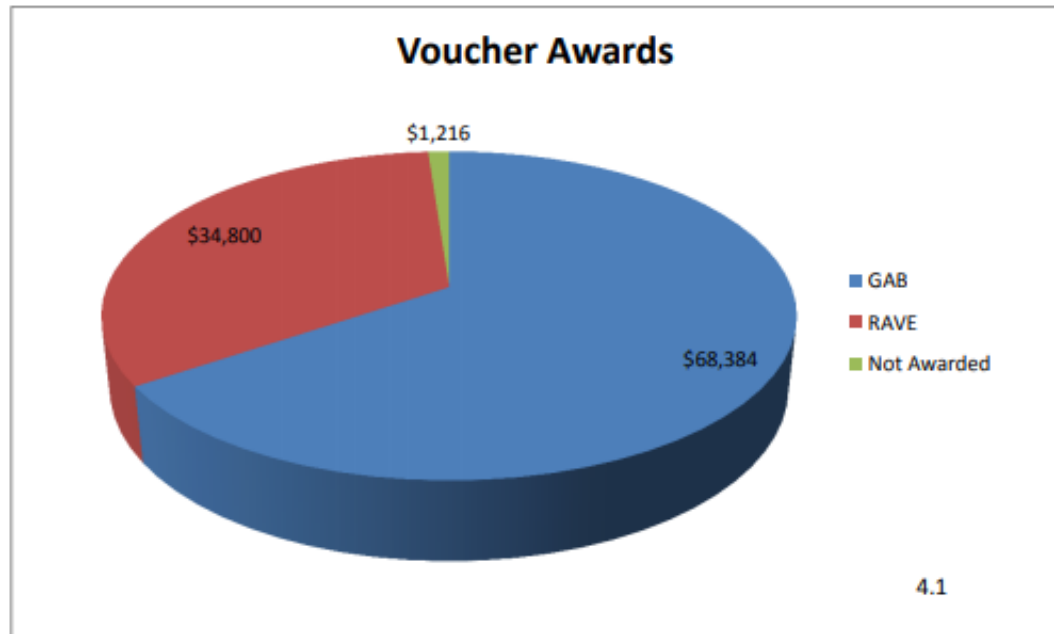
10. Where do you live?

City/Town: _____ ZIP: _____

Note: This question has been asked already on the LRBI application. Data has not been replicated here.

Voucher Claims & Use

As the LRBI grant has recently closed, voucher claim updates are still coming in. The data available on August 31, 2012, form the basis for the information and the illustrations below. Contact the Aging & Disability Services Division for the final report. The charts are labeled from 4.1 to 4.5.

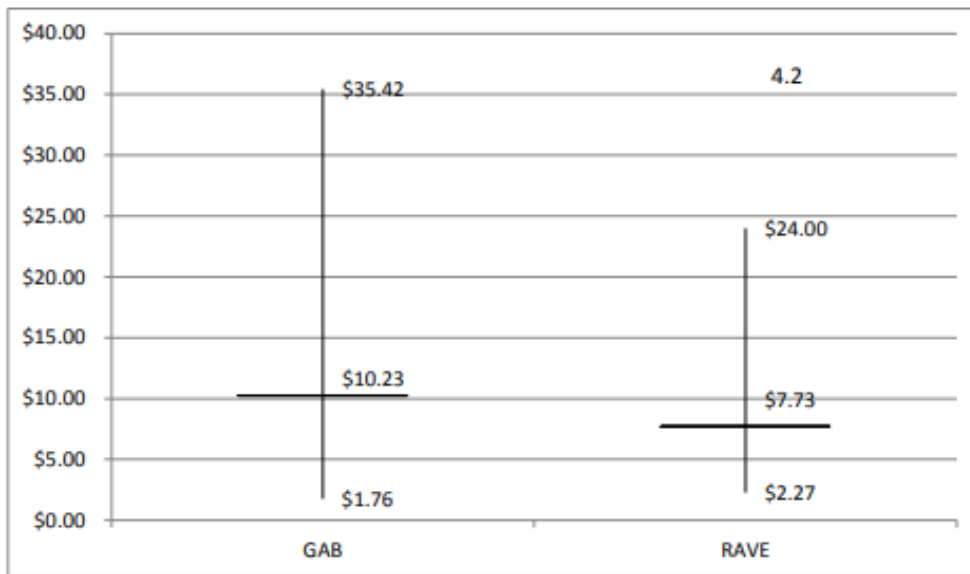


Under the LRBI Respite Expansion grant, 174 Vouchers of \$600 each were to be awarded, totaling \$104,400. As of the most recent reports from GAB and RAVE, \$103,184 had been awarded – leaving \$1,216 yet to be awarded.

GAB data shows \$68,384 in vouchers awards, with 118 families receiving vouchers. (Note: Update received 09/26/2012, GAB had 130 voucher recipients; most received full vouchers, but 7 received partial vouchers – totaling \$1784.00) With reassigned vouchers (three care recipients died before all or some of the vouchers could be used; four vouchers were reassigned for other reasons), GAB provided full or partial vouchers to families on the waiting list. These families received less than a full \$600 voucher when they indicated that they could not use the full voucher within the time remaining on the grant. So, 7 families received vouchers of varying amounts.

RAVE data shows \$34,800 in voucher awards, the equivalent of 58 vouchers, one more than originally allotted. This was permitted by ADSD to help RAVE hit our target of 13% rural residents on the project. There is no evidence that any partial vouchers were awarded by RAVE.

GAB recorded the full voucher claim amounts that clients gave, even if clients billed over their voucher amounts. Twenty-seven families submitted claims over the total \$600 available for reimbursement, so families supplemented the funds available in the voucher with their own resources. In (n=21) 78% of these cases, clients used their voucher incrementally and it may reflect an inability to keep track of how much of the voucher had already been expended. In the rest of the cases, (N=6) 22% of the caregivers used the voucher in lump sum claim.

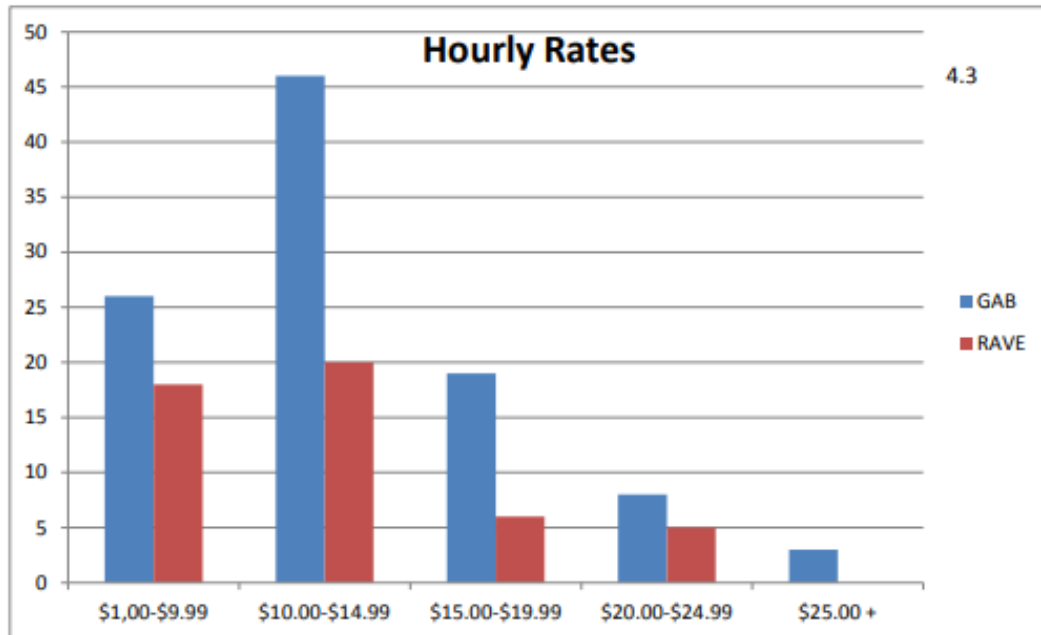


GAB voucher claims of \$58,074.51 represent 5674.75 hours of respite, at an average cost of \$10.23/hour. The range of hourly rates is between \$1.76 - \$35.42/hour.

Breakdown: \$1.00-9.99 = 2 6, \$10.00-14.99 = 46, \$15.00-19.99 = 19, \$20.00-24.99= 8, \$25.00+ = 3

RAVE voucher claims of \$26,225 represent 3392 hours of respite, at an average cost of \$7.73/hour. The range of hourly rates is between \$2.27 - \$24.00/hour.

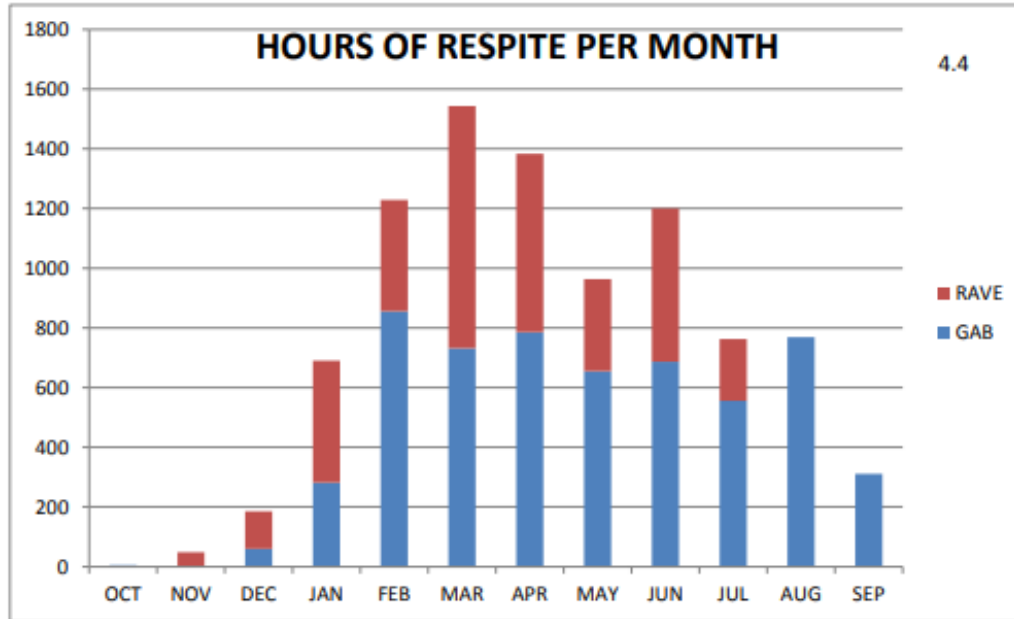
Breakdown: \$1.00-9.99 =18, \$10.00-14.99 = 20, \$15.00-19.99 = 6, \$20.00-24.99= 5, \$25.00+ = 0



Note: The LRBI Respite Expansion grant shows a cost-per-hour rate much lower than traditionally paid respite caregivers. The result is that families were able to purchase more hours of respite when they control the rate of pay.

Hours of Respite Per Month = TOTAL OF 9,088.75 HOURS OF RESPITE

Month	GAB	RAVE	TOTAL
OCT	5	0	5
NOV	0	48	48
DEC	60	125	185
JAN	282	408	690
FEB	855.75	373	1228.75
MAR	732	811	1543
APR	785.5	598	1383.5
MAY	654.5	309	963
JUN	687	513	1200
JUL	556	207	763
AUG	769	0	769
SEP	310.5	0	310.5



Below is the chart of how many voucher awards were made each month. Note: GAB made efforts to re-assign partial and unused vouchers, but RAVE’s data updates end July 31st, and does not contain information about whether or not RAVE re-assigned any vouchers.

Vouchers Awarded Per Month

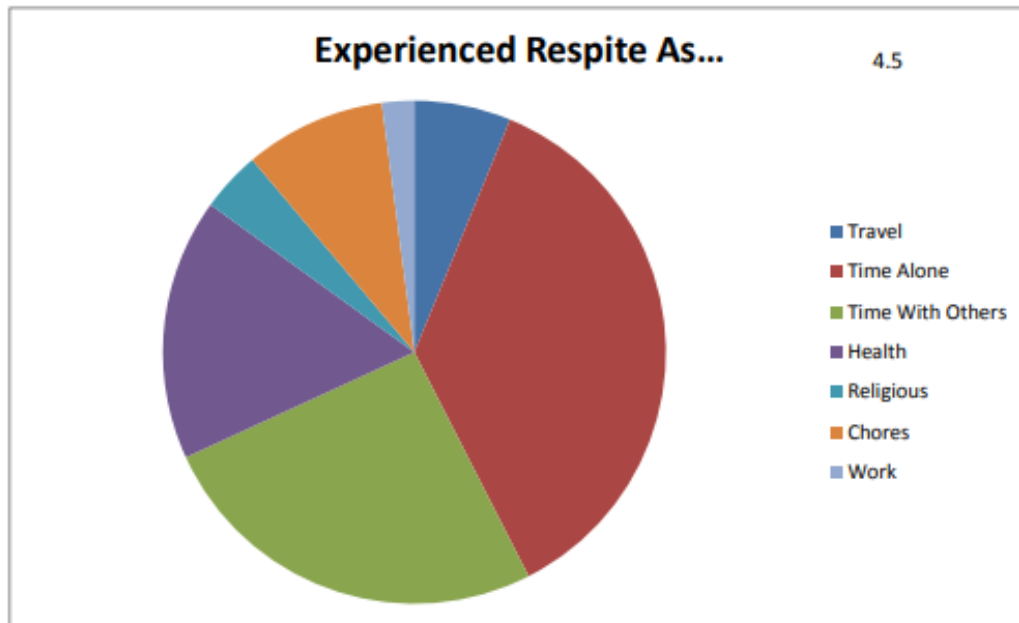
Month	GAB	RAVE	TOTAL
OCT	0	0	0
NOV	0	0	0
DEC	6	14	20
JAN	24	11	35
FEB	25	14	39
MAR	21	6	27
APR	18	5	23
MAY	2	4	6
JUN	4	3	7
JUL	5	1	6
AUG	12	0	12
SEP	1	0	1

The processing of application and awarding vouchers took at average of 28.22 days. GAB data shows an average time differential of 28.99 days; RAVE’s data was only 53% complete for application dates, but the data available shows an average time differential of 25.29 days.

Respite Time Used For

GAB Data: Travel = 14, Time Alone = 70, Time with Others=67, Health=38, Religious =11, Chores =20, Work = 5

RAVE Data: Travel = 10, Time Alone = 70, Time with Others =32, Health=27, Religious=4, Chores =15, Work =3



Post-Respite Survey

The LRBI Post-Respite Survey data is currently being collected and tabulated. It is not yet available to include in this report. The Nevada Respite Care Coalition and others interested in the additional data from the Post-Respite Survey should contact Aging & Disability Services Division for the report when it is available. The questions from the Post-Respite Survey are posted below for informational purposes.

1. Who were the people or programs who delivered respite to you under this grant? (Check all that apply)

- Family & Friends
- Neighbors & Community Members, including Volunteers from Faith-Based, Social or Service Organizations
- Volunteers/Employees from an In-Home Respite Program
- Volunteers/Employees from a Facility-Based Respite Program

Professional Care Providers from a Home Healthcare or Personal Care Service Program (Please Describe) _____

Professional Care Providers from a Day Care Program, Assisted Living, or Nursing Home Program (Please Describe) _____

Other (Please Describe) _____

2. Who would you prefer to use for respite services in the future, if the option is available? (Select One Only)

Family & Friends

Neighbors & Community Members, including Volunteers from Faith-Based, Social or Service Organizations

Volunteers/Employees from an In-Home Respite Program

Volunteers/Employees from a Facility-Based Respite Program

Professional Care Providers from a Home Healthcare or Personal Care Service Program

Professional Care Providers from a Day Care Program, Assisted Living, or Nursing Home Program

Other (Please Describe) _____

3. Regarding the use of respite services, do you feel ...? (Check all that apply)

More comfortable accepting help from others

More comfortable having respite workers provide support at home

More comfortable with respite support outside of home

That respite workers have provided competent care

That I should have used respite supports earlier

Other (Please Describe) _____

4. What was the most difficult responsibility given to you under this grant? (Select One Only)

Identifying potential respite worker/provider

Selecting a respite worker/provider

Hiring a respite worker/provider

Training a respite worker/provider

Planning/Scheduling with a respite worker/provider

Getting respite reimbursement paperwork completed/submitted

o Other (Please Describe) _____

5. Do you now have someone you know you can call on in an emergency to fill in for you as a caregiver? YES NO MAYBE

6. Have you felt a reduction in care-giving stress? YES NO

Rate your current stress level: LOW MODERATE HIGH

7. What do you do now to cope with stress related to giving care? Please Describe _____

8. How often do you now use of medication or drugs (including over-the-counter medications), smoking, or drinking alcohol to help you manage the stress of your care-giving and other responsibilities?

NEVER RARELY SOMETIMES FREQUENTLY NEARLY ALWAYS

9. I feel (Check all that apply)

- A sense of relief that someone else is available to provide care
- More confident about asking for help or assistance with care
- More balance in my life in giving care and also trying to take care of myself
- I have regained some enjoyable activities I had lost in caregiving
- I am taking better care of my own health (physically and emotionally) through respite
- Getting respite breaks was worth my time and effort in arranging them
- The quality of the care during respite was competent and adequate for our needs
- I am able to continue in my caregiving role for the foreseeable future
- That the care recipient has benefited from the interaction with the respite worker/provider
- More confident about finding/identifying/selecting a respite provider
- More confident about preparing/training a respite provider to give care
- More confident about how to use respite breaks effectively
- More convinced of the benefits received from respite

10. Has respite allowed you to spend time in the various activities that you enjoy (e.g., going to religious services, socializing with others, going out for a meal) or spend time on hobbies or activities you like to enjoy alone (e.g., reading or gardening)?

NOT AT ALL A LITTLE A LOT

11. Has the use of respite made a positive difference to you and your family? YES NO

12. How much benefit came from receiving respite services?

NOT AT ALL A LITTLE A LOT

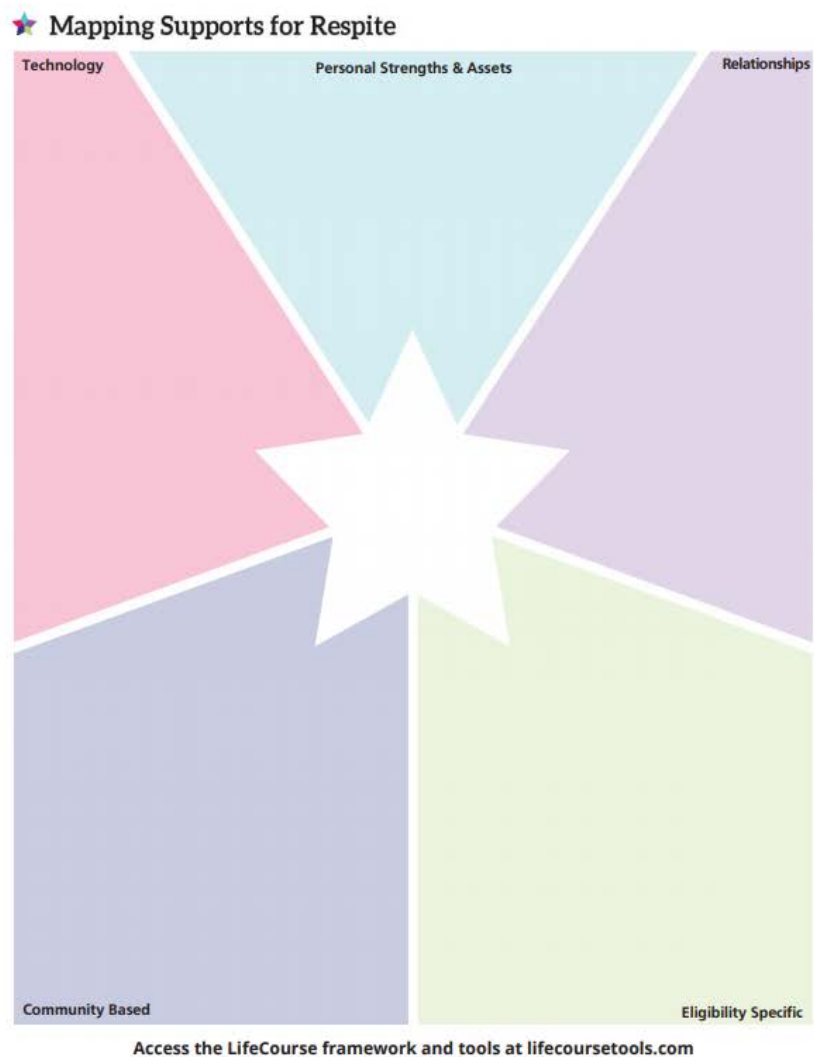
13. How critical is funding for respite to your continued use of respite supports?

NOT AT ALL A LITTLE A LOT

14. Should we have done anything else to assist you? YES NO

If YES, what would that be? Please Describe _____

Appendix B: Charting the LifeCourse Nexus- My LifeCourse Respite Portfolio



My LifeCourse Portfolio is a template of the UMKC IHD, UCEDD. More materials at lifecoursetools.com

MARCH 2017

My LifeCourse Respite Portfolio

What is going on in my life?

How would taking short breaks HELP me and the person I provide care to?

Making short breaks happen

What would I do if I had a break from caregiving?

Who would I spend time with during a break from caregiving?

What needs to be in place so I am comfortable leaving the person I am caring for?

My LifeCourse Portfolio is a template of the UMKC IHD, UCEDD. More materials at lifecoursetools.com

MARCH 2017

Respite Trajectory Worksheet

<p>What's working? Past experiences where taking a break was successful or helpful</p>	<p>What Would it Take? What would need to happen to have a positive caregiver break?</p>
<p>What's not working? Past experiences where taking a break didn't work</p>	<p>Barriers to overcome or avoid What are the barriers to taking a caregiver break?</p>



Write Age of Care Recipient Here



VISION FOR A GOOD LIFE

For the Care Recipient	VISION FOR GOOD RESPITE	For the Caregiver
------------------------	-------------------------	-------------------

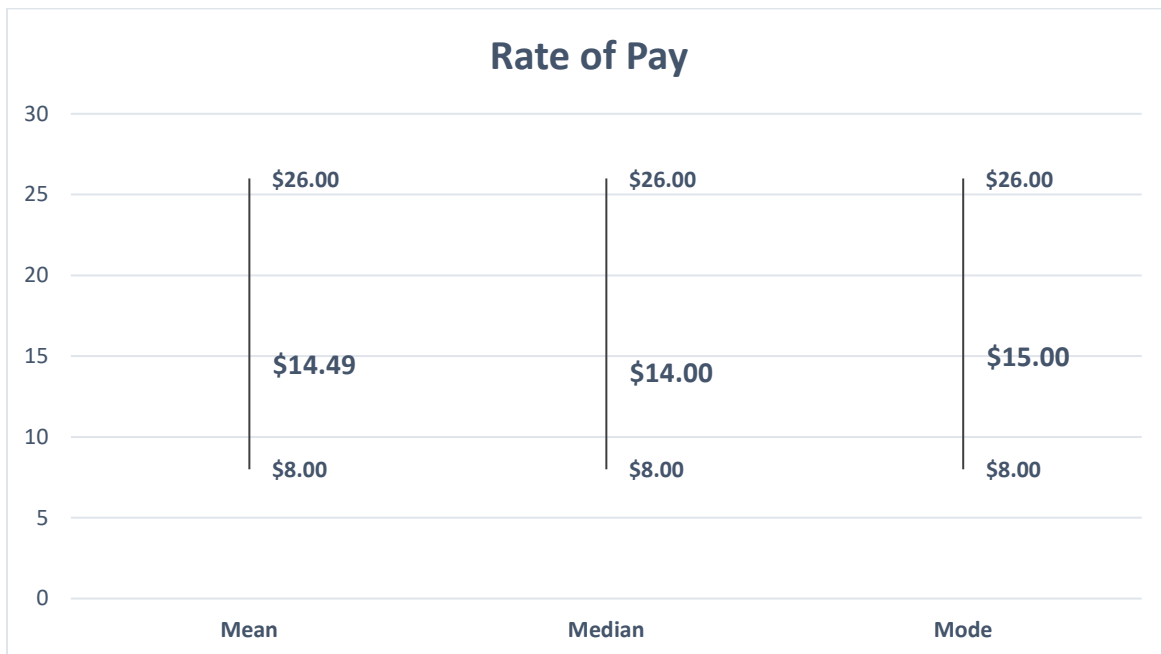
WHAT WE DON'T WANT

For the Care Recipient	NOT GOOD RESPITE	For the Caregiver
------------------------	------------------	-------------------

Appendix C: Pay for Respite Workers

Summary: Communication and coordination with an FMS agency is necessary to offer the flexibility needed in a self-directed respite program.

To determine the monthly allotment and maximum funding for caregivers participating in Respite Rx, some assumptions needed to be made. At a respite “dosage” of 2-4 hours per week for one year, an average cost per hour needed to be determined without any data resources that might suggest what caregivers could negotiate with their workers. The “predicted” average of \$15/hour was fairly accurate. The range was \$8 to \$26 per hour, with the average being \$14.49 statewide.



Getting respite workers hired and paid was another challenge, as a start date was dependent on FMS processes. Respite Rx asked that the start date included in the ADSD-approved spending plan be used for processing respite workers’ timesheets for payment, but respite workers would still not be paid until the FMS had completed enrollment, per their rules and regulations. This impacted the use of respite when caregivers did not know when respite sessions could start and lost hours of respite under “use it or lose it” policies or were embarrassed and reluctant to schedule upcoming respite sessions when workers experienced pay issues. ADSD requests for tracking updates on the status of participants and workers helped, but the updates were not conducive to quick response to caregivers on when they could start respite services or what enrollment issues needed to be resolved. Respite Rx staff could seek status updates through PALCO Customer Service, but only if a caregiver or respite worker joined the call. This became a regular case management role.

Respite Rx tried to offer flexibility that the FMS agency, unfortunately, could not support. ASD-approved Spending Plans were occasionally adjusted to accommodate caregiver requests for modification, such as pushing more funding/hours into certain months of the contract year and reducing funding/hours in other months. The FMS payroll system could not support variations in the funding amount each month. This unintentionally caused respite plan failures and difficulties in getting respite workers paid for past services rendered.

Taking the focus off “how much money do I get to spend” was also a challenge. The monthly allotment of \$308 needed to cover all payroll costs (including employer-paid taxes) so determining the number of hours of respite that would be available was a confusing process for caregivers and workers. Since there was not a “standard” rate of pay, caregivers sometimes struggled to decide if all the effort was going to be worth the benefit in respite hours. High and low estimates were given so that caregivers could help “stretch” the funding if they wanted more hours but having variables in the mathematical equation made it difficult to compare providers (with private pay rates) to hiring their own respite workers – and determining which choice would give them the most benefit.

Another issue with respite hours was that the allotments were given monthly, but the FMS agency had two pay periods each month. When caregivers hired mid-month, they had to decide if they had enough month left to use all the allotted hours available to them or wait to start the first of the following month. No one wanted to wait until the next month to start after the effort to get a worker/vendor set up. Unfortunately, getting ASD authorization, completing FMS enrollment processing, and caregivers waiting to hear when they could officially start, delayed things enough that caregivers initially lost hours under their first month of participation in the program. When they had unused hours in a month and could not rollover hours under “use it or lose it” policies, they have been understandably upset. When a worker quit or COVID restrictions happened, and caregivers could not rehire or adjust quick enough, they could also lose hours. Contracts all expired at the end of the 12th month, so some caregivers felt like their “year” was shortened. All these unexpected issues experienced during our pilot program meant that some policy details had to be worked out after we started. Revisions to the handbook were made to clarify these details.

Another recommendation would be to have respite invoices from vendors and timesheets from respite workers routed through (or copied to) ASD for tracking purposes. Instead of being the last to find out about expended funds, ASD should know what invoices are pending for FMS payment and that respite hours are being regularly used by participants. Errors in paperwork submissions could be caught earlier and prevent FMS payroll delays. During the grant, ASD experienced significant delays in receiving FMS invoices with documentation. Being able to match reimbursement and fee invoices from the FMS with records that ASD already knew were pending would allow for more accurate fiscal grant management and program projections.

To improve communication with ADSD and caregivers, the FMS agency should be required to send email confirmation about any change in status of a caregiver/employer, their vendors/workers, and include an effective date. This information would be valuable in improving program response time to caregiver and worker inquiries about their status.

Administrative and FMS Process

Caregivers were the employers-of-record and could hire (and fire) anyone of their choosing (workers had to be aged 18+ and eligible to work in the USA). Caregivers would negotiate the rate of pay with the worker they selected. They could also choose to use an existing respite provider and pay the hourly rate the provider charged. Caregivers could employ up-to 2 different workers/providers under their contract, to split hours or provide backup as needed.

Timesheets for respite services were submitted directly to the FMS agency for payroll processing. Biweekly payroll cycles were paid out against the funding limit of the caregiver/employer's contract. Nevada Aging & Disability Services Division reimbursed the FMS agency for these expenses.

The FMS charged a monthly fee per participant for the service, and the respite workers hired were listed as employees for payroll purposes. Respite provider agencies were engaged as vendors (selected by program participants) and compensated in the same pay cycles. The FMS performed background checks on workers for an additional fee. The FMS enrollment packets for the caregivers (employers) and respite worker (employee) packets were submitted together so the associated fees were charged to the appropriate months of respite utilization. Payroll tax withholding and payment were handled by the FMS. The background checks and monthly FMS service fees were also paid out of the grant funds. The actual number of respite hours each caregiver would receive varied, based on the rate of pay for the worker/provider they selected.

FMS Reimbursement Process

FMS provided invoice, supporting documents such as timesheet submitted by employer/employee and a breakdown of hours used, taxes charged, and totals for each pay period.

Program staff would review, ensure invoice and supporting documents were accurate and matched to be processed and paid. Internal reconciliation was completed once a month to ensure all payments were processed and paid.

The most challenging piece of reconciliation and ensuring workers were paid accurately was when ADSD would receive invoices for timesheets submitted anywhere from previous pay period up to six months back. Program staff ensured the past invoices were not duplicates before processing. The FMS indicated that in these instances, employers or employees would submit timesheets late.

Appendix D: Respite Rx Spending Plan Form

Respite Rx
Respite Spending Plan
 Check if Adjusted

Participant Number: _____	Caregiver/Employer: _____	Surrogate Employer (if app): _____
Service Plan Date: _____	ADSD Approved Budget: _____	Caregiver/Employer Phone Number: _____
Program Coordinator (PC): _____	PC Phone Number: _____	PC Email: _____

Respite Goals and Objectives

Goals	Objectives

Planned Individual Employee Services

Service	Employee	Start Date	Frequency	Rate of Pay	Units (Per Month)	Total
Respite	NAME: _____		monthly			
Total IP Services						

Planned Non-Employee Goods/Services

Service	Vendor	Start Date	Unit Cost	Units (Per Month)	Total
Total Non-Employee Goods/Services					

One-Time or Planned Savings

Items	Vendor	Estimated Cost	Start Date	Month to Save	Cost Per Month
Background Check (# of Employees=)					
Total One-Time or Planned Savings					

Caregiver/Employer (or Surrogate): _____ Date: _____ ADSD Program Coordinator: _____ Date: _____ ADSD Authorization: _____ Approved Date: _____	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td>Total IP Services</td><td> </td></tr> <tr><td>Total Non-Employee Goods/Services</td><td> </td></tr> <tr><td>Total One-Time or Planned Savings</td><td> </td></tr> <tr><td>Estimated Emergency Back-Up Fund</td><td> </td></tr> <tr><td>Month Total</td><td>308.00</td></tr> </table>	Total IP Services		Total Non-Employee Goods/Services		Total One-Time or Planned Savings		Estimated Emergency Back-Up Fund		Month Total	308.00
Total IP Services											
Total Non-Employee Goods/Services											
Total One-Time or Planned Savings											
Estimated Emergency Back-Up Fund											
Month Total	308.00										

Appendix E: Hiring Respite Workers

Hiring & Training Your Respite Provider

❖ Choosing a Respite Provider

Primary Caregivers are responsible for choosing their own respite worker/provider. They can hire friends or family, professionals, or non-professionals. The respite worker must be 18 years of age or older and not living in the same household. Each respite worker hired is a separate contract employee, but you can hire/use as many respite workers as you like. Consider emergency respite needs as well.

Remember, Respite Care is a temporary service, and can have an intermittent schedule.

❖ Use the telephone to save time and provide safety. Use phone screening to:

- Discuss important point about job and discuss money and hours.
- Get first impressions as you find out more about who they are.
- Let them know that you always do a criminal background check.
- If acceptable, set up a time to conduct a formal interview in person.
- Use a location other than your home for the initial face-to-face interview.

❖ Meeting Potential Respite Workers

- Be friendly and try to make the situation as comfortable as possible.
- Provide a job description and explain the disability of your loved one.
- Ask about jobs they currently have or had in the past, and what they like/dislike about work.
- Ask for two work references and one personal reference that you can contact.
- Check that they have reliable transportation, and if getting to work on time is a problem.
- **Do not hire** without checking references first! Let them know when you will decide.

About the Background Check –

This is included in the payroll services secured for this program, for up to two respite workers that you hire. Additional hires may incur fees for background checks performed by PALCO. Background checks may take a few weeks to complete; PALCO will notify you upon completion.

❖ Training of Respite Workers

- Explain technical words you use and emphasize issues of safety. Make sure they know how to respond appropriately to emergencies.
- Give step-by-step instructions for any procedures your respite worker needs to know, emphasizing any procedure that needs to be done in a certain way.
- Never assume they just know what you mean. Have them explain it to you in their own words to check for understanding.
- Be patient and give each respite worker the time they need to learn the routine. Use the services of others to help with the training process.
- Try to be aware of their feelings as you train. Do not correct or confront a respite worker in front of others.

❖ Terminating a Respite Worker

- If it is necessary to dismiss a respite worker, state your reasons clearly, face-to-face, without verbally attacking the provider.
- Do not withhold payment for services for any reason. If dissatisfied, simply dismiss and authorize any final payment owed to the respite provider.

Respite Rx Program

Intake/ Application Form

Providing care for someone can be incredibly challenging on many levels. Between managing prescriptions, budgeting, scheduling appointments and the countless responsibilities in-between, providing care can quickly become overwhelming and stressful. Do not forget to take care of yourself so you can take care of others. Find time to relax, do something you enjoy, sleep or find other ways to reduce stress. This precious time is called RESPITE!

I first heard about the Respite Rx Project from: _____

Caregiver Intake

Name: _____		<input type="checkbox"/> Male <input type="checkbox"/> Female	
Date of Birth: _____	Phone: (____) _____	Email: _____	
Physical Address: _____		Mailing Address: _____	
<input type="checkbox"/> Ok to Email <input type="checkbox"/> Ok to Text to phone			

Caregiver Demographics

Ethnicity:		Household Income: _____	
<input type="checkbox"/> Hispanic or Latino		<input type="checkbox"/> Below Poverty <input type="checkbox"/> Above Poverty	
<input type="checkbox"/> Non-Hispanic or Non-Latino		<input type="checkbox"/> Below 300% SSI <input type="checkbox"/> Above 300% SSI	
Race:		Do you live alone? <input type="checkbox"/> Yes <input type="checkbox"/> No	
<input type="checkbox"/> White, Caucasian		Are you disabled? <input type="checkbox"/> Yes <input type="checkbox"/> No	
<input type="checkbox"/> American Indian/Alaskan		Are you frail? <input type="checkbox"/> Yes <input type="checkbox"/> No	
<input type="checkbox"/> Native Hawaiian or Pacific Islander		Are you homebound? <input type="checkbox"/> Yes <input type="checkbox"/> No	
<input type="checkbox"/> Asian		Are you employed? <input type="checkbox"/> Yes <input type="checkbox"/> No	
<input type="checkbox"/> Black/ African American		_____ # Hours Per Week	
<input type="checkbox"/> Hispanic			
<input type="checkbox"/> Other			
Activities of Daily Living (ADLS)		Instrumental Activities of Daily Living (IADLS)	
Without assistance, I am unable to:		Without assistance, I am unable to:	
<input type="checkbox"/> Bathe		<input type="checkbox"/> Prepare Meals	
<input type="checkbox"/> Get Dressed		<input type="checkbox"/> Do Light Housework	
<input type="checkbox"/> Eat		<input type="checkbox"/> Take Medication	
<input type="checkbox"/> Use the Bathroom		<input type="checkbox"/> Do Heavy Housework	
<input type="checkbox"/> Walk		<input type="checkbox"/> Manage Money	
<input type="checkbox"/> Transfer In or Out of a Bed or Chair		<input type="checkbox"/> Use the Telephone	
<input type="checkbox"/> N/A - I can perform all		<input type="checkbox"/> Shop	
		<input type="checkbox"/> Use Transportation Services	
<input type="checkbox"/> N/A - I can perform all			
Have you served in the U.S. military?			
<input type="checkbox"/> Yes <input type="checkbox"/> No			
Special Accommodations			
To get services for Respite Rx, applicants will have contact with the Program Coordinator by phone or in person.			
Do you have a physical or mental condition that requires special accommodations during this program? <input type="checkbox"/> Yes <input type="checkbox"/> No			
Do you speak English? <input type="checkbox"/> Yes <input type="checkbox"/> No If NO, what language do you speak? _____			
Do you need an interpreter? <input type="checkbox"/> Yes <input type="checkbox"/> No			

Caregiving Information

Please select the choice that best reflects your role as a caregiver.

- Yes, provides *care regularly*. (Refer to respite)
 - Yes, provides assistance *occasionally, or as requested*. (Refer to respite)
 - No, does not provide support at a distance, due to not being physically present to provide assistance.
 - No, does not personally provided any assistance, but knows he/she has a need for some support.
 - No, does not personally provided any assistance, but has an increasing concern about his/her ability to manage things without help.
 - No, currently does not provide any type of direct care, support, or assistance.
 - None of the above. Statement (optional):
-

How long have you been giving extra care and assistance to the person in your care? Give an approximate length of time.

- Initial Request
 - < 1 year
 - 1-5 years
 - 6-10 years
 - > 10 years
-

How has giving care or assistance impacted your life? Please select all statements that apply.

- The care recipient is now living in my home, so I can provide care.
 - I now live in the care recipient's home, so I can provide care.
 - I often or regularly go to the care recipient's home to provide care, as I do not live with the care recipient.
 - I live in rural or frontier areas of Nevada where resources are limited.
 - I am providing support at a distance, so it's difficult to arrange.
 - I have taken leave from work or reduced hours at work to meet their needs or provide care.
 - I have felt worried, anxious or depressed since I began to provide care or support.
 - The demands of care giving are increasing, and I am struggling to meet them.
 - The care recipient cannot be safely left alone for extended periods of time.
 - Other (explain):
-

What tasks do you perform in giving care? Select all that apply.

- Transportation
 - Personal Care
 - Financial Management/Assistance
 - Other, please specify:
 - Shopping
 - Medical (medication administration, etc.)
 - Overall Management
-

Are you providing care to more than one person? (i.e. children, grandchildren, and/or other adults?) Yes No

If yes, give the ages of all the people you provide care to:

- 0-3
 - 4-17
 - 18-24
 - 25-39
 - 40-64
 - > 65
-

Caregiver Burden Interview

Do you feel...?	Never (0)	Rarely (1)	Sometimes (2)	Quite Frequently (3)	Nearly Always (4)
That because of your time you spend with your relative that you don't have enough time for yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Stressed between caring for your relative and trying to meet other responsibilities (work/family)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Irritated when you are around your relative?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
That your relative currently affects your relationship with family members or friends in a negative way?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
That your health has suffered because of your involvement with your relative?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
That you don't have as much privacy as you would like because of your relative?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
That your social life has suffered because you are caring for your relative?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
That you have lost control of your life since your relative's illness?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Uncertain about what to do about your relative?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You should be doing more for your relative?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You could do a better job in caring for your relative?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Caregiver Needs

What specific concerns do you have about caregiving?

Thinking of your own needs, what would help the most? (select all that apply)

- Good information about resources and services available.
- Advice from other caregivers, gathered from their experiences.
- Regular or temporary breaks from care giving role.
- Extra assistance or help so you can provide the care needed.
- Training so you can provide better care.
- Strategies to make your care giving easier.
- Other (please specify):

How likely would YOU be to use Respite?

- Extremely likely
- Very likely
- Moderately likely
- Slightly likely
- Not at all likely

If not likely, why not?

Respite Usage

Are you currently receiving any respite services? <input type="checkbox"/> Yes <input type="checkbox"/> No If yes, please provide more information (how frequent, who is paying for it, who provides the respite, etc.): _____				
Why are you interested in the Respite Rx? (select all that apply)				
<input type="checkbox"/> Choice/Flexibility	<input type="checkbox"/> In-Home Care	<input type="checkbox"/> After Hours Care	<input type="checkbox"/> Emergency	<input type="checkbox"/> Other
How many hours per week of respite would be ideal to have? _____				
Will you be using the voucher for a planned, larger respite purchase? (i.e. summer camp) <input type="checkbox"/> Yes <input type="checkbox"/> No If yes, when is the respite? _____ How much will it cost? _____				



Care Recipient

Person in your Care

Enrolled w/ ADRC: Yes No

Name: _____ Age: _____ Gender: <input type="checkbox"/> Female <input type="checkbox"/> Male Relationship to person in your care: _____	Veteran Status: <input type="checkbox"/> None <input type="checkbox"/> Veteran <input type="checkbox"/> Disabled Veteran <input type="checkbox"/> Veteran Dependent
Ethnicity: <input type="checkbox"/> Hispanic/Latino <input type="checkbox"/> Not Hispanic/Latino	
Primary Diagnosis of Care Recipient: _____	
Does he/she have a diagnosed dementia (i.e. Alzheimer's, dementia, Vascular dementia, etc.)? <input type="checkbox"/> Yes <input type="checkbox"/> No Specify diagnosis: _____ <i>If yes, what stage of dementia?</i> <input type="checkbox"/> Early <input type="checkbox"/> Mild/Middle <input type="checkbox"/> Severe <input type="checkbox"/> Unknown <i>If no, are you concerned about dementia or a memory impairment?</i> <input type="checkbox"/> Yes <input type="checkbox"/> No	
Assistance/Supervision Needed (Check all that apply):	
<input type="checkbox"/> Bathing & Hygiene <input type="checkbox"/> Eating or feeding <input type="checkbox"/> Standing or Walking <input type="checkbox"/> Medication reminders <input type="checkbox"/> Communication/Coordination <input type="checkbox"/> Manage Finances/Pay Bills	<input type="checkbox"/> Dressing & Grooming <input type="checkbox"/> Meal Preparation <input type="checkbox"/> Social/Recreation <input type="checkbox"/> Medical care (medication administration) <input type="checkbox"/> Behavioral Support <input type="checkbox"/> Shopping
<input type="checkbox"/> Toileting/Bladder Care <input type="checkbox"/> Transfers In/Out <input type="checkbox"/> Give/Arrange Transportation <input type="checkbox"/> Decisions/Advocacy <input type="checkbox"/> Light Housekeeping/Chores <input type="checkbox"/> General supervision	

Intake Notes & Referrals Made

<input type="checkbox"/> Care Consultation (ongoing caregiver support)	<input type="checkbox"/> Emergency Respite Voucher
<input type="checkbox"/> CarePRO (Alzheimer's caregiver skills building)	<input type="checkbox"/> Respite (provider: _____)
<input type="checkbox"/> EPIC (early stage Alzheimer's education and training)	<input type="checkbox"/> Caregiver Training (REST, Online, etc.)
<input type="checkbox"/> CDSME (provider: _____)	<input type="checkbox"/> Other, specify: _____
Notes: _____	Resource Center Contact (Name & Number): _____

Intake Application can be submitted via email or regular mail. Send completed application to:

Nevada Aging and Disability Services Division
 Attn: Wendy Thornley
 3416 Goni Road, D-132
 Carson City, NV 89706
 Email: wthornley@adsd.nv.gov

Please NOTE: In subject line of email- Respite Rx- (Last Name of Caregiver) and please provide a brief summary of anything you think may be pertinent or important for Program coordinator to be aware of.

Please Read and Initial Each Statement Below:

_____ I attest that the information included in this application is true and complete. I understand that any falsification of information will result in the termination of services.

_____ I attest that I have read and understand the Respite Rx Project policies and procedures. I agree to abide by the guidelines and provisions set forth. I understand my signature below authorizes a release of information, for program purposes only.

_____ I understand the use of all funds available to me through the Respite Rx Project is to compensate respite workers or respite programs for respite services that have been provided to me during the grant period. I understand that these funds cannot be used for any other purpose. I am also responsible for any respite service charge over the voucher limit I am awarded.

_____ I acknowledge that I am responsible for hiring the respite worker(s) of my choice and am responsible for negotiating the rate of pay for respite services I acquire. I understand that I am also responsible to provide any training or instruction that the respite worker(s) of my choice may need to provide care.

_____ I will sign and submit respite timesheets promptly, and budget authority will end on July 31, 2020. Any unspent portion of my respite voucher budget can be forfeited if I have not made prior arrangements for my planned use of voucher funds.

_____ I agree to regular program monitoring and will complete and return the required surveys and assessments. I also understand that the Respite Rx Project is a pilot program only, and no continuation of respite services under this program will extend beyond the grant period.

Nevada Aging & Disability Services Division and the Respite Rx Project will operate the grant program that provides funding to pay for respite services but will not be providing those services directly or indirectly. The applicant recognizes and agrees that these entities are not liable for any damages that may result from the services received and holds them harmless from the same.

Applicant (Caregiver) Signature

Date

ADRC Verbal consent done by: _____ Date: _____

OFFICE USE ONLY - Please do not write in this box

Received: _____ **Priority Rating:** _____ **FMS Date Processed:** _____ **PALCO ID#:** _____

Pre-Respite Survey completed on: _____ Approval/ Letter Sent on: _____

Respite Design scheduled on: _____

Recruitment Plan

Job Description needed/ completed on: _____ Job Description approved by caregiver on: _____

PALCO Paperwork review and paperwork Sent on: _____ Spending Plan finalized on: _____

Paperwork sent to ADSD for approval on _____ Paperwork submitted to PALCO on: _____

Background requested: Y or N

Appendix G: Risk Assessment & Agreement



Respite Rx
Risk Assessment & Agreement

Caregiver Name:	Date:
Program Coordinator:	

Description of Service Change Being Considered:
Options Discussed:
Potential Risks:

I, _____, have discussed the potential risks and understand there are other service options that may help to reduce or eliminate those risks. I take full responsibility for my choice to pursue the following options:

Caregiver Signature: _____ Date: _____

Program Coordinator Signature: _____ Date: _____

Distribution: ADSD Caregiver File, Respite Rx, Caregiver

Appendix H: Sample Job Postings

The following are a few examples of job posting creating for Respite Rx participants:

Reno Caregiver needs assistance! Man in 50's needs companion care, mobility assistance, light housekeeping, and way to go shopping 2 blocks away with transportation and assistance. Some speech/memory games, and light meal prep on occasion. Mornings best before heat of the day, flexible schedule, 3-4 hour session weekly. Great part-time job, \$12-15/hr.

Reno Caregiver needs assistance! Senior husband would like to read on Kindle, access email, and use cellphone but needs to relearn how to do so. Has a weak side and trouble with speech & balance. Loves to get outside, hear about current events, and have meals heated and served. Companion care for safety and conversation. Spanish-speaking family. Needs respite Friday afternoon or Saturday morning, 4 hours per week. Great part-time job! Pays \$10-12/hr.

Caregiver in Boulder City 89005 needs respite! Active older man with TBI was an avid golfer and traveler, but now stays close to home. Takes care of dog but needs some mobility assistance due to fall risk. Need early morning monitoring/prep daily meds for an hour, plus 2-hour evening visit for dinner, meds monitoring, and companionship. Meal prep, cooking, and meal cleanup of dinner required. Great part-time job! Hiring for 3-4 days per month, Friday-Monday. Pays \$15-20/hour.

Henderson 89052 Caregiver needs Respite! Senior woman loves to participate in arts & craft activities, song & dance, and loves to clean but needs to be reminded how to do so. Needs exercise and reminders to groom and dress appropriately. Quieter, calming influence needed when anxious. Big friendly dogs in home. Great part-time job on flexible weekdays, 3-4 hours per day, twice a week. Pays \$10-12/hour.

LV 89144 Caregiver needs rest! Wife is up all hours of the day & night. Need a night owl who can give calming care and talk her back into bed. Companion care to walk & talk with her and keep her safe at night. Quiet activities like reading if she's in bed. Looking for one night of uninterrupted sleep per week, at least a 4-hour block. Pays \$12-15/hour.

Caregiver in Gardnerville needs respite! Older couple needs assistance with tube feeding and mobility, training provided. Couple enjoys fantasy sports, game shows, and bible study. Occasionally, young granddaughter will also need a friend to do puzzles with. Great part time job, flexible schedule, pays \$10-12/hour, for non-smoker who loves dogs. Afternoons from 1-3pm preferred, twice a week, for 2-3 hour sessions.

Caregiver in Yerington needs respite! Older couple needs assistance but still like to do things their way. Husband loves old western shows, needs loud voice for hearing, and some assistance with mobility, blood sugar, and hydration (training provided). Wife wants someone to talk to, assistance with light housekeeping and meal prep. Would love hair/nails done to look nice. Friendly dogs in home. Great part time job! Weekend sessions for 3-4 hours/day, flexible, prefer Sunday mornings. Pays \$10-\$12/hour.

Henderson 89074 Caregiver looking for respite. Easygoing elderly woman needs companion and care on Sat and/or Sun mornings, to assist with shower, dressing & grooming to look nice. Hard of hearing. Two small friendly dogs in home. Require non-smoker with strong voice. Great part-time job! Pays \$12-15/hr.

LV 89123 Caregiver needs respite. Older woman loves to eat, Elvis & Beatles music, and coloring but gets easily confused. Needs companion who can assist with shower and meal prep. Have pets in home. Great part-time job! Late mornings, 2-3 hour sessions twice per week, Sun/Mon/Tue preferred. Prefer non-smoker. Pays \$12-14/hr.

LV 89121 Caregiver needs respite care for 2 people! Companion care and assistance needed. Husband 60s loves watching sports but needs help getting things. Sister 50s loves to visit but needs assistance with light chores and cooking. Pay \$12-15/hour for 2-3 hours sessions, 1-2 times per week.

Appendix I: Caregiver Recognition Honoree Stories 2020

The following are a few examples of caregiver recognition summaries provided at the Caregiver Recognition Summit:

J. F. – Reno

J. F. made a life-changing decision about her daughter's life, choosing to become a fulltime caregiver for her daughter when others encouraged selecting a lifetime of institutional care. J. F.'s daughter has Rett Syndrome and has struggled with medical conditions her whole life. Now, after 26 years of 24/7 care, J. F. claims caregiving gives her "dharma" – a true purpose to her own life. This past year has been especially difficult, when her daughter's gallbladder surgery developed complications and resulted in hospitalization with sepsis and pneumonia when hospitals were the last place anyone wanted to be with COVID-19 spreading. Being a caregiver fulltime is rough, and J. F. used to rely on some relief from a day program that shutdown amidst the COVID pandemic. With a medically fragile daughter, J. F. is grateful for a few hours of relief from a program that is understaffed and overworked, great neighbors, an understanding boyfriend (who has been a caregiver himself), and a place to live – thanks to her own mother. J. F. served as her mother's caregiver – during the last 20 months of her 95-year-old mother's life. While caring for two may have called for superhuman endurance, it taught J. F. that she is "stronger than you think." As a caregiver, she certainly qualifies as a Wonder Woman!

S. O.– Winnemucca

S. O. knows the toll Alzheimer's has taken on both her and her mom. She cannot call her "Mom" because Mom does not remember their familial relationship anymore, and it upsets her. Mom does say they are "Best Friends" and thanks her daughter every day for letting her stay there with her. Emotionally this is hard, but S. O. deals with her mom where Mom's memory takes her. One day Mom is a 5-year-old girl just starting at school, so S. O. adapts to tell Mom that she is getting good grades and does a wonderful job coloring. S. O. used to take her mom to a community respite program, but it shut down – S. O. was the only one utilizing it. S. O. realizes that to take care of Mom, she also needs to take care of herself, but she cannot go to her own doctor's appointment without taking Mom along and fearing the COVID risks. Depression sometimes cloud the days, but S. O. keeps moving forward. She provides a helping hand when Mom refused the walker and tries not to complain about providing care while her siblings continue to work, volunteer, take trips, and call to give her advice. While smiling and singing along with Mom, watching the only movie Mom will watch (Seven Brides for Seven Brothers), S. O. represents the type of loving caregiver we all would hope to have. No doubt that we would be grateful too!

J. O. – Cold Springs

J. O. is a compound caregiver, caring for her stepmother who needs oxygen and pain management for her health conditions, and her husband who is disabled due to an accident. With their health challenges and a COVID pandemic, she has not been able to even hug her son or go to the stores to shop without concerns about bringing viruses home to them. She has

learned how to shop at stores with pick-up/delivery service, and only visits stores that enforce a mask mandate for employees and shoppers. She grits her teeth at doctor's requests to see her stepmom in person, when office staff openly admit that the waiting room is wiped down only once a day. So, they stand in the waiting room until they can get moved to a patient room that is wiped down after each visitor. Recently, wildfires caused evacuation warnings in her neighborhood. As she quickly gathered supplies, medicines, and made plans for getting them all in the vehicle to leave, she hit a snag. How was she going to get the heavy oxygen concentrator downstairs and into the vehicle with them? Just another life-or-death decision she makes on a regular basis. The reality is that if anything happens to Jenna, they will all be "out on a limb." Putting others first makes J. O. an extraordinary caregiver and worthy of recognition!

S. P. – Gardnerville

It takes a village. S. P.'s parents moved in with her and her family 2 years ago. Dad's health and Mom's stroke had left them unable to care for one another. S. P. welcomed them into her life, but the duties entailed kept her close at home and had her assisting with tube feedings every 2-3 hours. A granddaughter also comes frequently into her care as well. Juggling care demands, meals, and keeping the house clean makes S. P. feel like a Cinderella. Even though she is working under less than ideal circumstances, she would not have it any other way. Sadly, after 60 years of marriage to his dear wife, Dad recently passed away. Now Mom is numb, and S. P. feels the void in her life as well. How does she keep her own marriage strong? By making time to take walks in the park with her husband, to enjoy a moment of sunshine out of doors. S. P. soldiers on in giving care, knowing she has also been "aged" by the experience of caregiving. With the support of family and friends, she is determined to "keep on keeping on." Somehow, she manages to make it all work!

N. B. – Sparks

"Mi casa es su casa." N. B. is a compound caregiver trying to work and care for her father with Alzheimer's and her sister with Downs Syndrome. When N. B.'s mom died, N. B. brought her sister back to live with her. N. B. had already worked as a professional caregiver for 7 years in nursing homes and realized she did not want anyone in her family to be dependent on care in a setting where they could not have the necessary care and attention they needed and deserved. Dad was retired and living in Lima, Peru, but when he started needing more help, the family sent him to the United States to live with N. B. as well. N. B. found she could not work for someone else and take care of both her dad and sister at home. So, she became what they needed. She opened her own home-based care agency, and with the help of her employees, N. B. can manage their care and help take care of her clients and their families as well. She loves her work and is grateful for the opportunity to be the caregiver she feels everyone deserves to have. That selflessness is why N. B. is being recognized as an exemplary caregiver.

S. S. – Nixon

S. S. has been a caregiver for several years as she cares for her dad in Nixon while he deals with complications of glaucoma, diabetes, and kidney disease. As a Native American, she sees caregiving as a community responsibility as they all strive to honor their tribal elders. So, she naturally stepped in to provide any support needs her father might have, although it has been

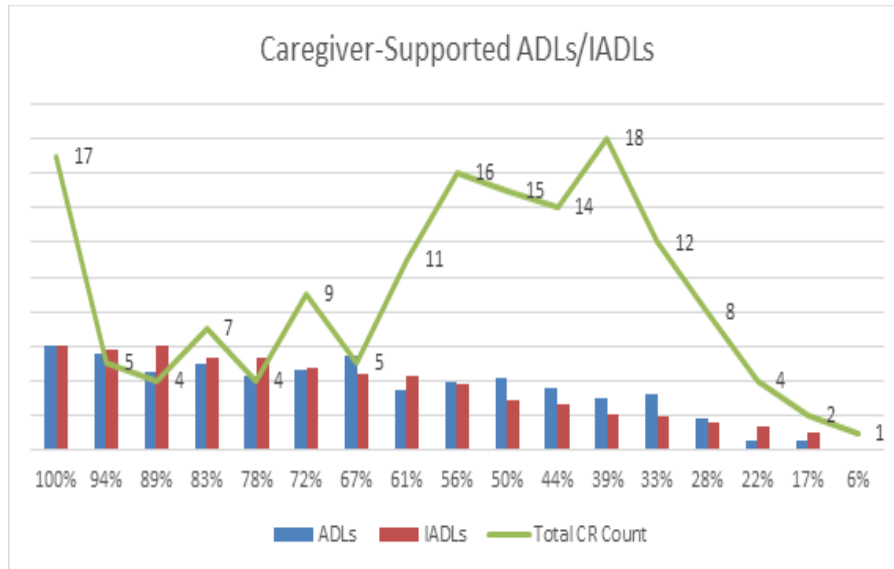
stressful to care for a relative living 75 miles away from her own home, while also trying to meet her other responsibilities. She would dearly love to have more time to spend at her own house, but as a tribal elder, her dad's role (even at 91 years of age) is to share stories and history about the tribe and the Nixon area. Taking him away to her home would prevent him from doing that. So, she monitors her own house through the property cameras she has placed, and quips that she can look at her home anytime, but she just cannot go there! An occasional run home gives her time to check on the house and grab her mail. But seeing her father, sitting on his porch, watching the breeze play across his field of alfalfa, fills her with pride and makes all her dedication worth it!

D. W. - Yerington

Yerington would be hard for most Nevadans to find on a map, but D. W. calls this home. His parents have lived here for 52 years. Dad is a World War II veteran, diabetic, with prostate & bone cancer, and bedridden. Mom has tried to provide for Dad's care, but she has had a heart attack, and is also diabetic with COPD. Mom's mobility has increasingly limited her abilities too. In 2018, D. W. found himself and his wife living with Mom & Dad so he could "help" Mom provide care. D. W. has EMT training, so he was the right "fit" for the job. But when care for Dad caused mother and son to not see eye-to-eye, Mom would get combative, insisting that things be done her way. So, D. W. works hard to get her agreement on anything so they can move forward. That is just part of the battle! Finding things like a Hoyer lift and other supports in rural Nevada, where resources are limited, can be challenging, too. D. W. found that caring for them both left him with little time for himself. So, when D. W. developed hernias and other health issues, he pushed off surgeries and self-care for as long as he could. Just recently, his dad passed away – at 98 years of age. D. W. now mourns with Mom, who feels bereft and useless right now, while he can focus his attention to his own health and recovery. Mom still needs him, more than ever, and D. W. sees eye-to-eye with her on that!

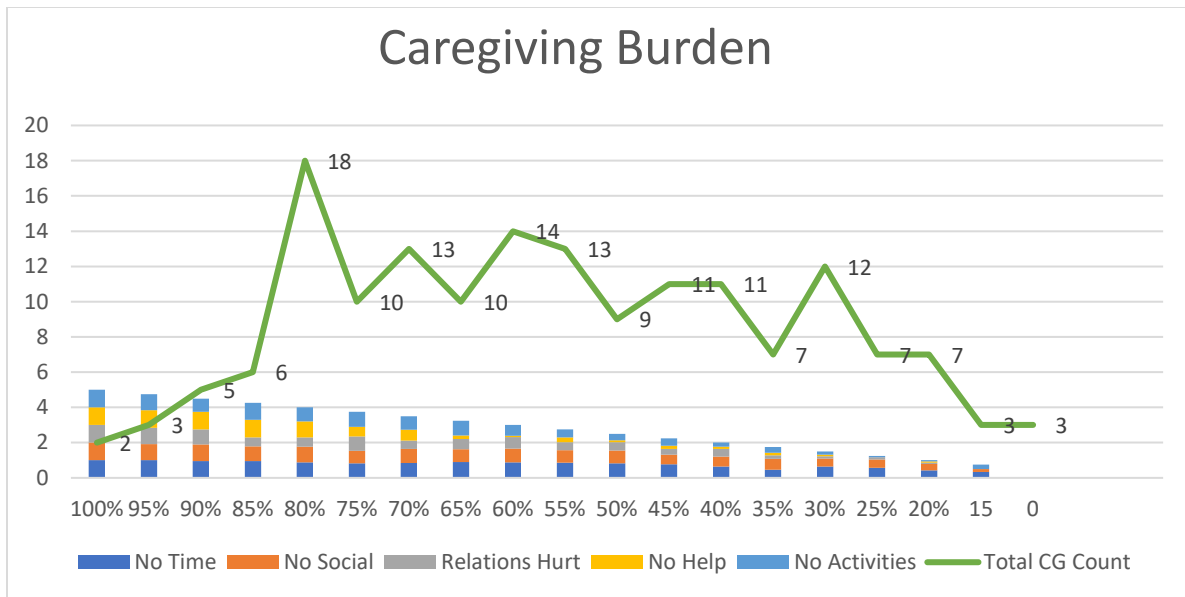
Appendix J: Caregiver Burden

Summary: Demand for respite increased as care required greater sacrifices from caregivers, by taking more & more time away from self, time with family & friends, and time for enjoyable activities.



Caregivers seek respite (the green line on the chart below) when care levels for Activities of Daily Living & Instrumental Activities of Daily Living are relatively low – as indicated by the red & blue bars along the bottom of the chart. The peak demand for respite was when 39% of the Care Recipient’s ADLs/IADLs now require assistance. Caregivers already felt the impact of these care demands.

The following chart reflects the “care burden” placed on the shoulders of caregivers. The impact of caregiving on the life of the caregiver shows a more consistent need for respite (on an upward trend), when caregiving takes away more & more time for self, time with family & friends, and time for enjoyable activities that would refresh & revive them. The bars on the bottom show the impact of no time for self, no social connections, no help with care, no choice in activities, and seeing relationships hurt because of caregiving demands.



This is consistent with the longings expressed in the Respite Design sessions with participants when they were asked the following questions:

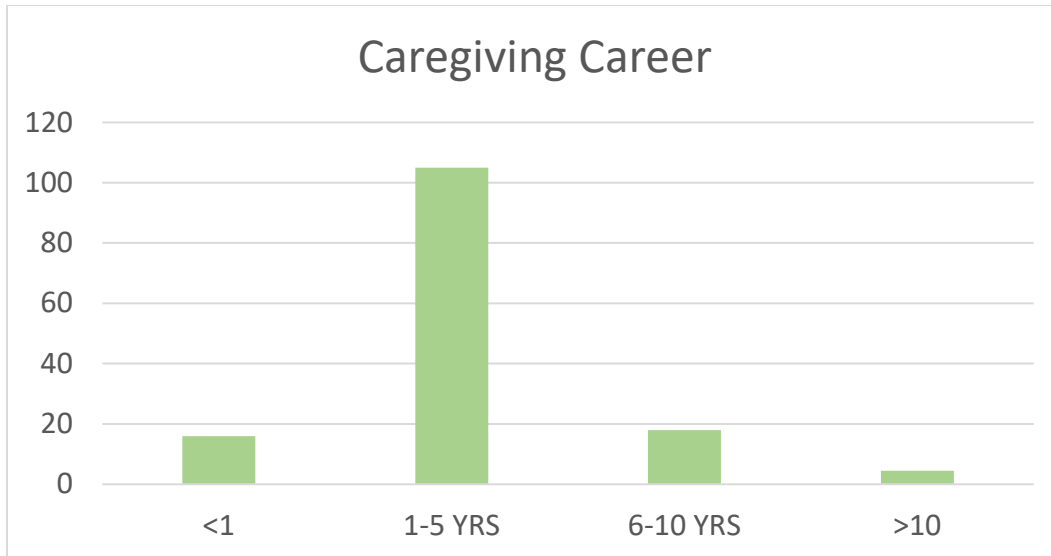
- What would I do if I had a break from caregiving?
- Who would I spend time with during a break from caregiving?

This comparison strongly supports Dr. Dale Lund’s research on the Continuity Theory of Life Course Aging which states that “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 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.

Emerging research on the “essential ingredients” of respite, as cited in studies by Gaugler et al. (2017) focused on caregiver motivation, shows freedom, support, and connection found through respite can counteract some of the negative impacts of caregiving.

Appendix K: Commitment & Confidence

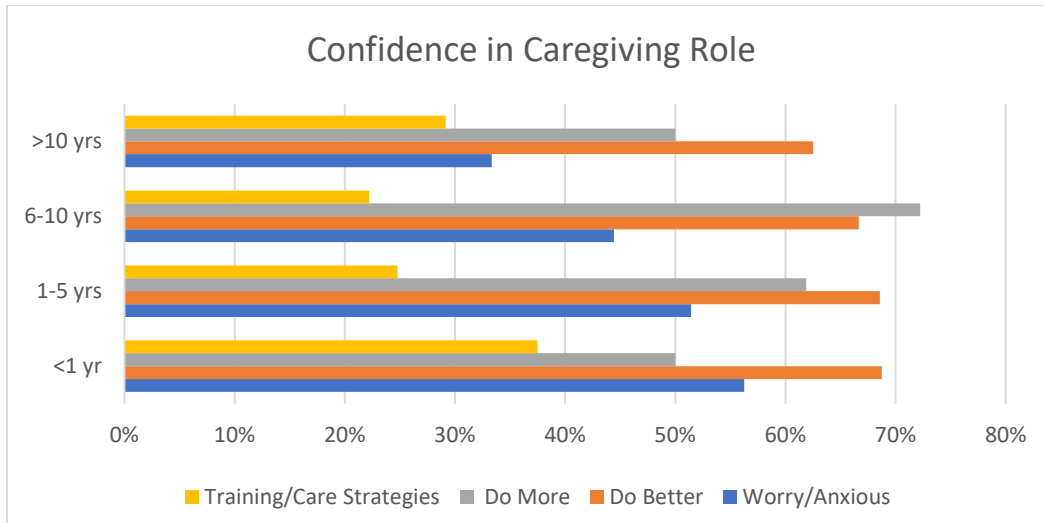
Summary: Caregivers have low confidence in the quality of their care, feeling the need to do more or do better at delivering care. Not as a demand for training and skill development, this may be a plea for shared experience with others towards combating loneliness.



The commitment to care (and to continuing care at home) was extremely high among program participants. Most have provided 1-5 years of service already, so they were experienced "long-term" caregivers. But their confidence in how they were doing as caregivers was surprisingly low.

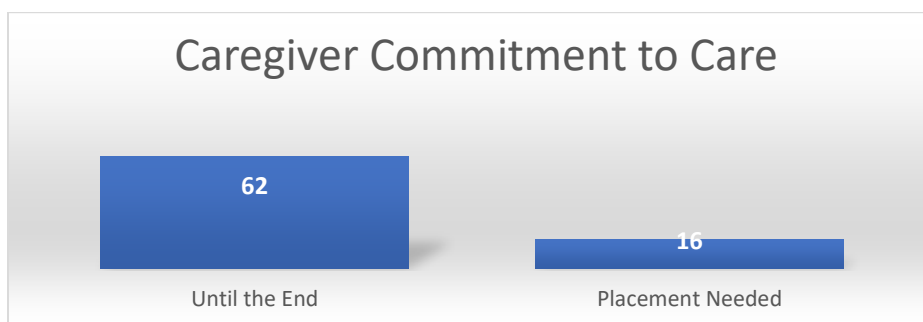
By comparing the years of caregiving experience with the worries or caregiving concerns of those caregivers who have committed to providing care, it appears that caregivers feel they should do a better job than they are doing (the red bars – all above 60%) – so confidence in the quality of their role is missing. Also, the sense that they should be doing more for their loved one increases with time in caregiving (the green bars – again all at or above 50% of our participant pool).

As caregivers are a "lifeline of care" in the long-term care system, these levels of worry, concern, and lack of confidence in doing this important "job" need to be addressed. Caregivers appear to need support if Nevada wants them to maintain their long-term commitment.



However, training in care skills and strategies for addressing care needs does not seem to generate any demand, as none of the participating caregivers accepted offers for training, whether for themselves or for their respite workers. Respite Rx data shows that their interest or need for training and caregiving strategies decrease slightly as their years of experience increase (see the purple bars on top of each stack), and their worry and anxiety appear to decline as well (the blue bars on bottom of each stack). So, it might help to offer these training and skill development opportunities to caregivers early on in their caregiving career, but the lack of interest in such offerings seem to suggest a different solution is needed to increase confidence.

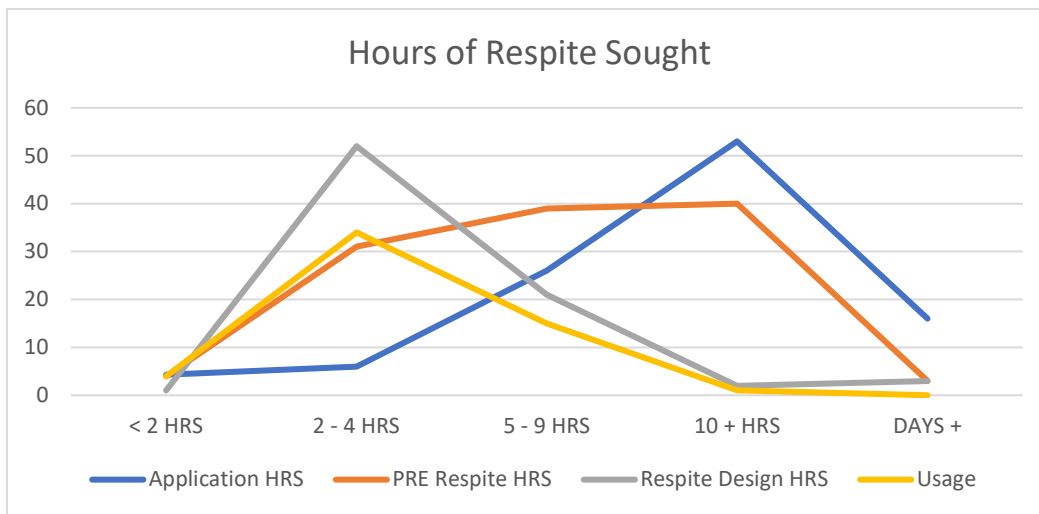
Nationally, caregiver support groups and caregiver consultations have been reported to be effective at reducing worry and stress among caregivers, so this may also need to be considered and incorporated in respite programming. These “Listening Ear” approaches may tie in with loneliness studies that recognize the social impact and isolation of caregiving, and the need to find someone who cares about them. However, this need for connection does not diminish a caregiver’s commitment to care, because whether driven by cultural, moral, or familial reasons; Respite Rx caregivers were fully committed to their continuing role in providing care. A research correlation between confidence and caregiving commitment will need further study.



Appendix L: Demand of Respite Hours

Summary: From program intake to respite usage, caregiver demand for respite fell from 10+ hours per week to 3 hours per week. Fitting respite into their lives takes dedicated planning.

Nevada’s respite pilot program, Respite Rx, the demand for respite hours was assessed at 3 different points: at the time of referral and application, from the pre-respite survey completed, and during the respite design planning session. The demand at application (the blue line on the chart) was much higher than the other measures. The majority requested 9-12 hours on a weekly basis for respite breaks.



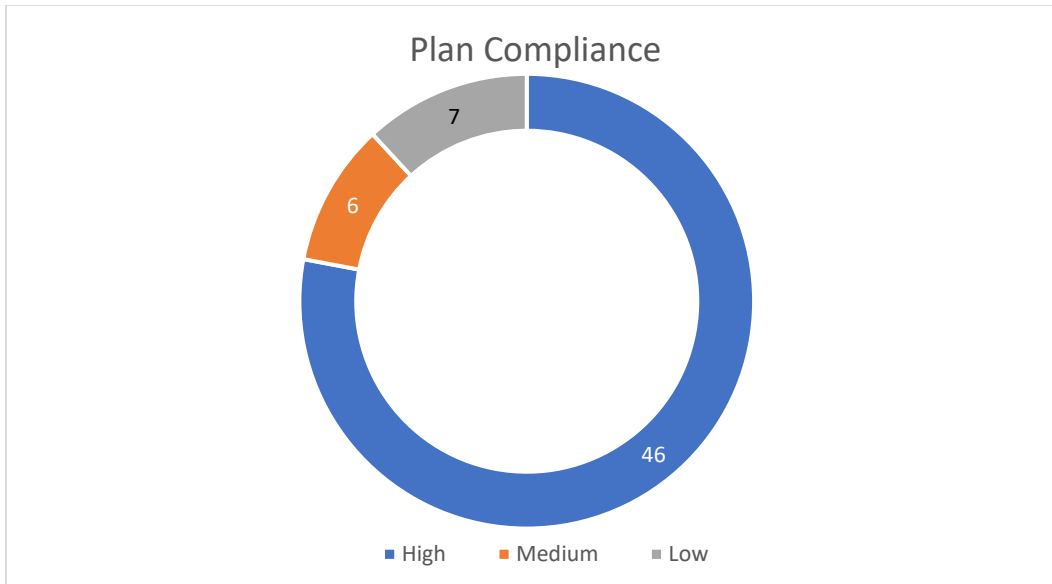
Demand changes between application, tailored respite planning, and usage.

On the pre-respite survey, the results (see the red line) leveled out significantly. The majority still requested 10+ hours per week, however the average fell from 14.7 hours (for the blue line) to 6.6 hours (for the red line) per week.

After a person-centered planning process to determine how respite would “fit” into their lives, the requested hours of respite fell significantly again. The majority selected a 3- to 4-hour block of time per respite session, and the average plan for hours fell to 4.4 hours per week.

Caregivers discussed what they would like to do with their respite time, and could identify many activities they wanted to engage in. However, they struggled to “fit” time for those activities into their caregiving lives or figure out how to rebuild aspects of their lives that had been lost to caregiving. Stepping away from their caregiving role or regaining relationships that had slipped away was not easy.

The demand for respite was also compared to the usage data. Given the planned respite designed for them individually, did they use it? Did they group the respite hours as they had planned? For most, the answer is Yes. However, the average hours used on a weekly basis did fall to 2.99 hours.



When comparing caregiver plans for respite and actual usage, alignment was strong. Respite Design compliance data shows 78% of participants received respite as they planned. Unfortunately, 8% did not receive any respite, despite the effort and planning invested. Death of the care recipient, placement decisions, COVID restrictions, and the need to find/replace respite workers caused respite plans to be unsuccessful.

Caregivers (in light blue and teal) who did not have full compliance with their plans chose to use fewer hours per respite session (to receive more respite sessions per month) or used respite providers who limited the service hours per session, due to scheduling/staffing issues.

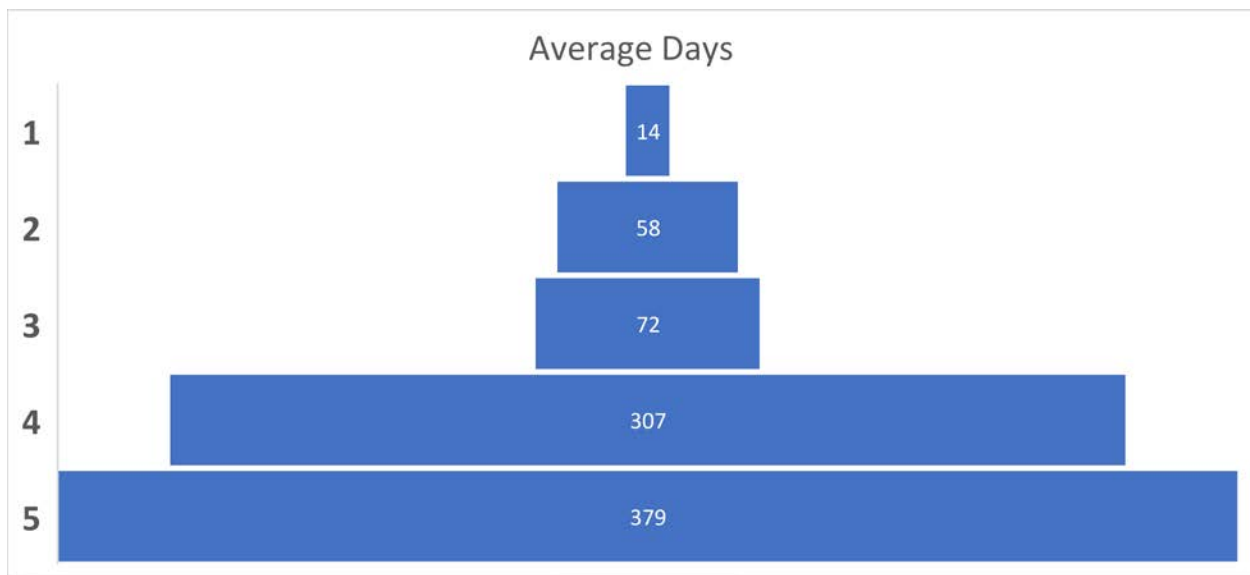
Appendix M: Getting Respite

Summary: Recruitment and selection of respite workers required an investment of time and effort and additional interventions. Strategies for quickly identifying and hiring respite workers need to be developed.

The process for getting caregivers for respite was tracked, using dates for referral, respite design, spending plan authorization, and contract exit. Using a self-directed model meant letting the caregivers lead the process, with support and encouragement from Respite Rx staff.

Level 1: Completing Respite Design

It took an average of 14 days for Respite Rx staff to contact the referred caregiver, complete pre-respite surveys, and have a person-centered respite design session with each participant in Respite Rx. This upfront investment of time and effort was necessary to prepare caregivers to participate in the Respite Rx model. (Median=11; Mode=9; Range=0 to 46 Days)



Level 2: Recruitment & Enrollment

With the respite design session completed, caregivers sought their respite workers, through word-of-mouth recruitment, contacting friends and family, and placing ads for these part-time positions in local businesses, community centers and organizations, through online and social media platforms such as Craigslist and Facebook, and with contacts at CNA/Nursing programs, Adult Education, Workforce Development Programs, and Career Counseling & Employment Centers. Respite Rx staff assisted with drafting and disseminating job announcements for respite positions. It took an average of 58 days for caregivers to find, interview, and hire workers, complete FMS enrollment paperwork, gather support documents, and submit spending plans for ADSD authorization. This was a time-consuming, paperwork-intensive step to complete, and Respite Rx staff assisted by providing caregivers with hiring & interview

guidance and by conducting FMS paperwork reviews with caregivers and respite workers. (Median=46; Mode=17; Range=5 to 216 Days)

Level 3: Time Elapse Since Referral

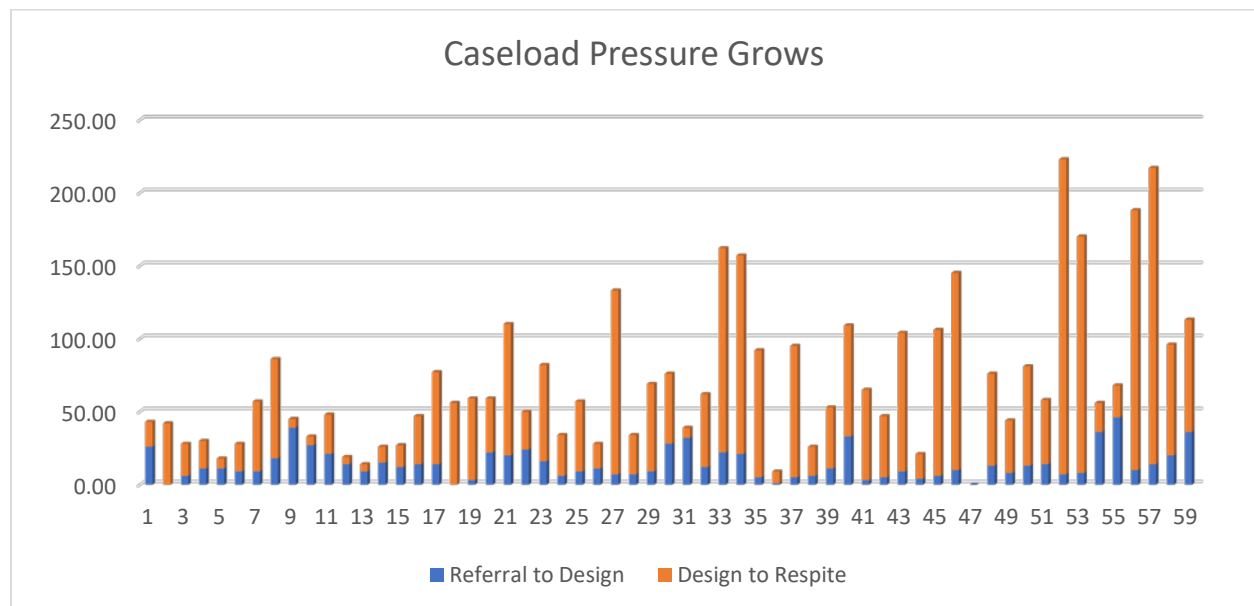
With the 14 days Respite Rx staff dedicated to getting caregivers started with the program added to the time needed to recruit workers, caregivers waited on average 72 days to achieve access to respite. This upfront investment of time and effort had to be balanced against the year-long benefits they hoped to receive, and some applicants backed out of the program. Caregivers who valued respite and did not have other respite options made the commitment. This may explain the high number of caregivers who completed their year-long contract for respite.

Level 4: Time in Respite Contract

Caregivers stayed in respite contracts for an average of 307 days, as they utilized their respite funding in monthly increments. Death, long-term care placement, moving, COVID fears, and loss of contact were reasons caregivers exited the program prior to contract end. Because of delays caused by communication challenges with FMS agency and/or Respite Rx staff, a few caregivers were given small contract extensions, to allow them to utilize their respite funding up to the contract maximum limits. (Median=350; Mode=366; Range=50 to 383 Days)

Level 5: Caseload Time Commitment

Respite Rx staff worked with caregivers from referral to the final respite surveys conducted after their contract ends. The average time a participant remained on the caseload was 379 days. (Median=396; Mode=436; Range=68 to 570 Days)



As the program grew, Respite Rx staff efforts to contact each caregiver and provide the needed support, encouragement and problem-solving during the recruitment phase occurred less frequently, and it resulted in longer time delays to getting respite workers hired and working. This recruitment step was the most difficult for caregivers to complete independently and will likely need dedicated staff time (and smaller caseloads) to reduce delays in getting caregivers to respite until additional resources and strategies for recruiting are explored.

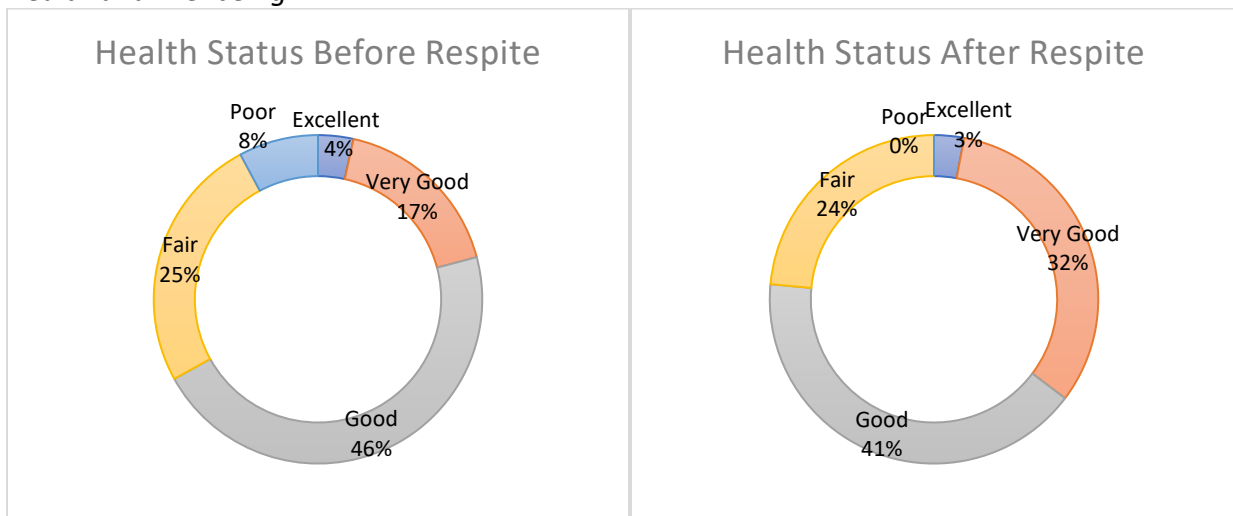
Appendix N: Pre, Quarterly, & Post Survey

Summary: When a referral was made to Respite Rx program, Nevada Care Connection (NVCC) staff conducted a stress/burden questionnaire with the identified caregiver. Caregivers who applied for the Respite Rx program were also asked to complete a survey prior to receiving respite services. 115 pre-surveys were completed with caregivers who were referred to the Respite Rx program.

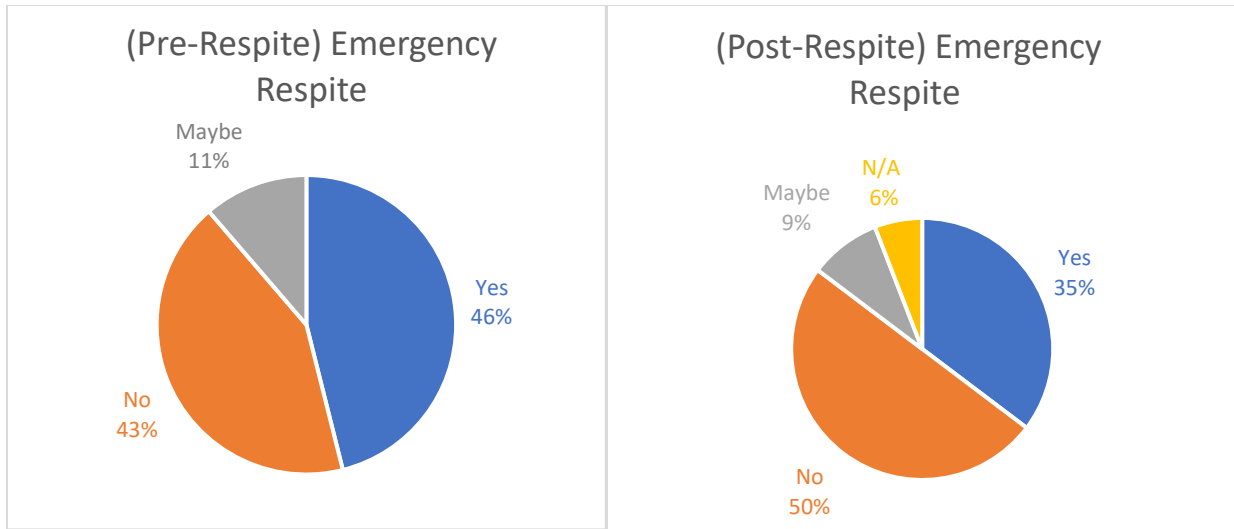
Quarterly check-ins were also conducted every three months via phone or through an online platform. However, quarterly surveys were difficult to collect, as this was an extra burden added to caregiving duties. ASD program staff were able to collect 60 quarterly surveys; however, this number does include surveys that were completed by a caregiver more than one time.

Post-respite surveys were also completed to get a sense of how caregiving and respite has changed over the course of the caregiver's time within Respite Rx. Out of the 59 participants in the Respite Rx program, there were a total of 34 post surveys.

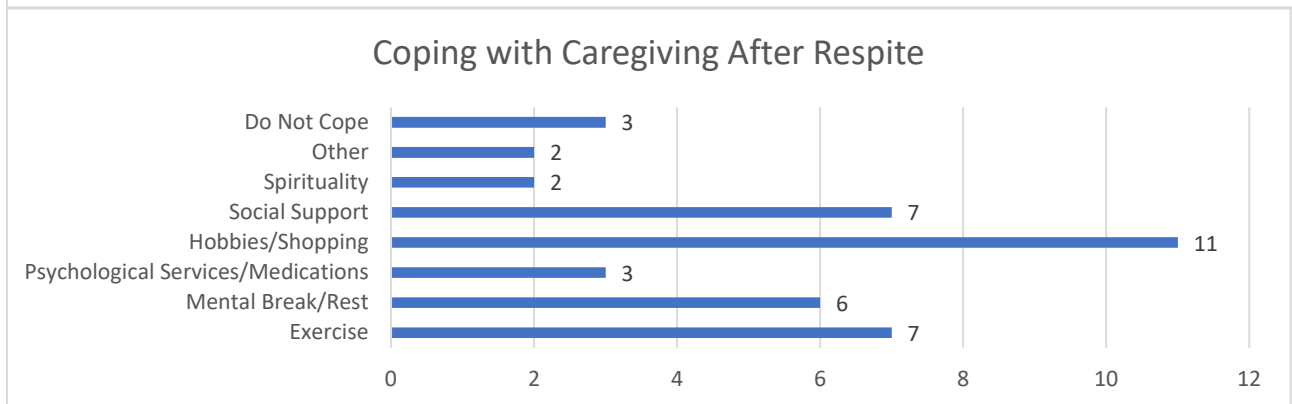
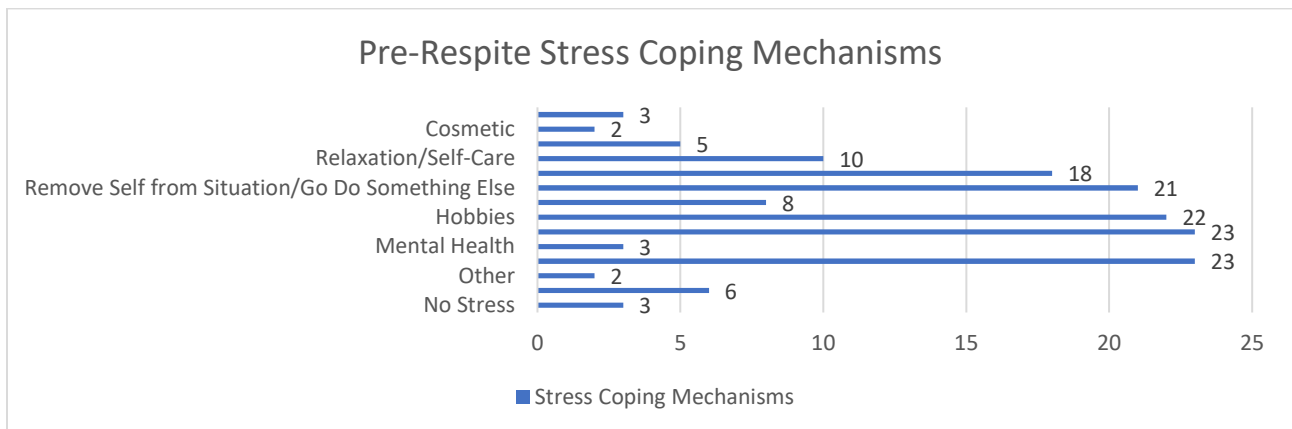
Pre- and Post-Survey Comparison *Health and Wellbeing*



Caregivers rated their health status before respite: good, very good, or excellent 67% of the time. After respite, this percentage increased to 76%.

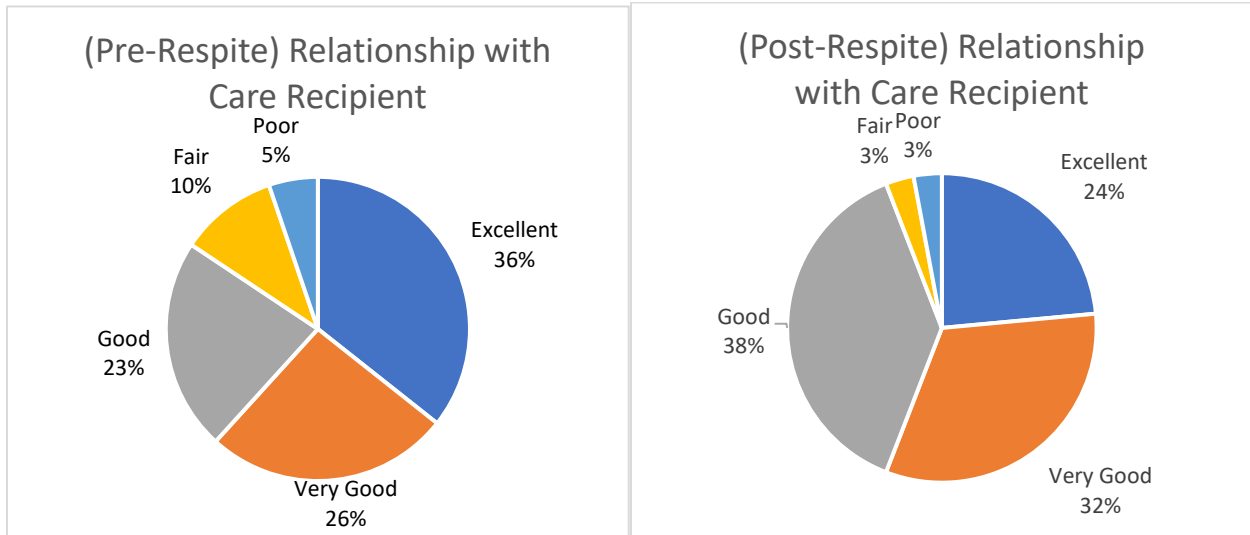


Interestingly, before respite services, caregivers identified 46% of the time that they did have someone to provide respite in case of an emergency. After respite, this number dropped down to 35%. In conjunction with this, the percentage of caregivers who did not have someone in case of an emergency increased from 43% to 50%. Caregivers who provided an answer without enough information to determine if they did or did not have someone who could provide care in an emergency are grouped in the N/A category.

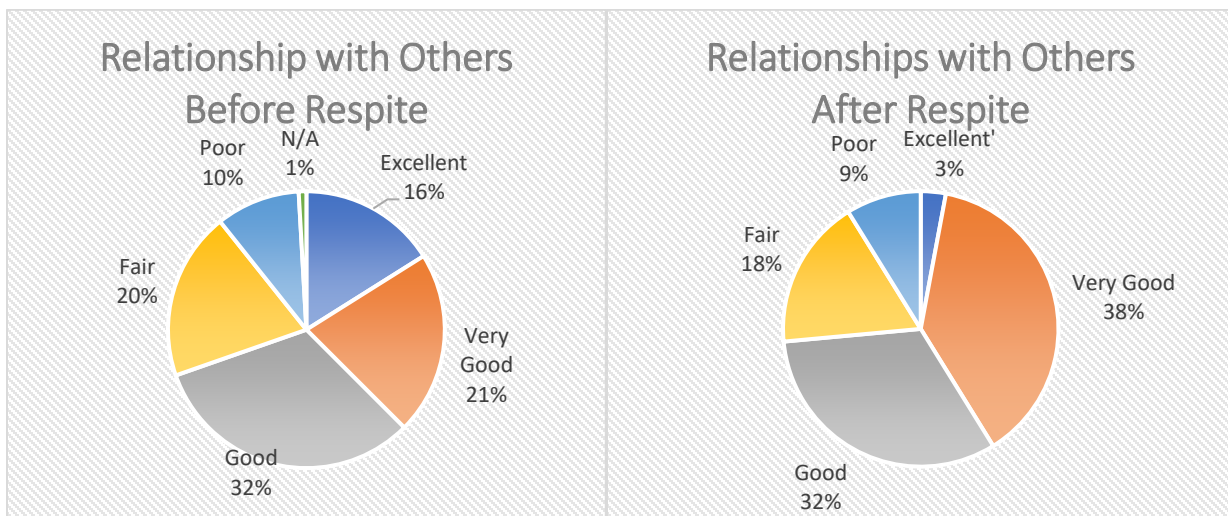


Because the pool of caregivers who completed the post-survey was much smaller for caregivers that completed the pre-survey, this information is a bit difficult to pull comparisons to. Caregivers were also able to discuss multiple ways that they dealt with caregiving stress. Caregivers still seemed to use very similar ways to cope with stress related to caregiving.

Relationships



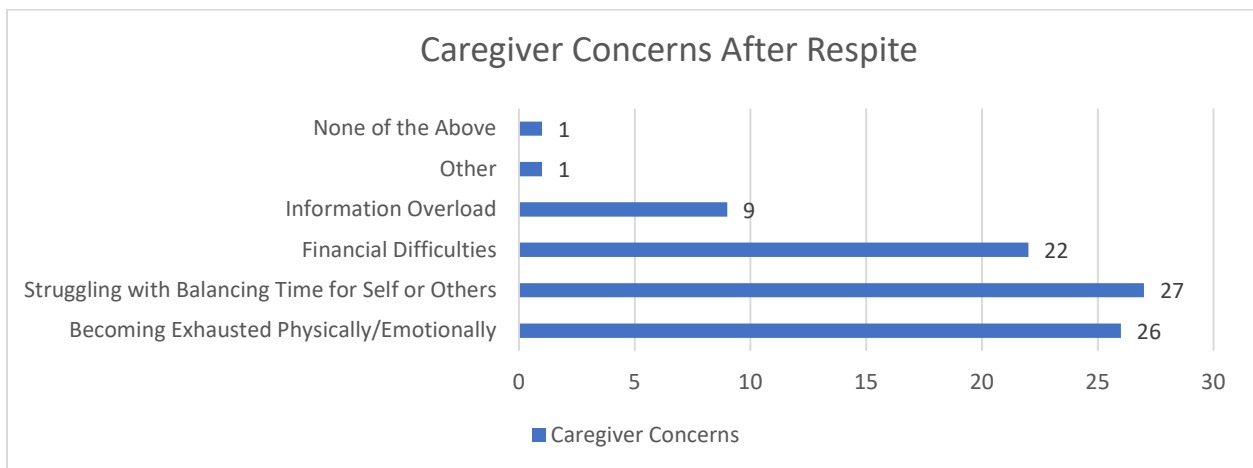
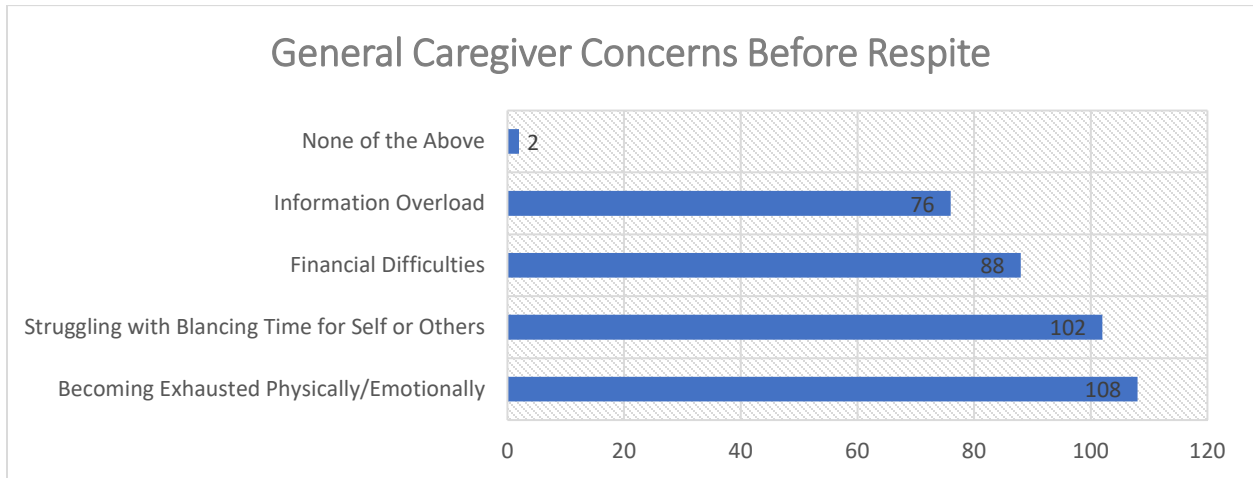
Caregivers reported that before respite, they felt their relationship was either good, very good, or excellent with the loved one they provide care for 85% of the time. After respite, caregivers reported 94% of the time that their relationship with their care recipient was either good, very good, or excellent.



Caregivers reported before respite that their relationship with others (friends, family members, etc.) was either good, very good, or excellent 69% of the time, and 30% of the time their relationships were either fair or poor. The caregivers in the N/A section did not provide an answer. After respite,

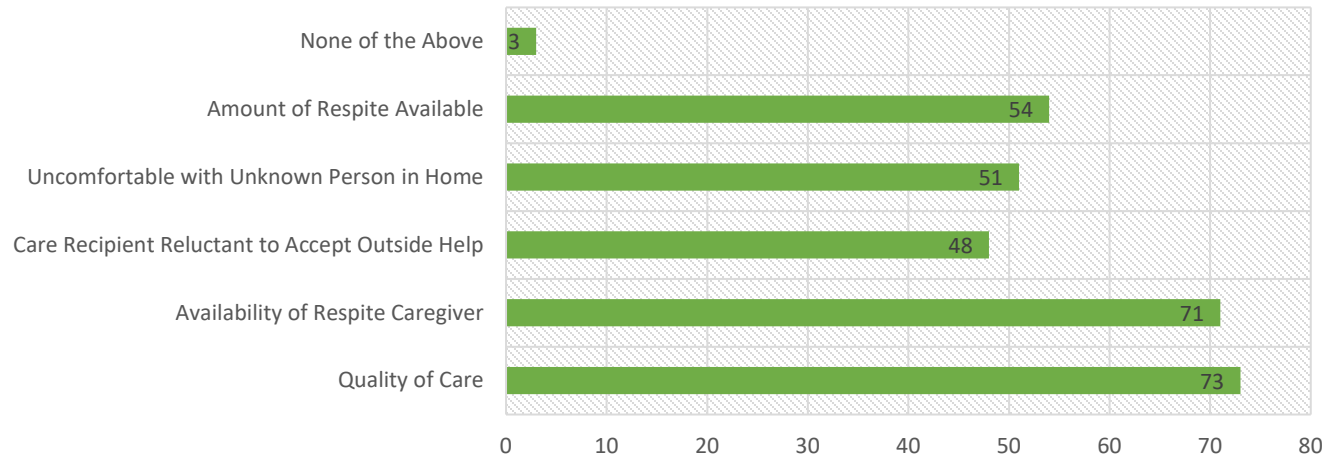
caregiver's relationships with others improved to 73% and caregivers only reported that their relationships were either fair or poor 27% of the time.

Caregiver Concerns

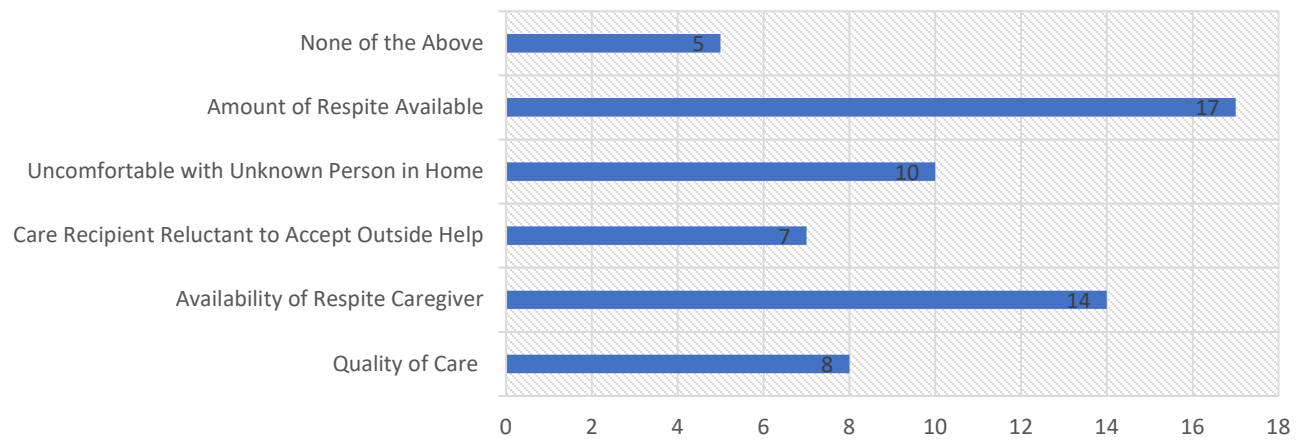


Caregivers seemed to answer very similarly when discussing concerns they had about their caregiving role, including “struggling with balancing time for self or others” and “becoming exhausted physically or emotionally” being the most common areas of struggle.

(Pre-Respite) Concerns About Receiving Respite

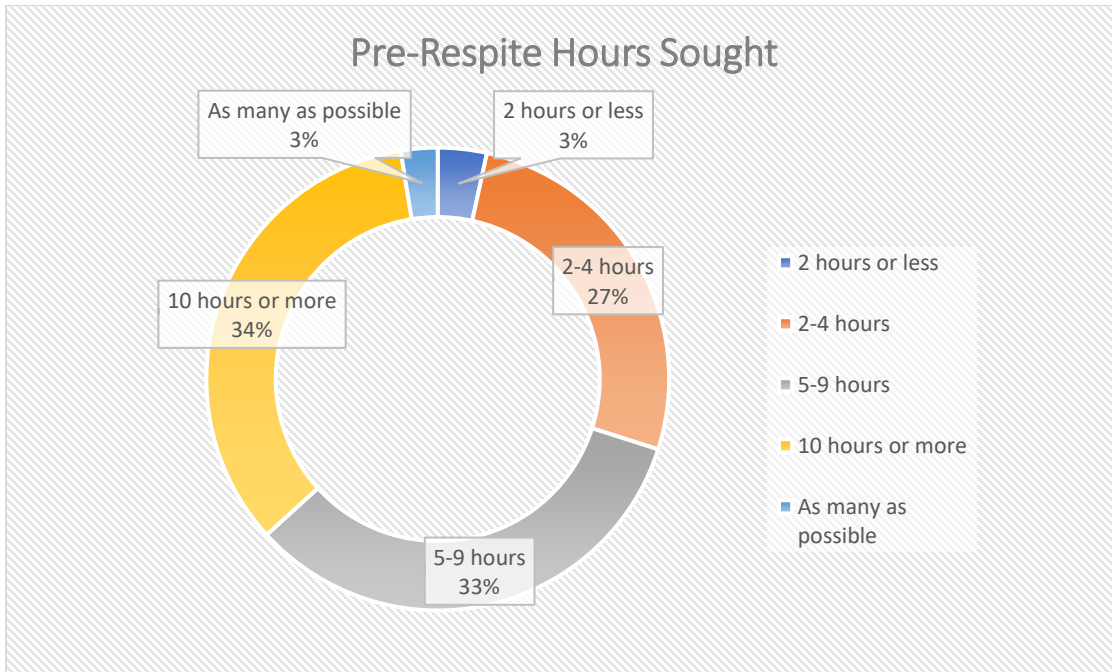


(Post-Respite) Concerns About Receiving Respite



Caregivers before respite identified that “availability of the caregiver” and “quality of care” were their top two concerns about receiving respite. Caregivers identified after respite that their top two concerns were “amount of respite available” and “availability of the respite caregiver”.

Additional Information

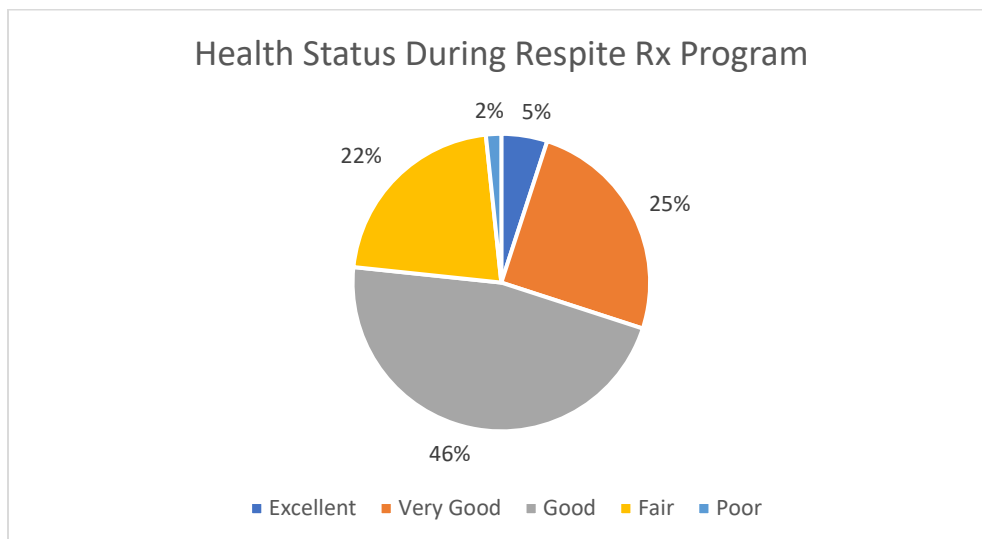


Before respite was provided, we asked all caregivers who applied for our program what their ideal amount of respite would be.

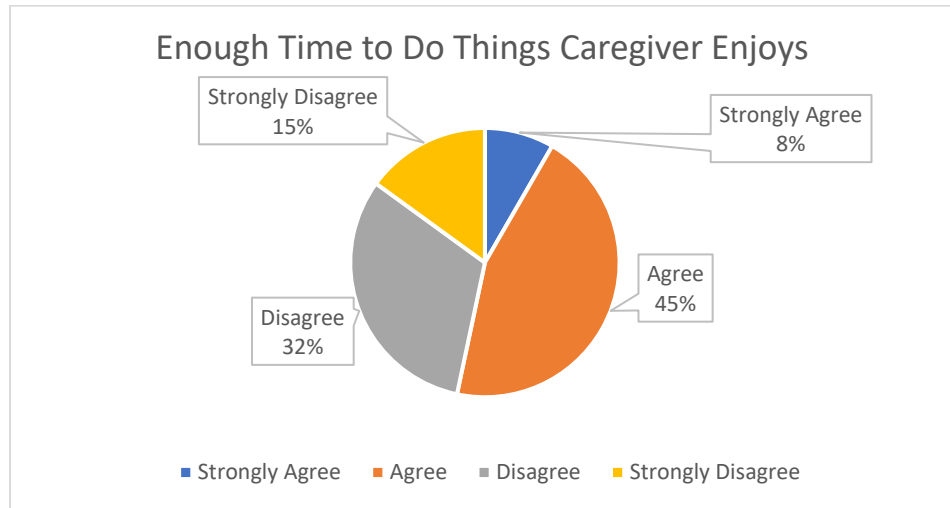
Quarterly Survey Data

As stated above, quarterly survey data was compiled on caregivers participating in the Respite Rx program.

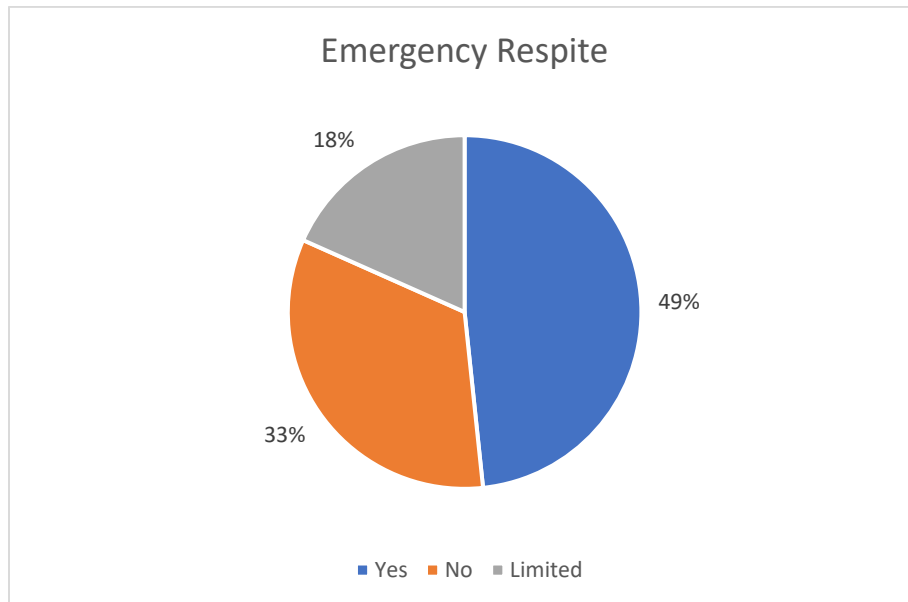
Healthy and Wellbeing



Caregivers rated their health status as good, very good, or excellent 76% of the time during their program. Fair and poor ratings were used to describe caregivers' health 24% of the time.



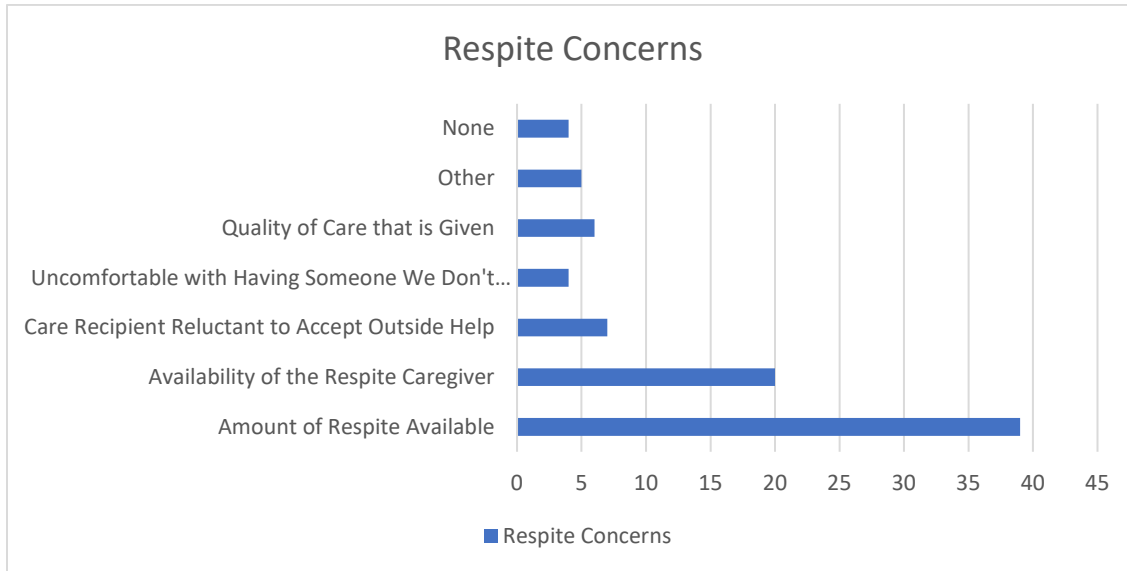
Caregivers stated that they had enough time to do things they enjoyed 53% of the time (strongly agree and agree answers). Caregivers reported 47% of the time that they did not have enough time to do things that they enjoyed while receiving respite.



During Respite Rx, 49% of caregivers reported they did have someone to provide emergency respite. This answer often included the current respite worker that they had through the Respite Rx program. 33% of caregivers answered that they did not have someone to help them in an emergency, and 18% of caregivers stated that they had someone they could call but the individual was limited in the amount of respite they were able to provide (for example: they were living out of town, had limited availability, or had disabilities or other physical limitations).

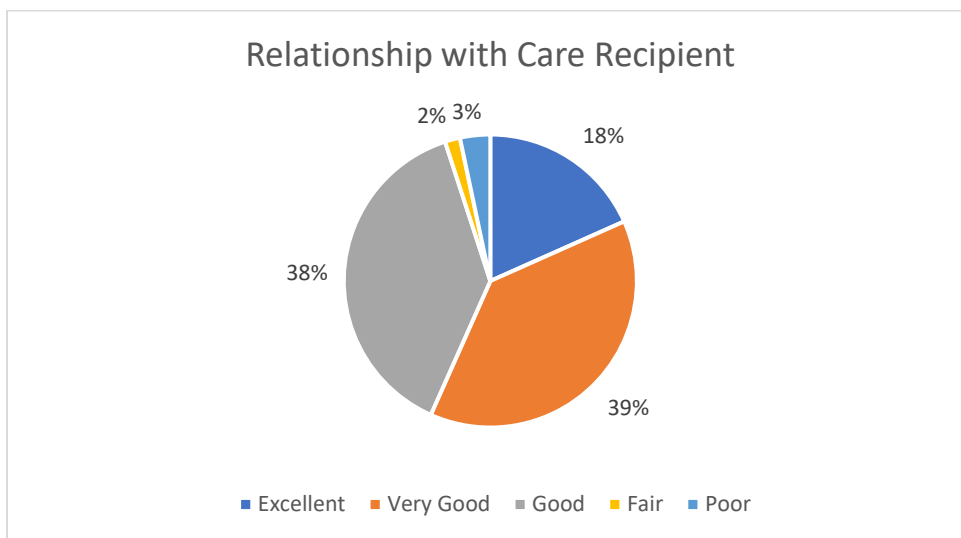
Caregivers were relatively consistent with their answers on their coping mechanisms during Respite Rx, including similar answers to the pre and post surveys. Answers on coping with caregiving included items relating to exercising, hobbies, spending time with family and friends, outdoor activities, running errands or working, travel, taking care of their physical or mental health (going to doctors, psychiatrists, therapy, etc.), taking personal time away, going to church or meditating, outside social support, respite, and sleeping or rest. Caregivers also used similar answers to discuss how they used their program time with Respite Rx.

Caregiver Concerns

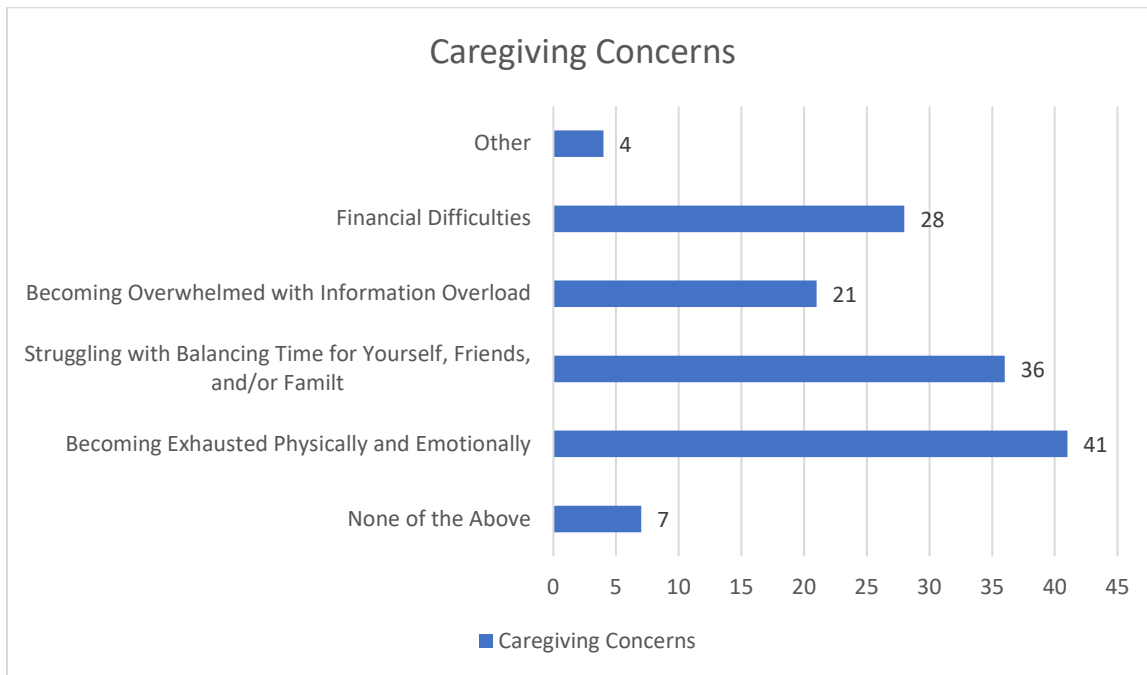


Other concerns included COVID-19 concerns including caregiver PPE and exposure to COVID and concerns about payment for respite.

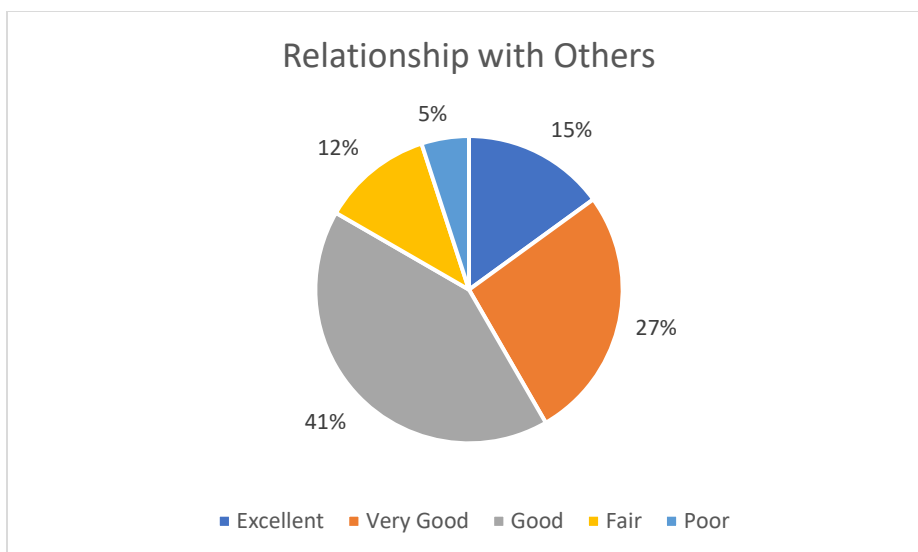
Relationships



Caregivers stated 95% of the time that their relationship with their care recipient was good, very good, or excellent. Only 5% of the time, caregivers stated that they had a fair or poor relationship with their loved one.

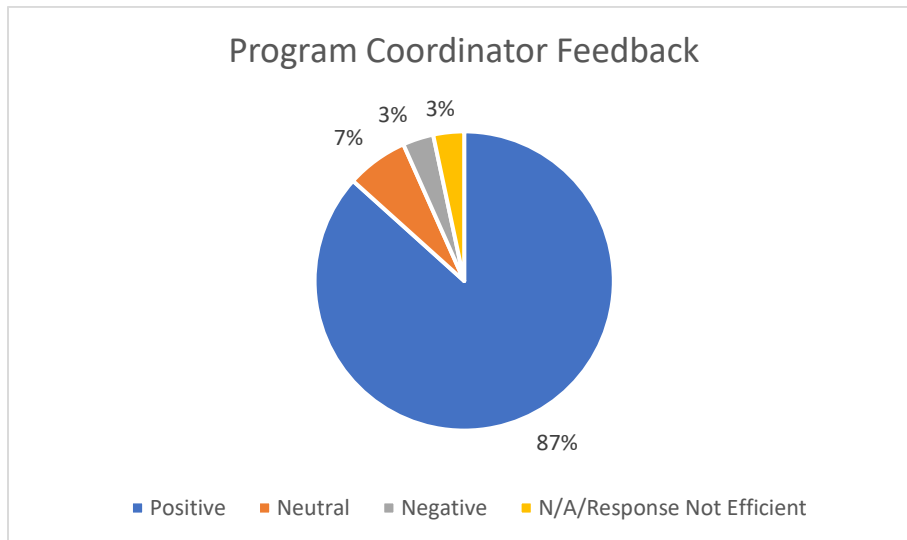


Caregivers stated 83% of the time during their program time that they had a good, very good, or excellent relationship with others (family, friends, etc.). 17% stated that their relationship with others was fair or poor.



Program Feedback

Caregivers provided information on how the program went and on service set up and processing. The caregivers on the Respite Rx program also provided information on how they were referred to or discovered the Respite Rx program. These responses included the Nevada Care Connection Resource Centers, senior centers, Nevada Early Intervention Services (NEIS), Aging and Disability Services Division (ADSD), the ADSD Medicare Assistance Program (MAP), hospice social workers, non-profit agencies, community centers, social media, and personal research.



Most feedback about the Program Coordinator was positive (87%), including the comments below. 3% of the comments were neutral, including information such as “Fair”, and “Fine.” 3% of comments included responses such as “N/A” and “Yes.” Negative comments included discussion of the paperwork, problems with pay, and differences in personality.

Examples of positive feedback about Program Coordinator:

"She was there for me whenever I need it. She is right there"

"The Program Coordinator helped us through all the steps to receive the respite care"

"Very professional with an attitude of concern for me and my wife in our situation. Made it easy"

"They [ADSD Staff] were ALL amazing very helpful and understanding and sensitive to our needs and our culture"

Caregivers stated that from submitting their request for respite to receiving respite services, it took anywhere from a week to several months. Some caregivers did experience challenges and were not able to receive respite for over 6 months. This wait time was due to several factors including paperwork processing from the Financial Management Services (FMS) Agency, not being able to find someone to provide respite care, the care recipient being moved to a higher level of care during application process, or other FMS complications.

Caregivers were also asked if they had plans to continue respite after they completed their time with the Respite Rx program. Unfortunately, many caregivers stated that they did not have a plan to continue respite after the program. Others stated that they would have to look into other programs. Because this program had loose eligibility requirements for the caregivers (including no income restrictions or limits on the population of care recipients), many caregivers on the Respite Rx program do not qualify for other voucher programs to help with respite services. Every caregiver on the Respite Rx program was referred to their local Nevada Care Connection Resource Center to explore other respite options and supports after their program time concluded.

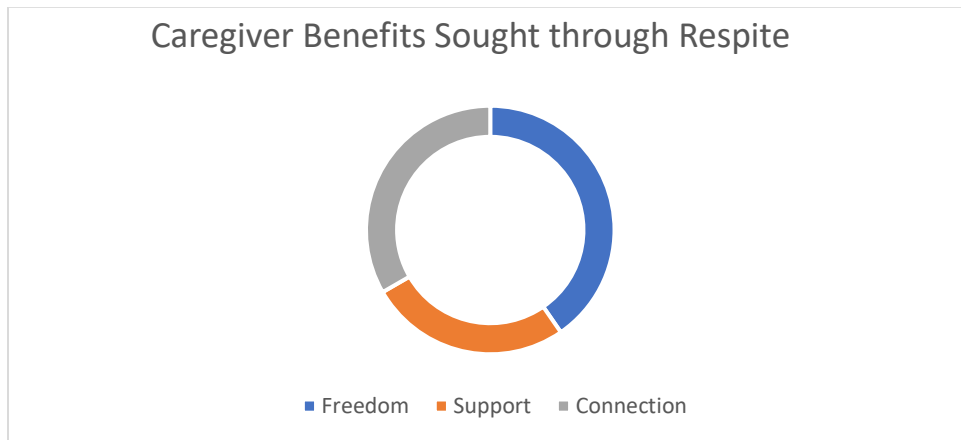
Conclusion

The Respite Rx program provided much needed relief to caregivers who traditionally would not qualify for other programs. We received much positive feedback from our surveys about the program including comments such as, “This is a much-needed service to caregivers who need a break from the demands on them”, “I am grateful for the program coordinators of Respite Rx”, “Thank you for all you have done for us.” Many caregivers also inquired about the program being extended or being renewed.

Appendix O: Respite Benefits Sought

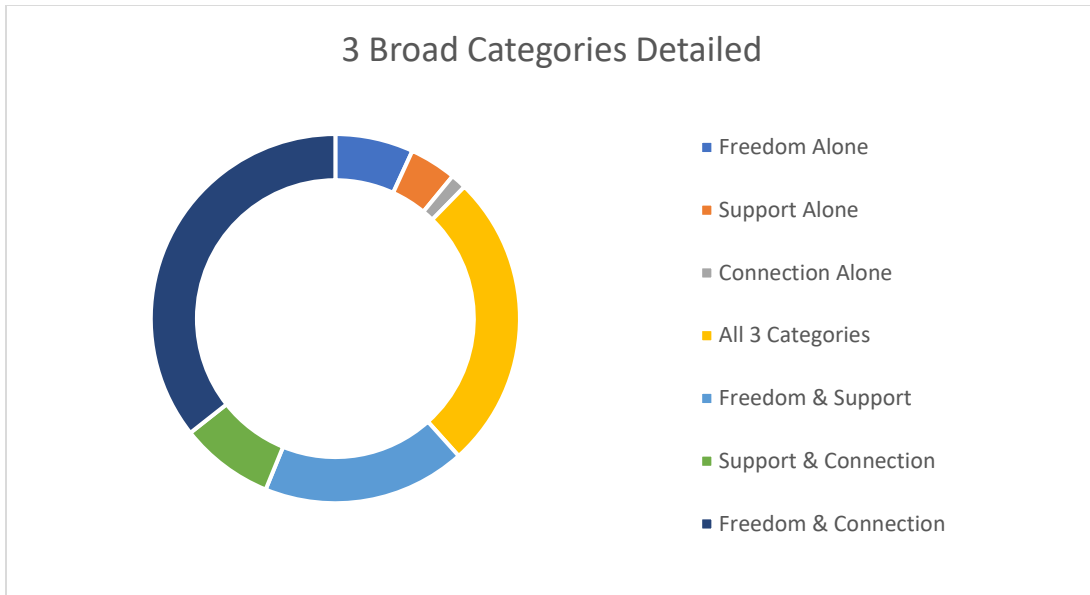
Summary: Caregivers who sought respite were motivated by the respite benefits of freedom and connection. Respite awareness messaging described respite as a supportive break from care but also needs to be directed at these other motivations. National studies underway are looking at caregiver benefits from respite that align with one or more of three broad categories: Freedom, Support, and Connection.

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. 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, enable caregivers to function or act, strengthening their ability to endure or tolerate the situation, and provide a source of comfort or encouragement while they care for others. Connection refers to a relationship in which a person is linked or associated with, emotional bonds and interactions, strengthen by mutual experiences, and people with whom one has social or professional contact or to whom one is related.



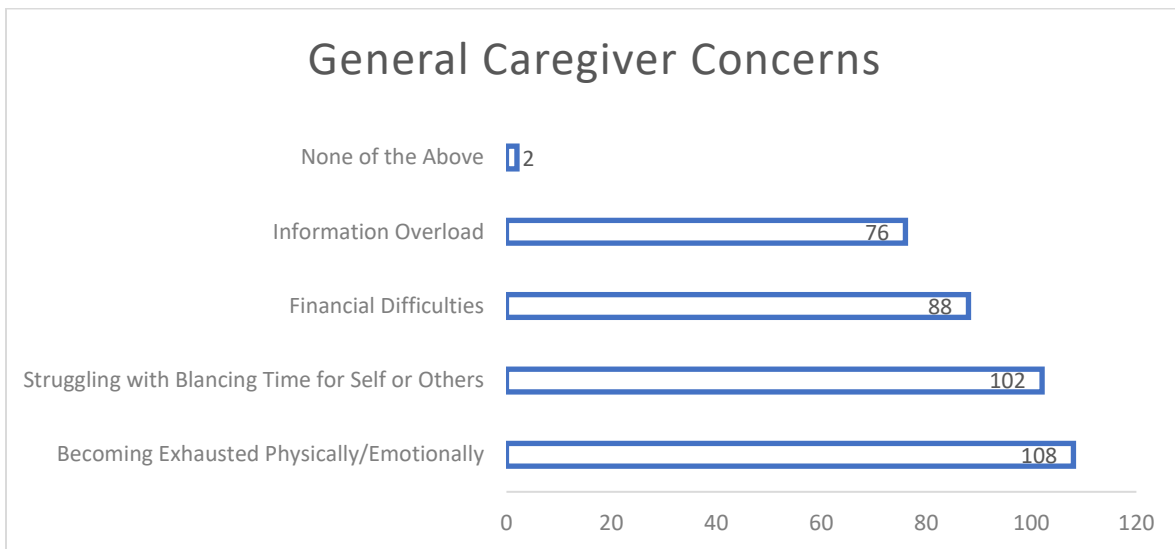
The person-centered Respite Design Sessions with each caregiver were used to determine which of the 3 categories were sought by participants. Eighty-six percent of caregivers expressed a desire for Freedom; 71% sought Connection, and 56% needed Support.

These were further detailed when more than one of these benefits were sought. The chart below shows that caregivers desired freedom and connection more than any other single choice or combination.



Awareness campaigns for respite, such as “Respite Refuels Caregivers” and other messages that respite provides a supportive break in care may not be effective in reaching caregivers motivated by freedom or connection. Future messaging campaigns conducted by the Nevada Lifespan Respite Care Coalition and others will need to be retargeted to address these other motivators.

Additional credence comes from pre-respite surveys conducted with each caregiver that indicates that physical and emotional exhaustion were of highest concern (Freedom and/or Support), and the struggle to find time for self and relationships with others (Connection) was the next highest.

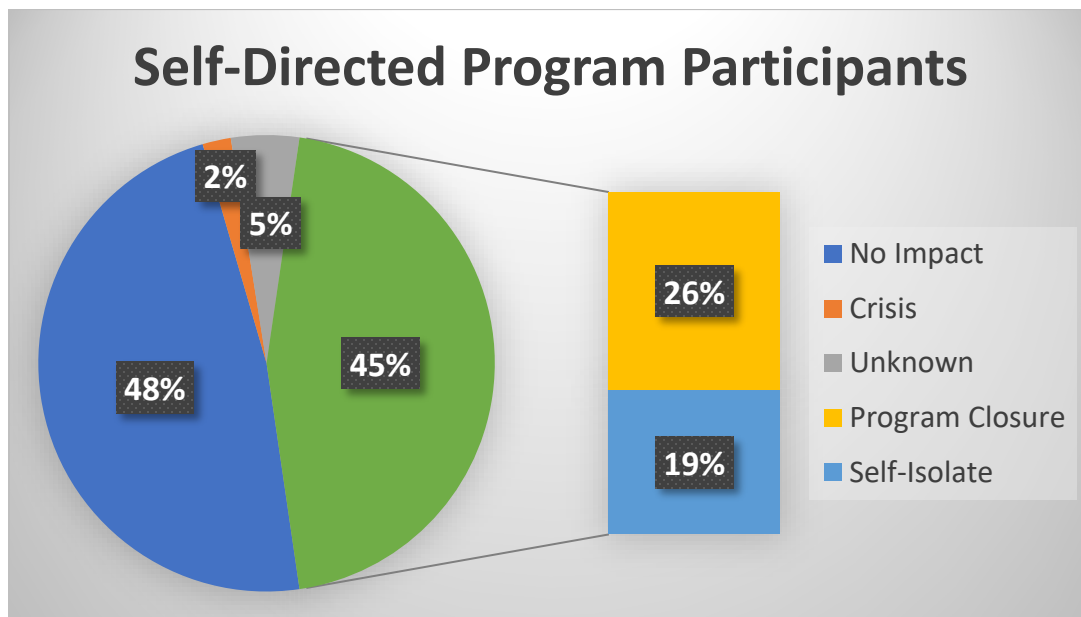


Appendix P: COVID Impact on Respite Rx

Summary: Respite Rx participants had lower interruption and cessation rates on services, owing primarily to the exclusivity inherent in hiring friends and family for respite services.

Nevada was impacted by COVID-19. Providers of respite care shut down operations, limited their services to only essential services or shifted to other activities to help bring caregivers & their families some relief. Nevada’s unpaid family caregivers are a huge part of the long-term care support system, but caregiver supports, such as respite, were considered a non-essential service despite the size of the workforce it supports.

Because of its unique design, Respite Rx held up well under COVID restrictions. About 48% of our participants (in dark blue in the pie chart) did not see any impact at all as these participants hired family or close friends who exclusively served a care recipient and limited their risk of bringing germs to the household. Also, a few vendors continued to send workers under strict service policies to mitigate risks. Some said that Respite Rx services were the only thing they were still receiving.



About 45% of the participants (in orange in the pie chart) did see impacts to their respite services. Of those, about 19% (in light blue box) self-imposed or suspended services over COVID-19 fears. Another 26% (in purple) had program closures, respite workers under self-quarantine, or impacts to respite plans because of event cancellations/business closures & travel restrictions.

Those who had respite throughout the COVID pandemic fared far better than those who had to restrict their access to respite or who lost their access to respite due to program shutdowns or restrictions. Mental health supports against risks such as “compassion fatigue” were mostly

displaced by emergency response for food, medical care, and PPE, but there were signs that caregivers did get some care that they desperately needed – a break in loneliness when someone reached out to check on them. Regular contact to check in on caregivers and their families was the right COVID-19 response – letting people know that someone cares.



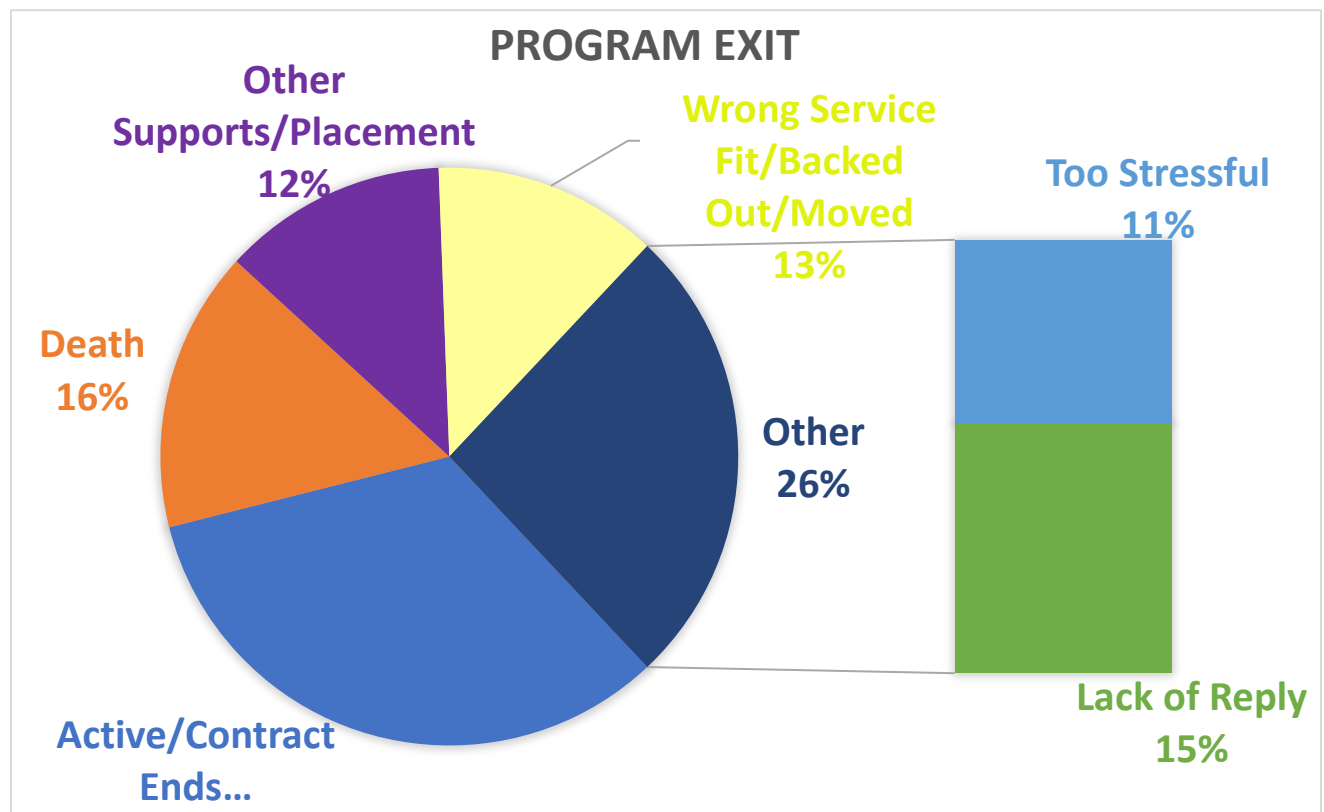
“One of the greatest gifts we can give other people is the gift of our full attention.”

During participation with Respite Rx, only one caregiver reported contracting COVID-19 himself, which spread to his mother and father (both who receive care) and other family members. While the caregiver eventually recovered, hospitalization was necessary for both parents. They each succumbed to COVID within 2 weeks of each other.

Appendix Q: Program Exit

Summary: Knowing the reasons for program exits will help respite programs in developing messaging, resources, training, and case management services to support participation. This data report provides a baseline for measuring improvement.

Respite programs have always had a high drop-out rate. No one really knew why. Respite Rx determined to find out. Here are the program exit results collected by Respite Rx.



Looking at causes for exit, staff members at Respite Rx became alarmed early on when they could not get people into the program fast enough and death (the red section) had claimed a loved one before the caregiver could get any respite! For many others, death prevented caregivers from getting the “full-year of respite” experience planned for. Other caregivers had to make hard placement decisions (displayed in purple) for their loved ones. Respite was too late for them as well. As a future goal, catching caregivers much earlier in their caregiving career to offer respite supports is clearly needed.

Caregivers would say “I don’t know why I waited so long to accept respite, because it was wonderful to receive.” So, messaging about respite needs to have stronger targeting to help caregivers understand how important respite is.

Understanding respite, however, was an issue. (See the Yellow section.) Applicants thought respite workers were housekeepers or respite would cover work hours for working caregivers or that respite was some other service type – so respite was the wrong fit and Respite Rx staff had to redirect these caregivers to other resources or back to the Nevada Care Connection sites for referral.

The most troubling were the families too stressed to complete the process (those in blue box to the side). Some caregivers knew they needed respite, but the "care recipient" would just not allow them to accept it. Others were troubled by the responsibilities of a self-directed respite program. They were deterred by the need to find & hire their own respite provider. "Don't you just send someone?" was the typical response. Respite Rx staff members tried to assist as much as possible, even helped caregivers write job ads for the respite positions. Unfortunately, as a "gap" program, Respite Rx was likely the only option available to them, outside of private paid respite. These caregivers simply could not move forward.

Some balked at the paperwork or the information they would have to share. To assist with the required paperwork, a case management service was added to spend a specific paperwork review session with caregivers (and respite workers) to walk them through the forms they needed to complete. Other applicants wanted respite, but they did not want to do the search for a respite worker or provider agency. Caregivers would say they would never hire a stranger, even one sent out by an agency, but they did not have any friends or family they would hire either. It was hard to move past these barriers to get to respite.

Whether the "lack of reply" category (in the orange box) were people overwhelmed by the process, unconvinced they needed respite, or facing a barrier that might have been addressed, the reasons could not be captured. Nevada has a very transient population. There were also several caregivers who simply moved away after applying for our program. Trying to keep track of these applicants was a difficult job. However, the Respite Rx data gives a much clearer picture of the real drop-off rate and provides insight on the need for strategies to address similar situations in the future.

The self-directed respite model piloted during our current project was successful for families who would not have otherwise accessed respite. However, it also highlighted some new challenges in caregivers accepting respite. Respite Rx provided a higher level of "case management" support to participants than most voucher programs expect to provide. The respite model of "self-direction" was not a perfect solution on its own, particularly because families have become so isolated & disconnected in their communities that they had no one to call on to provide any help.

As learned during this grant, Nevada families needed significant support in connecting to worker resources for respite. According to the report *Caregiving in the United States, 2020*, approximately 29% of caregivers who are the sole provider of care reported having no sources of help or the information to help them find services and supports for themselves and their care recipients.

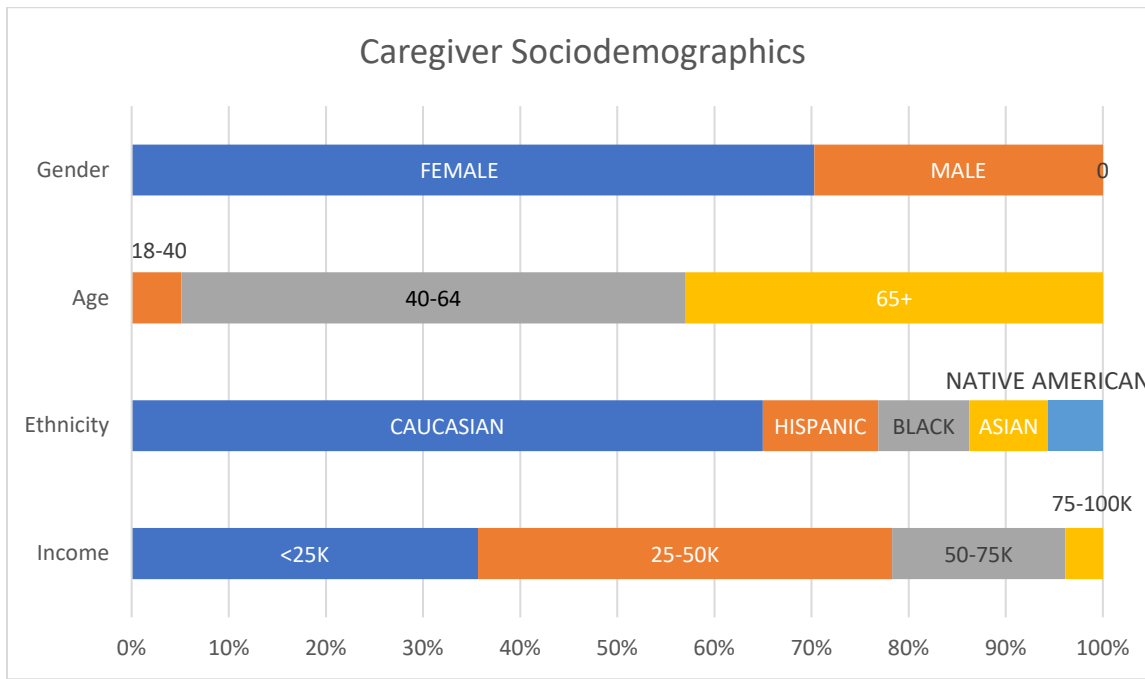
Connecting families with respite workers and providers is a significant need Respite Rx struggled to meet. While building connections with appropriate resources was attempted, outreach on behalf of some caregivers met with little success. How to attract workers and how to make workers & providers feel more like friends (so caregivers and care recipients will allow them to "share the care") will hopefully be a focus for future respite projects.

Respite Rx received 165 referrals to the program; 151 referrals completed applications. Pre-Respite were collected on 115 applicants, but only 104 were officially accepted into the program. Respite Design sessions were conducted with all 104 participants, but only 59 completed FMS paperwork. The requirement to complete FMS paperwork had 45 participants back out of the program before they received any funding.

Appendix R: Respite Rx Demographic Data

Summary: Nevada caregivers are older than national averages; diversity difficult to achieve without targeted outreach.

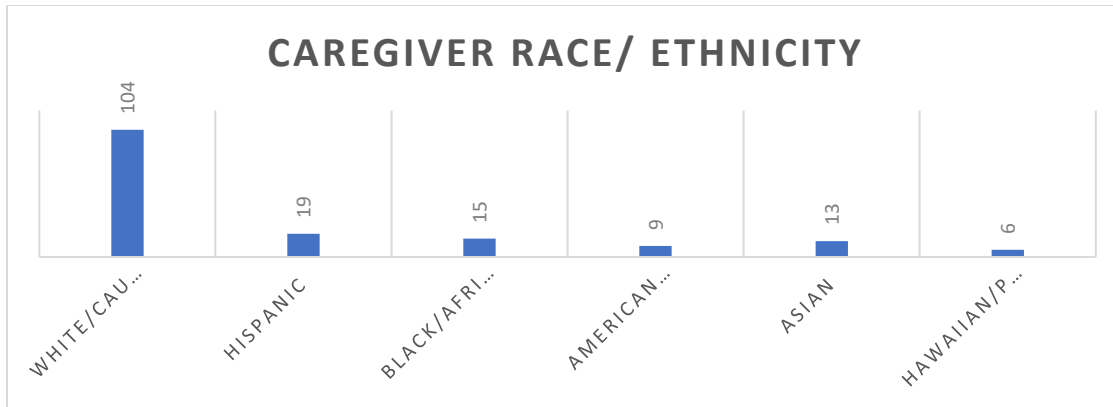
The demographic data collected represents ethnicity, age of both caregiver and care recipient, disabling condition, support needs, income levels, and the complexity of care. It represents all the applicants to the Respite Rx, not just the participants who received funding. It is compared with the data from 2012, which was collected as part of the Lifespan Respite Balancing Initiative expansion grant funding Nevada received.



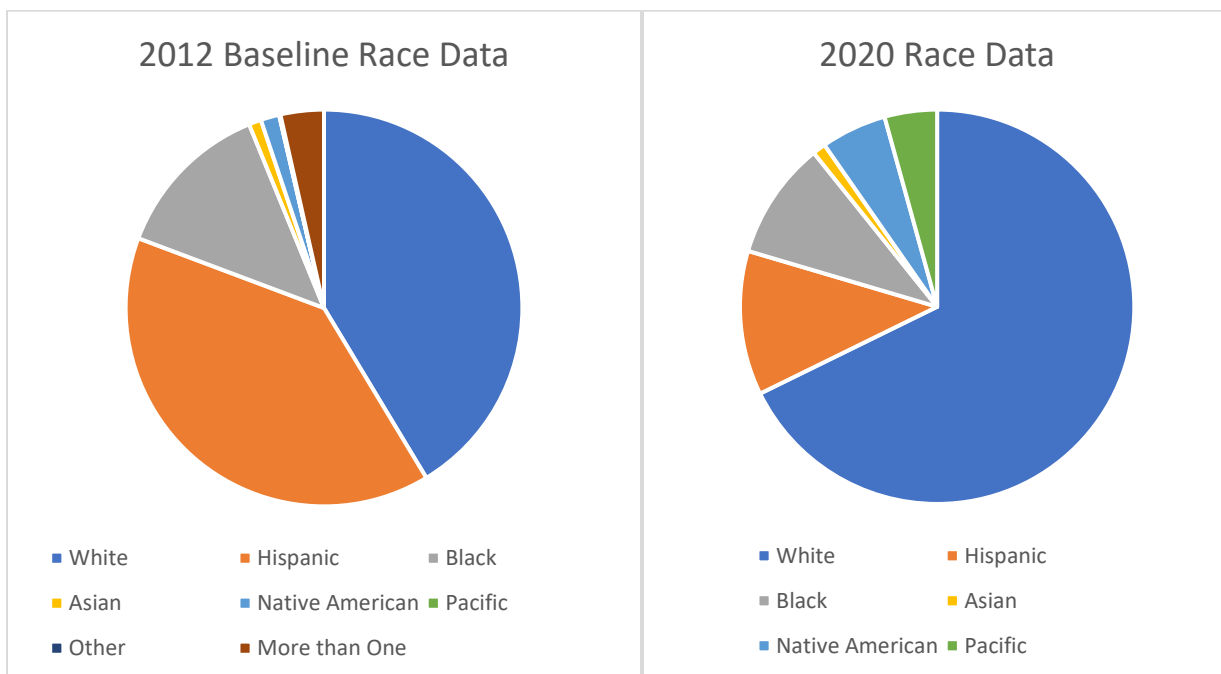
Ethnicity

The challenge of outreach to an ethnically diverse population of caregivers includes language issues (both written & spoken) and strong cultural barriers that prevent care from someone outside the family. While efforts were made to reach Hispanic families, our data still shows a predominance of White/Caucasian caregivers who were seeking and accepting respite services. (Note - The data reflects that one individual identified as both an American Indian/Alaskan and Hawaiian/Pacific Islander.)

This points to the need to frame respite services differently for other ethnicities, possibly allowing them to opt for extra assistance (or even “eyes on” care) over temporary care with a substitute caregiver.



Baseline data from 2012 shows Hispanic participation at 39%, African American at 13%, Asian at 1%, Native American at 1.5%, Hawaiian at 1%, and Caucasian at 41% - compared to results in Respite Rx where Hispanic participation at 11%, African American at 9%, Asian at 1%, Native American at 5%, Hawaiian at 4%, and Caucasian at 63%. The difference can be explained by targets and outreach activities. Baseline data targets were Hispanic & age 18-59; Respite Rx data reflects outreach to rural communities and age 18-59 targets.



In 2018, there were 3.23 times more white (non-Hispanic) residents (1.47M people) in Nevada than any other race or ethnicity. The 5 largest ethnic groups in Nevada are White (Non-Hispanic) (48.4%), White (Hispanic) (15%), Some Other Race (Hispanic) (11.4%), Black or African American (Non-Hispanic) (8.78%), and Asian (Non-Hispanic) (8.06%).

The most common foreign languages spoken in Nevada are Spanish (606,278 speakers), Tagalog (Incl. Filipino) (86,983 speakers), and Chinese (Incl. Mandarin, Cantonese) (32,506 speakers).

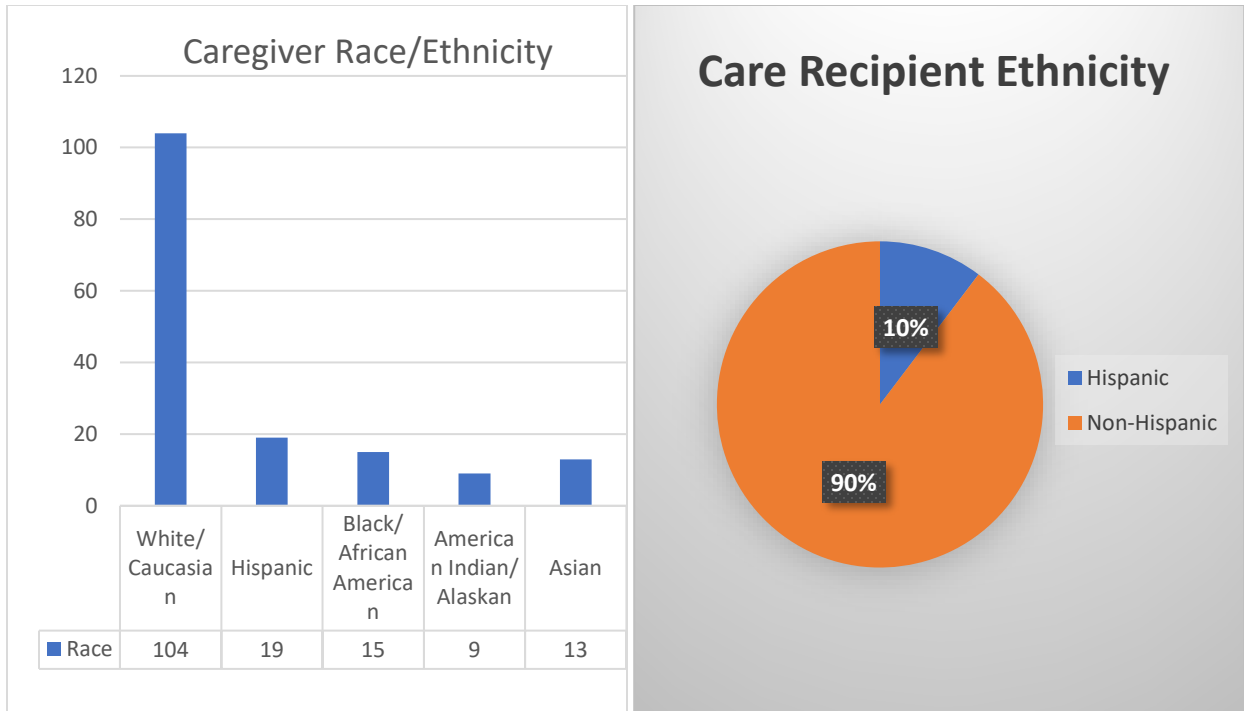
Diversity/Inclusion of Minority Groups

If diversity is defined as “different perspectives,” the Respite Rx program had good diversity among caregivers. Of the social identity constructs that would create diversity, caregivers were polled only about a small fraction: race, ethnicity, ability, age, sex, geographic region, marital/relationship status, and use of English. Nothing was polled regarding citizenship, educational levels, religion/spirituality, gender identity/expression, indigenous/tribal affiliations, nation of origin, parental status, political affiliation, or skin color/physical characteristics. Any awareness of these only came through staff interaction with caregivers but were not well documented in case files.

In future respite programs that aim for inclusive practices, “feeling welcome” would be the best criteria for measurement, based on emerging research. To achieve equity practices, then “fairness” would be the right criteria to measure - in allowing caregivers to receive and use the same funding benefit but tailored for their unique circumstance. These criteria were not included in the Respite Rx program for measurement but were essentially incorporated into program practices.

Through self-direction and person-centered design, Respite Rx did honor inclusive practices, such as allowing caregivers to set the rate of pay for their workers, removing limits on the pool of providers, or accepting use of familial/friend relationships for care – barriers that may have prevented use of respite.

Caregivers were asked for both their race & ethnicity (see chart below).

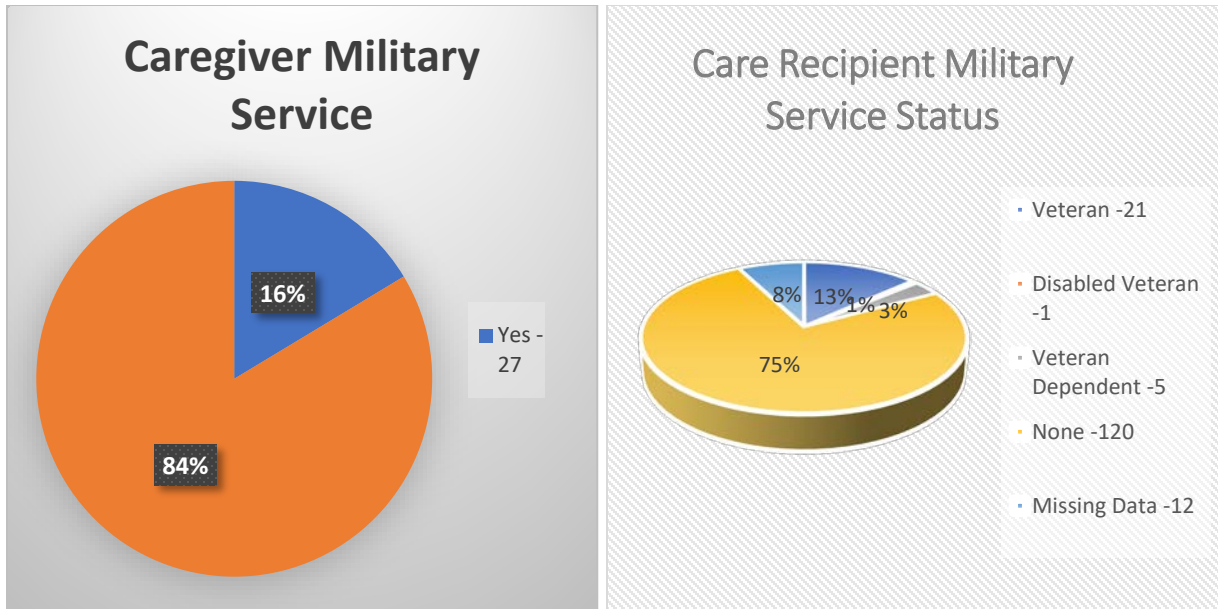


Care Recipients were only asked about their ethnicity (see chart to the right).

Inclusion in LGBTQ community might only be drawn from relationship data. When a male was a spouse/significant other of another male (Total Count 1), or female espoused to another female (Total Count 1), an assumption was made to their inclusion in the LGBTQ community. Respite Rx staff also learned through communication with applicants about identifying names or terms they preferred to use. One care recipient was listed as a male, for example, but preferred to be called by a female name, allowing for a similar assumption. Otherwise, no data reference can be used to determine LGBTQ diversity.

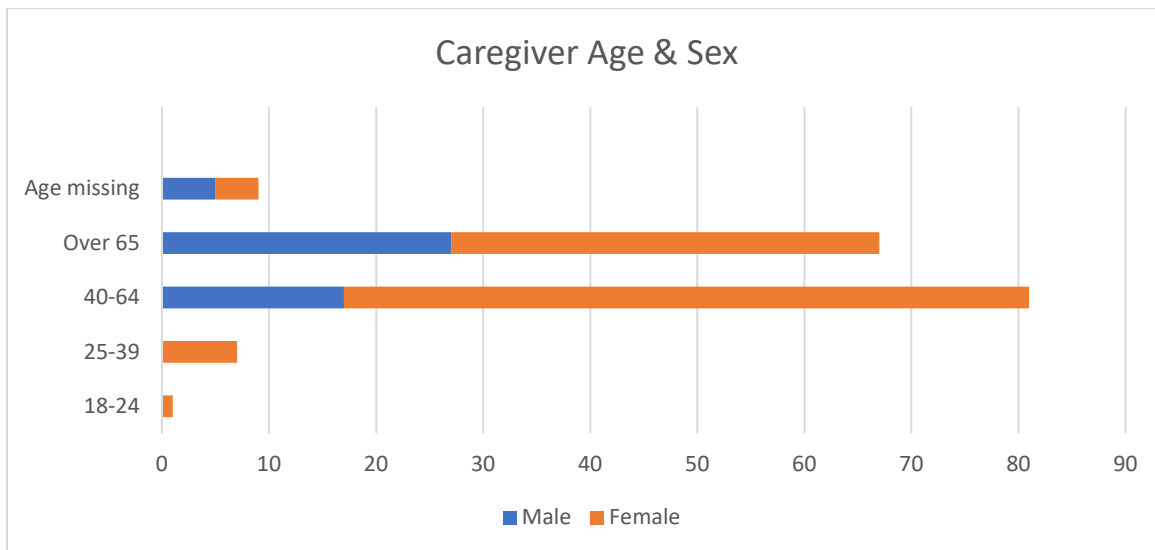
Military Status

Both caregivers and care recipients were asked if they had served in the military, but military service status was only asked of care recipients. Those applications missing military status have been grouped with the “NO” responses and are included in the following charts.



Caregiver Age & Sex

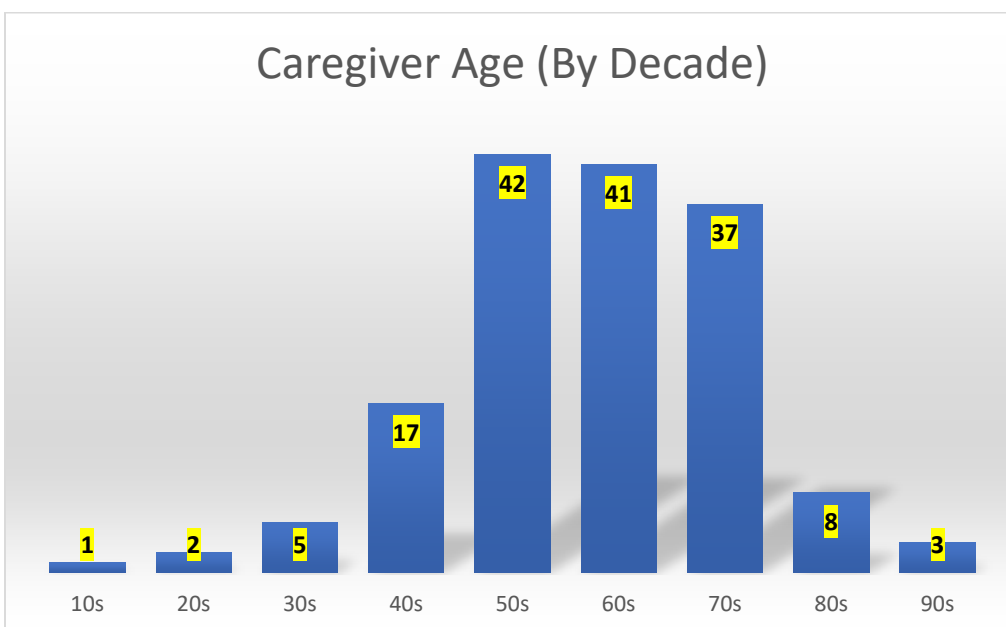
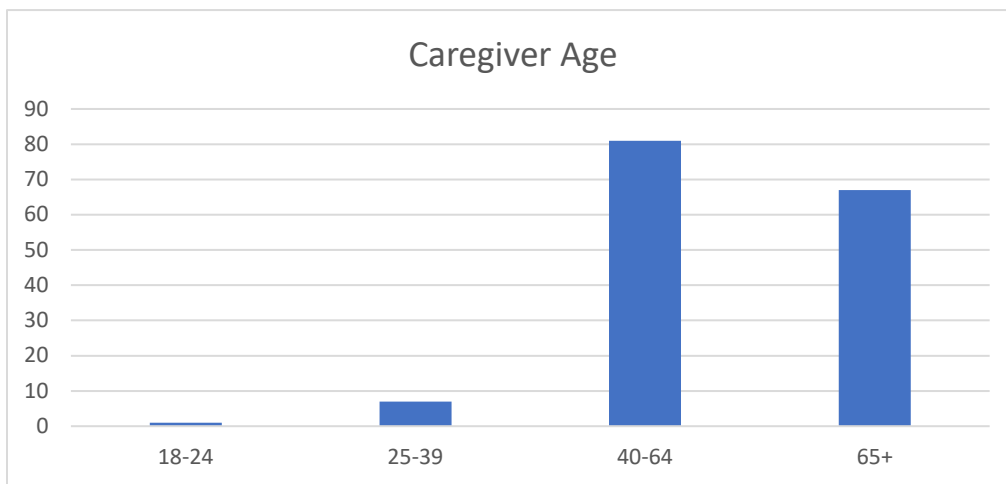
National studies in 2015 show caregivers of older adults (aged 50 and above) have an average age is 49 – and 34% were seniors themselves. Our data showed Respite Rx caregivers are significantly older (at 62 years of age on average) – and 43% were aged 65 or older.

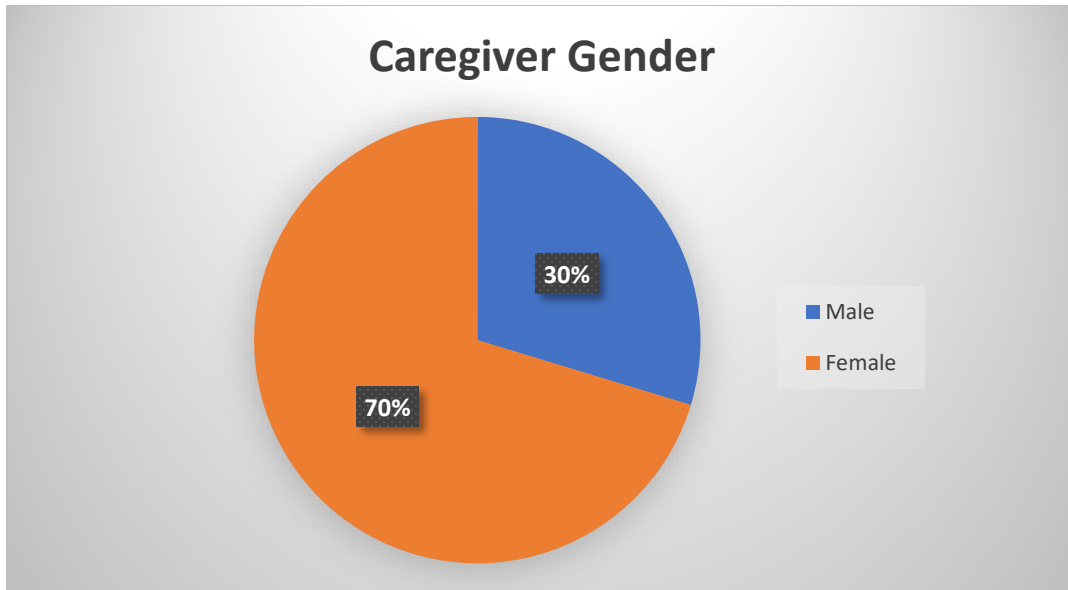


The average age of a family caregiver is 49 — but nearly 10% are seniors themselves. Caregivers over the age of 75 are most likely taking care of a spouse or partner. Caregivers spend an average of 24.4 hours a week providing care, but 23% spend more than 41 hours per week caregiving.

- Distribution of caregiver age:
 - Average age: 49.2 years old
 - 48% of caregivers are 18-49 years old
 - 34% of caregivers are 65+ years old

Forty-nine percent of the caregivers were aged 40-64. Our oldest caregiver was 92 years old. Our youngest caregiver was 18 years of age.



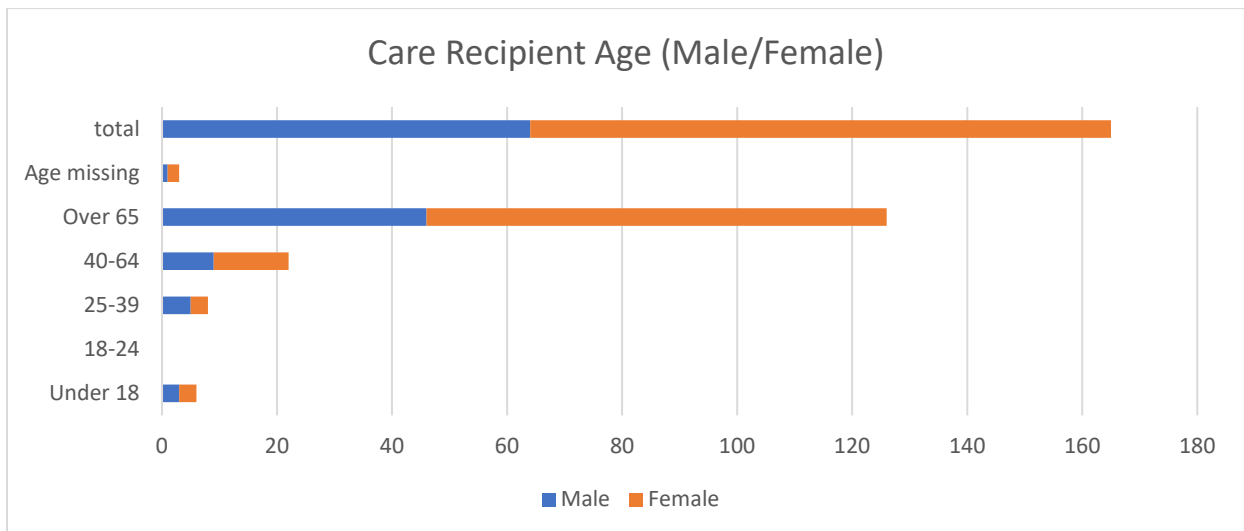


Compared to 2012 baseline data, we have more male caregivers in our program (30% vs. 17%), matching trends nationwide that show men are becoming caregivers at much higher rates than previously studied.

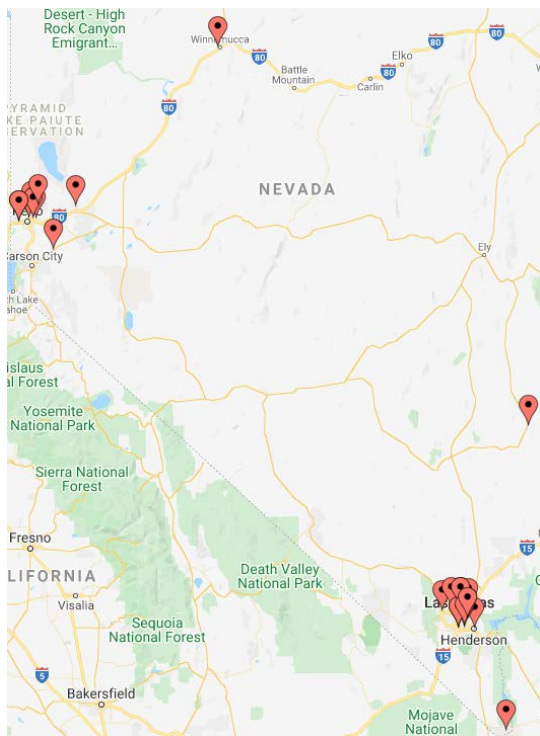
According to the Caregiving in the U.S. 2015 survey, 40 percent of family caregivers of adults are men, which equates to 16 million male family caregivers in the United States.

While our target for care recipients continued to be the underserved aged 18-59 group, we did not limit eligibility or participation in Respite Rx to any age range.

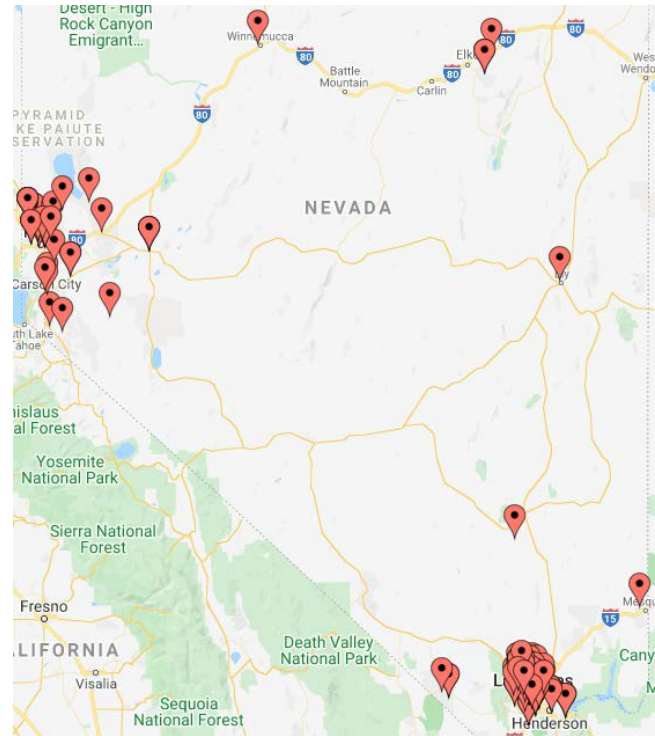
In the Respite Rx program, 61% of the care recipients were female; 39% were male. Given that women typically outlive men and the large weighting of the program in the 65+ age group of care recipients, our program experienced typical imbalance in gender demographics.



The weighting of senior care recipients in the program is also reflected geographically, highest in the urban areas of the state. Because rural areas of the state are aging, Respite Rx picked up more senior care recipients in the rural areas than those in the target age group of 18-59.



All applications with care recipients ages 18-59



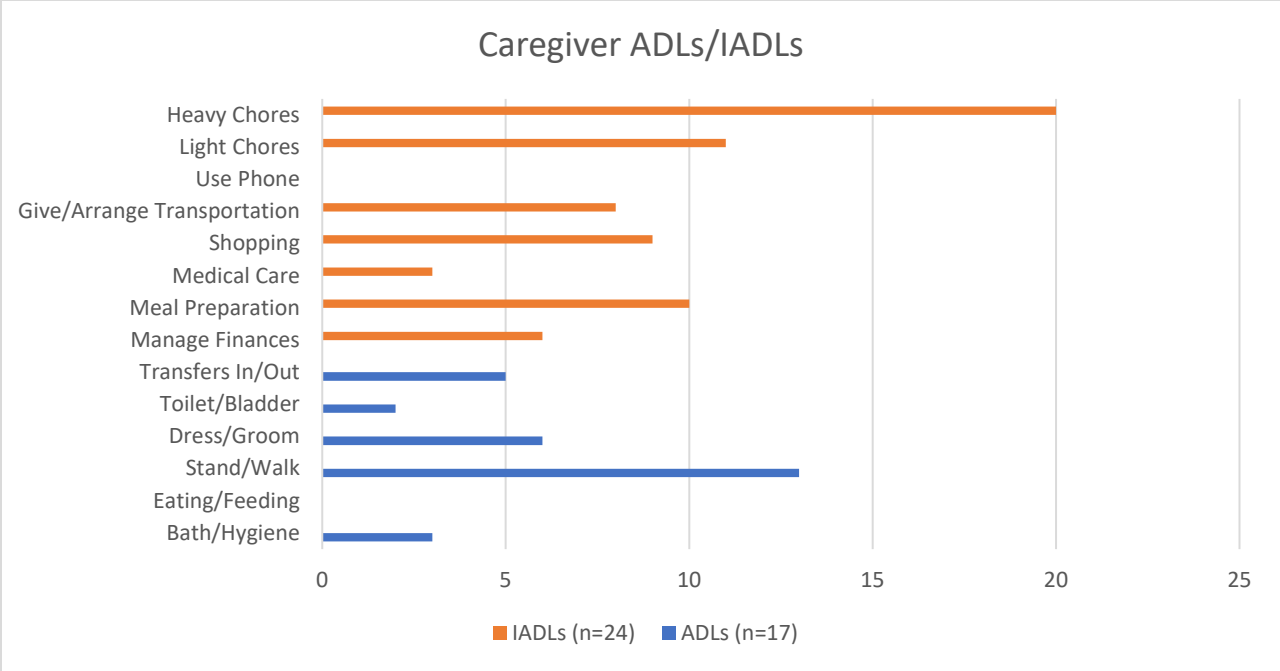
All applications with care recipients age 60 and older

Caregiver Support Needs/ADLs/IADLs

Most caregivers had no health limitations of their own. However, 14.5% of caregivers in Respite Rx did have their own health limitations or concerns while also giving care to another.

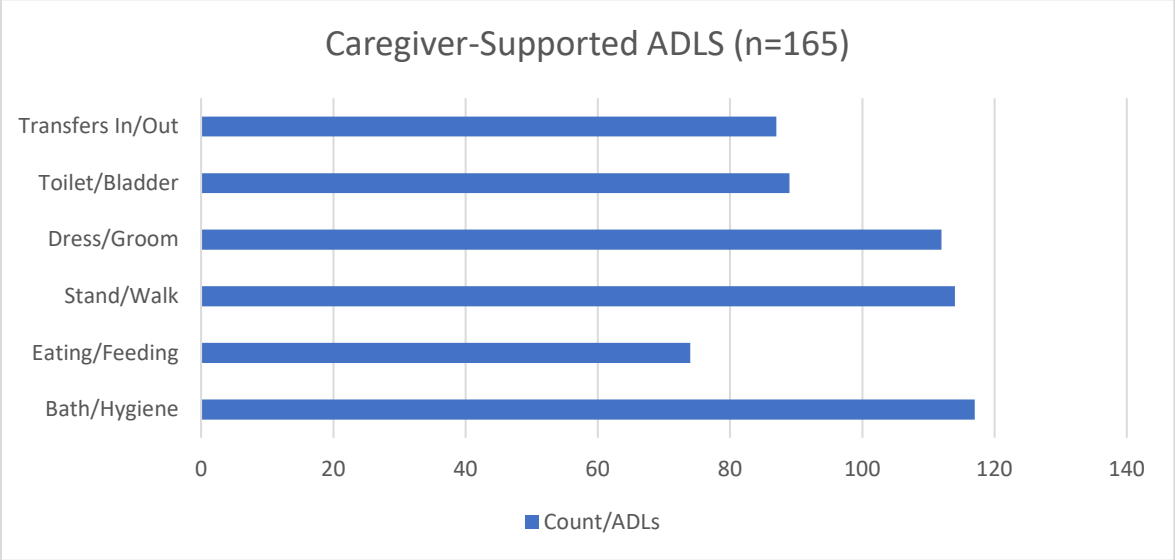
Instrumental Activities of Daily Living (IADLs) - Caregivers with IADL limitations were noted for their advance age, minority culture and language barriers, or even inexperience in managing certain aspects of their lives. Limitations prevented caregivers from completing heavy chores (20) or light chores (11), preparing meals (10), or using transportation (8). Cultural differences or inexperience with managing certain aspects of their lives may have interfered in IADLs for specific caregivers, as shopping (9), using transportation (8), and managing money (6) were the most common among this group.

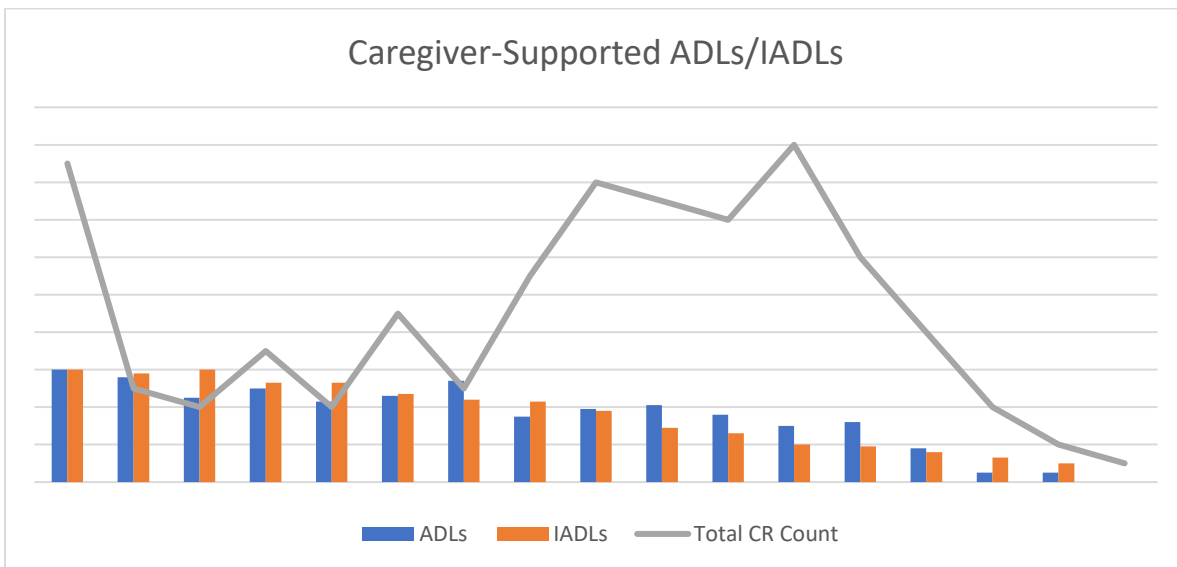
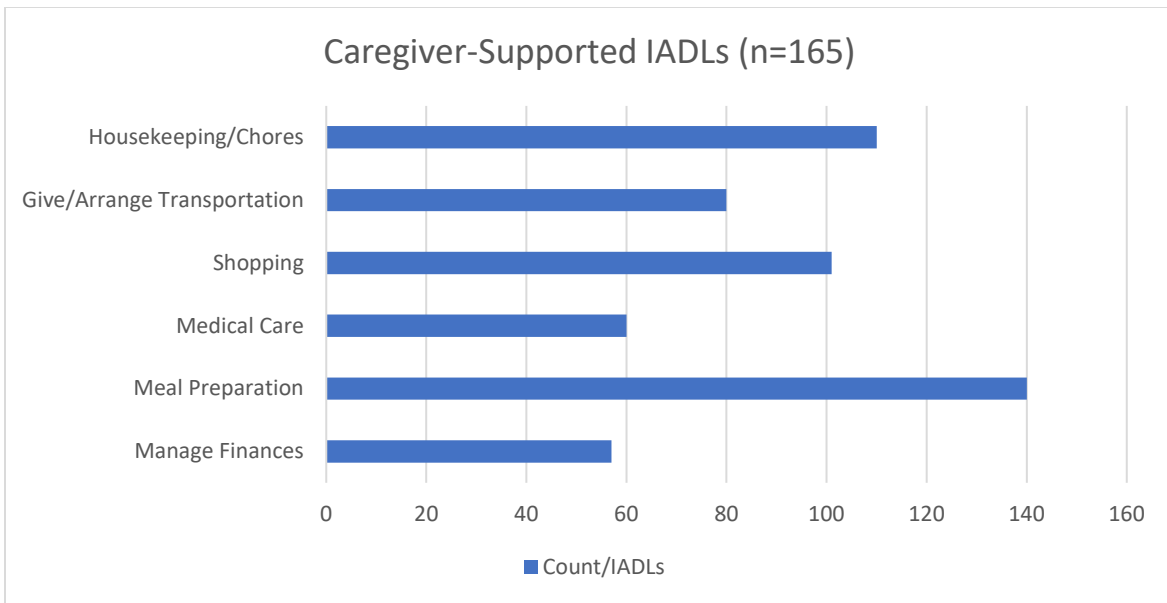
Activities of Daily Living (ADLs) - Two caregivers had limitations due to recovering from surgery, one is receiving weekly kidney dialysis treatments, but most caregivers reported difficulty walking (13). Of the caregivers who cited ADL limitations, ten of them were 70+ years old and may have age-related challenges.



Care Recipient Disability & Support Needs

Respite has typically been recommended to caregivers dealing with high skill levels of care or for care recipients who have greater loss in activities of daily living. This may force caregivers to wait until near the end of their caregiving role before finally receiving respite services. Respite Rx did not put a limitation on when respite could begin. Many caregivers who sought respite support were already dealing with high levels of care but still did not qualify for or receive respite that met their needs, until a “gap” program was available to them. Priority funding for respite has been tied the Medicaid eligibility.



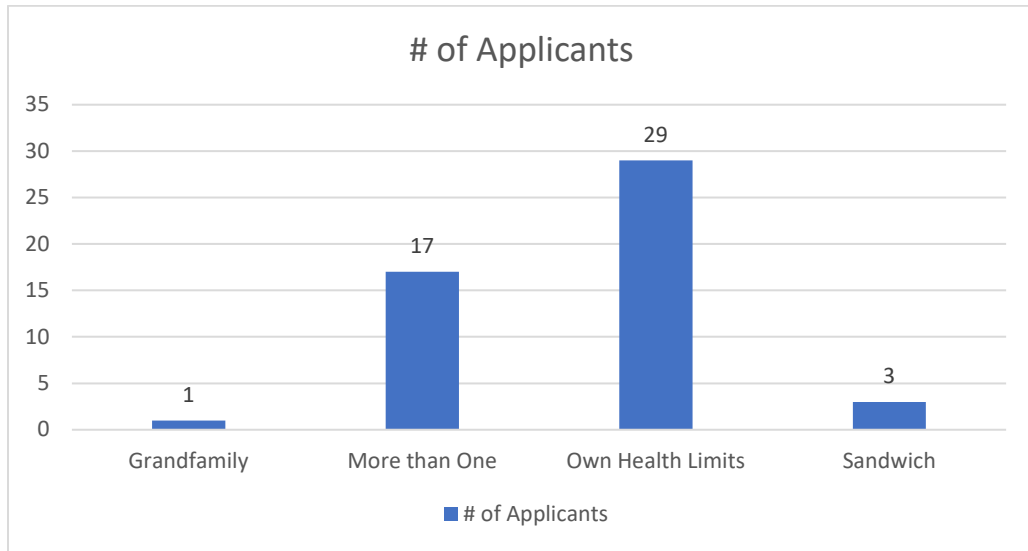


One thing the Respite Rx data shows is that the demand for respite begins to grow when the assistance needed with ADLs/IADLs is just starting to grow. The peak demand for respite was when only about 39% of the Care Recipient’s ADLs/IADLs now required assistance. The average number of supported ADLS at that point is 3; the average in IADLs is 2. At that point, the ADL care needs are highest for Meal Preparation (17), General Supervision (15), and tasks associated with potential fall risks (Stand/Walk – 13, Bathe/Hygiene – 12, Transfers In/Out – 10).

Complexity/Compounding of Care

If a caregiver cares for an older person yet also has minor children at home, they are part of the “sandwich generation.” Grandparents raising grandchildren are called “Grandfamilies.”

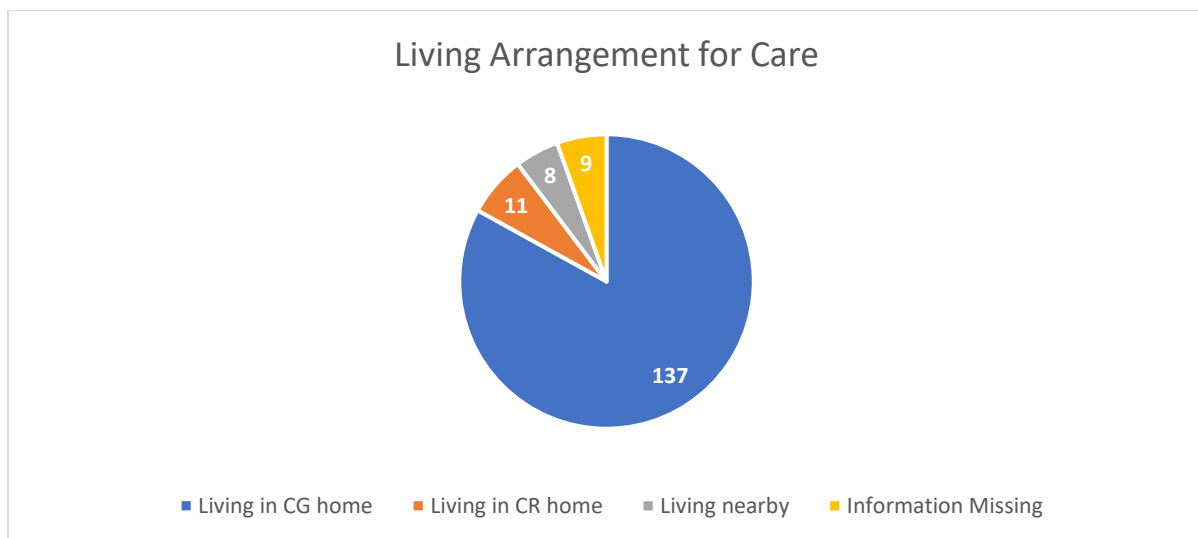
If the caregiver cares for more than one person with special needs (including minor children), they are a “compound caregiver.” This term also applies to caregivers with health or physical limitations of their own who are providing care to another.



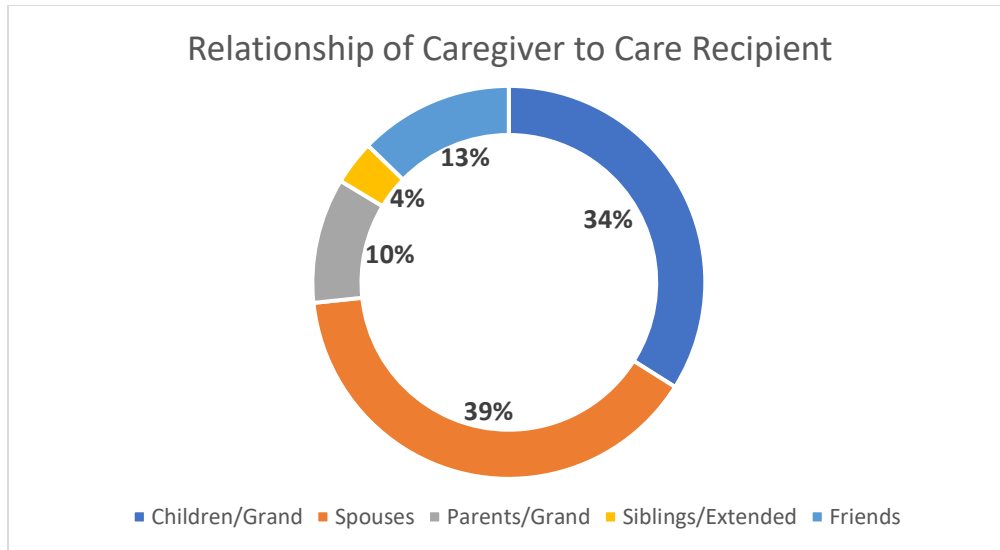
It is not well documented whether caregivers entered their care role with existing health issues or whether caregiving contributed to these health issues. Both are likely true.

Caregiving Role/Relationships/Living Situation

Most caregivers have the care recipient living in their home (137), with only eleven caregivers living in the care recipient’s home. Another eight caregivers live nearby and go to the care recipient’s home to provide care.

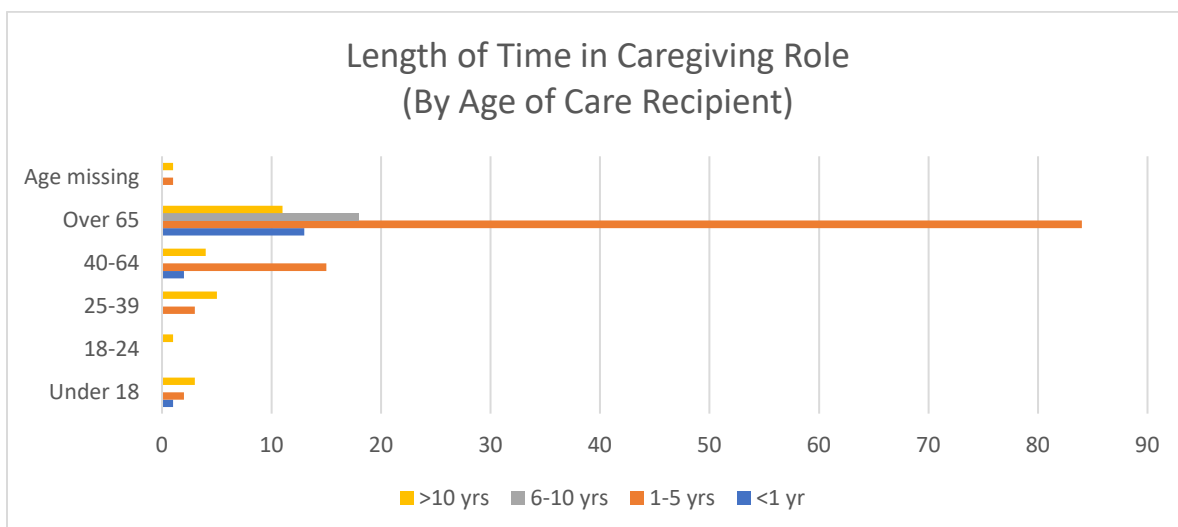


The caregiver is most often a spouse (39%) or a child (34%), but friends are also stepping up to provide care (13%). Continued development of friendships and preservation of friend relationships needs to be a future focus of study and effort for care recipients who are single and childless.



Length of Time in Caregiving Role

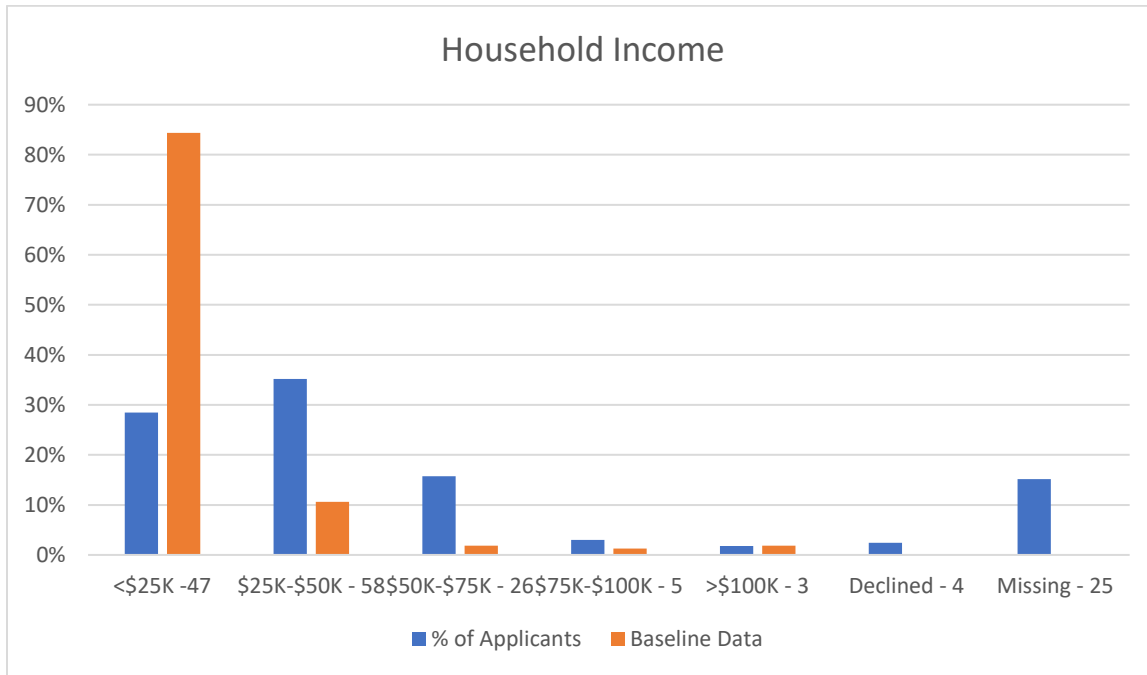
Most caregivers responded that they had been providing care for 1-5 years (63%), and they predominately served care recipients over the age of 65 (84 total). This indicates that respite is sought when the experience of care is already long-term. Familiarity with the caregiving role takes precedent over respite services.



Household Income Levels

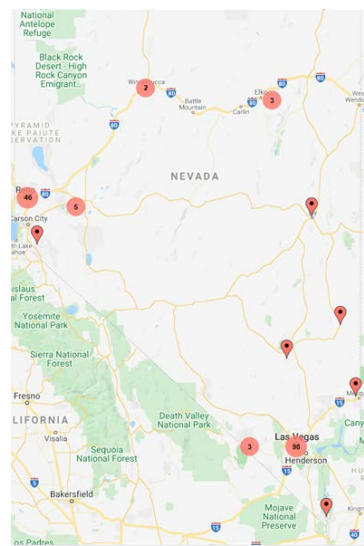
Respite Rx placed no income limits on applicants. Although not placing income limits on who received voucher funding could have unfairly benefited families with higher incomes, Respite

Rx shows no evidence that the distribution of vouchers was given to families who might have had less need for funding. For comparison, baseline data from 2012 has been included. (The 2012 baseline data did not provide missing/declined numbers to provide data for comparison).



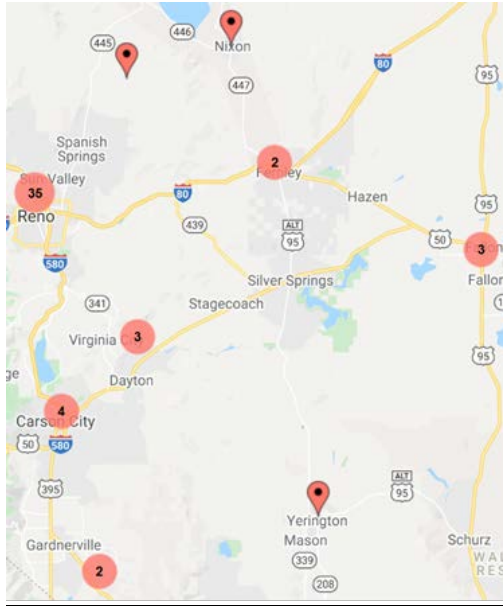
Geographic Reach of Respite Voucher Program

With two large urban areas in a mostly rural state, most of the applicants were concentrated in Clark and Washoe counties. While good statewide outreach would generate caregiver representation in every county in the state, Respite Rx reached 11 out of 17 counties (Clark, Lincoln, Washoe, Carson, Lyon, Churchill, Douglas, Elko, Humboldt, White Pine, and Nye). However, Zip Code Mapping shows a nice distribution statewide and in the heavily populated counties.



*View of all applications received by zip code in NV
(does not include one application from NY state)*

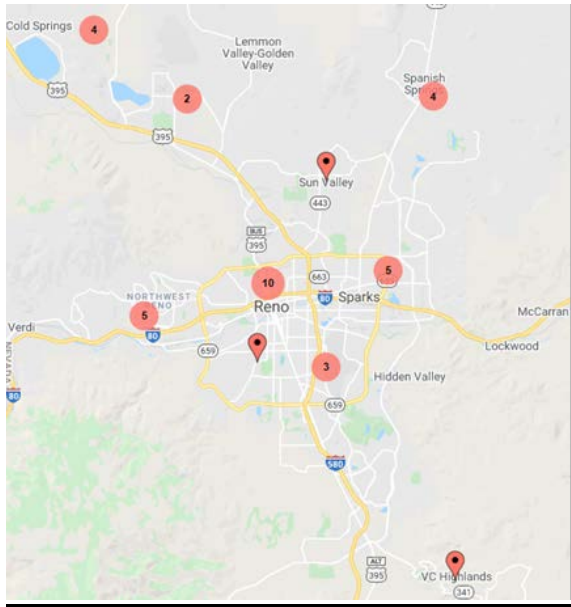
Northern Nevada Metropolitan and Rural Areas



*View of all applications received in **Northern Nevada** towards the **North-Eastern** side of the*



View of all applications received by zip code in NV (does not include one application from NY state)



*All applications received in the **Washoe County, Reno-Sparks** area.*

Southern Nevada Metropolitan Rural Areas

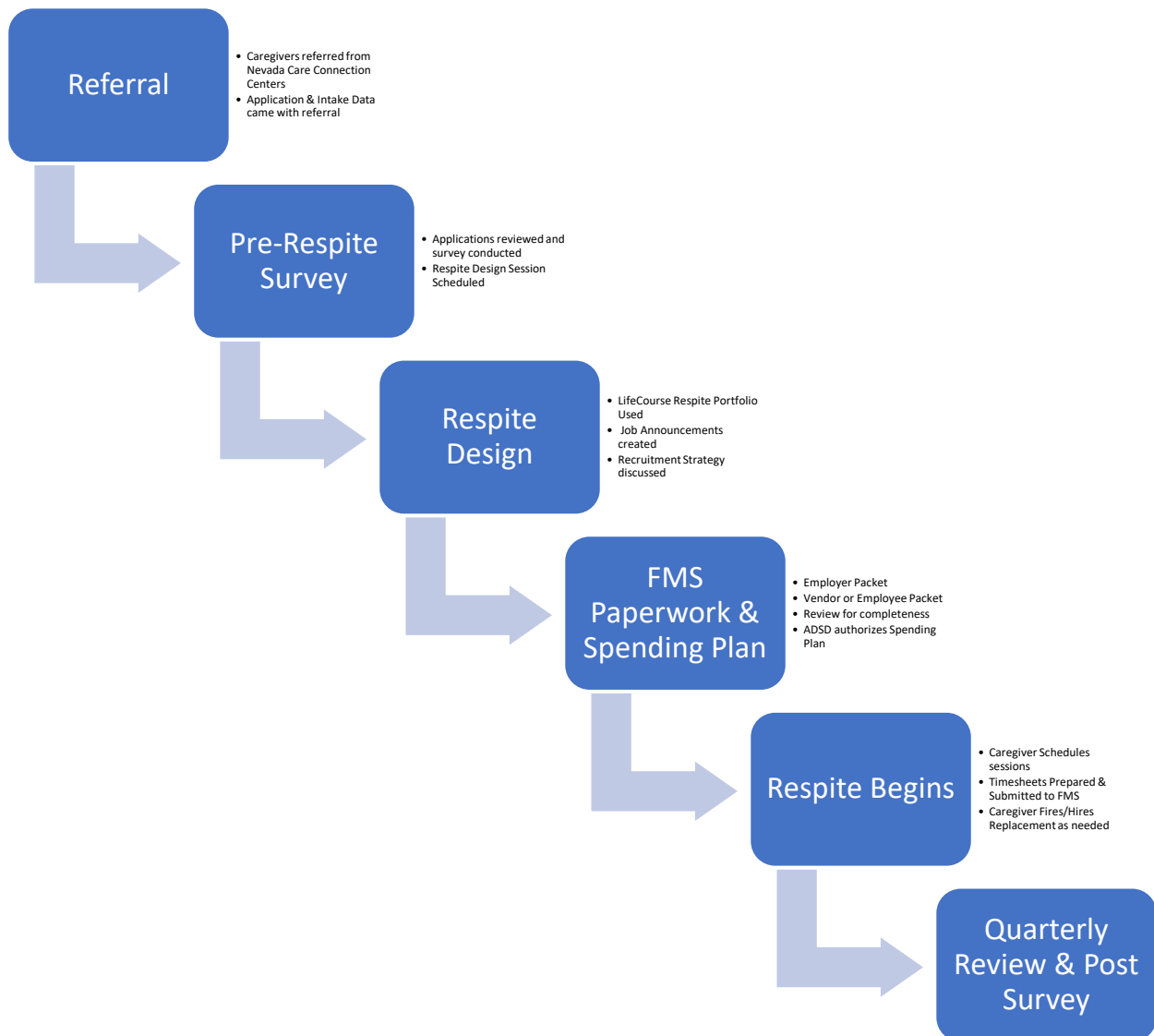


All applications received in Las Vegas metropolitan and rural areas.



Las Vegas Major Metropolitan area

Appendix S: Administrative Process



Referral

Nevada Care Connection Centers identified caregivers, provided Respite education, and referred into existing respite programs, including our “gap” program, Respite Rx.

Staff time at the Nevada Care Connection Centers is estimated at 45 minutes per caregiver for Respite intake, application, and referral. Data collected at intake was sent on to Respite Rx for analysis. Referrals would occur within a couple of days from intake.

Pre-Respite Survey

Caregivers were contacted within 3 days of application, via phone, and a pre-respite survey was conducted. Application materials were review and the Respite Rx program explained.

Caregivers were accepted into the gap program and notified. A Respite Design appointment was scheduled with the caregiver during the upcoming week.

Staff time estimates of 30 minutes per caregiver to conduct survey, review, and prepare acceptance letter.

Respite Design

Using the LifeCourse Respite Portfolio, information on the caregiving situation was gathered. Caregivers discussed what they needed and when respite would fit in their lives. Recruitment and/or vendor selection was discussed. Job descriptions were prepared, as necessary. Caregivers had the responsibility to recruit or select their respite workers. Staff provided some assistance in dissemination of job announcements. Staff time commitment to these Respite Design activities averaged 1.25 hours.

Caregivers often had friends or family members they wanted to hire. Unfortunately, if caregivers did not already have someone quickly identified for respite work, it could take 2-3 months to recruit, select, and hire a respite worker. This caused significant delays in receiving respite services. Staff provided guidance as needed to keep recruitment efforts moving forward. Staff time estimates for developing job announcements and recruitment dissemination on average 15 minutes for each caregiver needing additional assistance.

FMS Paperwork & Spending Plan

As required by the FMS agency, several forms and additional documents were needed to establish an employer-employee relationship for payroll processing. Employer packets had 8 pages of forms to complete, and employee packets had 9 forms and a few additional documents to include. Vendor packets had 3 forms to complete. Signatures of both parties were required in several forms.

ADSD also required a Spending Plan to be written for each caregiver to authorize funding for respite services. The Spending Plan sets the rate/number of respite hours available to a caregiver and identifies the worker(s) or vendor(s) to be paid under the contract. Caregivers would sign off on this spending plan and the contract limits associated with their participation in the Respite Rx program. Spending plans could be adjusted to accommodate caregivers with unusual circumstances, but this was rarely needed. If necessary, a Risk Assessment form was used to explain how to handle the Spending Plan differently.

The hourly cost of respite ended up being very close to the “working hypothesis” average of \$15/hour. The range was \$8 to \$26 per hour, with the average being \$14.49. That is statewide.



The authorized Spending Plan allows the FMS to bill ASD directly for the payroll expenses associated with the respite services delivered. It includes any employer-paid taxes and background check fees. The FMS receives the authorized Spending Plan with the other documents submitted. The FMS would process these “enrollment” documents within 1-2 weeks, depending on when background checks were completed.

These documents were unfamiliar to caregivers and required sensitive information. Employment verification eligibility, banking information, tax information, and other identification was collected. Staff provided paperwork reviews with caregivers, respite workers, and vendors as needed. This was necessary to prevent errors in the paperwork and to assess if anything was missing before submitting it to the FMS agency. Staff spent an average of 15-20 minutes per caregiver in paperwork overview, and another 15 minutes in reviewing submitted paperwork for completeness.

Respite Begins

When FMS enrollment was complete, a caregiver could begin to use their respite hours and schedule their respite session with the vendor/worker they had selected. The FMS would process timesheets on a bi-weekly basis. Problems would usually occur during the first few payroll cycles. FMS communication with the caregivers and respite workers was minimal, and Respite Rx staff would need to get involved to resolve FMS issues with timesheet errors, missing documents, and other irregularities. Staff estimates of time to intervene when issues arose was 30-45 minutes with each caregiver.

Financial Management Service

We know that pay issues for their respite workers have been the top problem we have encountered. Usually, it is problems submitting the timesheets accurately, and the problem is first noted when an employee missed a paycheck deposit. We run interference between the employer/ employee and FMS to resolve these issues as quickly as possible. It has been a problem that we know is best addressed through communication with the FMS, but it leaves caregivers worried about scheduling respite with a worker who is not getting paid on schedule.

Experience with the FMS payments against the Spending Plan indicates that the full allotment of hours is not getting used – something expected, based on the experience of other states and other voucher programs. So, we use the quarterly review to gather the “why” to their usage, and the response varies. Respite is not something they have regularly fit into their lives, and they struggle to give themselves that opportunity. This is one of the main reasons we want them to schedule regular doses of respite – to experience life with respite built in.

Check-ins and survey data collection

quarterly review is a check in with caregivers on how the program is working for them, any problems or changes that need to be made to their spending plan, and any feedback on their respite experiences. This review was informal and conducted typically via phone or through Microsoft Forms. Unfortunately, we lose a lot of care recipients in that first quarter of services, reinforcing the idea that we are getting caregivers at the END of their caregiving career, rather than at the beginning.

The Post-Respite surveys are to be conducted after the caregivers had completed their time with the Respite Rx program. This survey mirrors the Pre-Respite survey, and asks about the health, safety & wellbeing of the caregiver. It also provides the program with feedback on participation in Respite Rx.

Administration Program

Although self-direction may have a meaning of having the caregiver drive their services there was a huge administrative undertaking by program staff to ensure caregivers were provided support to access respite. The Program Coordinator assisted each caregiver from having initial contact after referral was submitted, to getting the caregiver to utilize the self-direction pilot program on the front end. On the back end, Aging and Disability Services Division staff tracked expenditures for each caregiver, reconciled timesheets and invoices sent to us by the FMS, tracked monthly and yearly expenses, and kept documentation on the financial piece of the program. As the project coordinator’s case load grew, ADSD staff supported in various ways from contacting clients for quarterly and post surveys to working with clients as questions or issues arose from time to time.

Products Developed:

Respite Rx Products

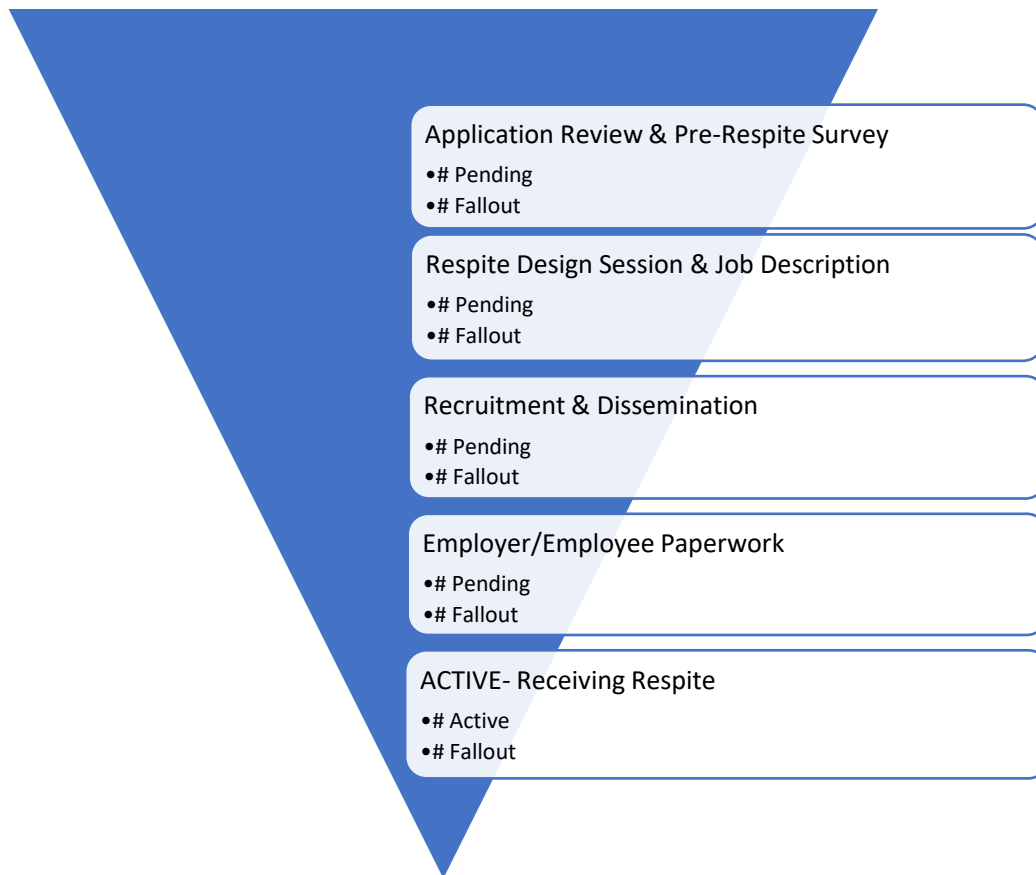
- Intake form and application for caregivers to complete or referral partners to complete on the caregiver’s behalf
- Training Information for referral partners to use
- Spending Plans for participants to plan out respite usage
- Caregiver Handbook to help guide participants on program activities, FMS paperwork, do’s and don’ts, etc.
- Letters to Participants at different stages of their program (application to program, acceptance into the program, put on a waitlist, withdrawn from the program, thank you, etc.)
- Pre, post and quarterly surveys to examine program effectiveness and gain feedback
- Outreach materials including PowerPoints, flyers, brochures to publicize and inform the public/target populations of program availability and purpose
- Flow charts and policies and procedures for internal program processes

Dimension	Definition	Options
Mode	Method of contact between interventionist and participant	Telephone contact with primary caregiver only or including other family members at primary caregiver’s discretion. Secure web conferencing with primary caregiver only or including other family members at primary caregiver’s discretion. Email Text, if preferred by primary caregiver Mail, if preferred by primary caregiver
Materials	Materials used in the delivery of the intervention	Manual Internet resources, including links to websites, videos, and articles. Printed resource materials for those without internet access
Location	Where the intervention is delivered	Telephone or secure web conference calls are placed to location of primary caregiver’s preference (often their home; cell phone use is common, so location is frequently varied.)
Schedule	Duration and intensity of intervention	Application & Referral – Nevada Care Connection Pre-Respite Survey/Application Review Respite Design Session Job Position Announcement PALCO Paperwork Review Ad-hoc sessions COVID-19 checks Post-Respite/Quarterly Reviews

Scripting	Level of detail guiding interaction between the interventionist and the participant	Semi-structured intervention Some specific language provided with elaboration encouraged Topics specified but not necessary to discuss. Decisions of which topics and when discussed is personalized based on the primary caregiver's needs and preference General guidelines provided
Sensitivity to participant characteristics	Extent to which participant background, experience and abilities are incorporated in the delivery of intervention	Outside of personalization of session content/topics, language preferences, literacy, visual supplements/augmented communication have not been incorporated (nor requested by participants)
Interventionist characteristics	Qualifications and training. Concordance with participant characteristics	Educational level Personal or profession experience working with individuals with special healthcare needs and their families Understanding and experience working with family systems.

Appendix T: Respite Rx Funnel

Respite Rx Funnel:



This process funnel helps visualize the 5-step process for a caregiver to get respite services. Numbers tracked on pending or fallout applicants allows the program to see where additional intervention or strategies may need to be employed.

- 1. Application Review & Pre-Respite Survey-** Once the Intake Referral and Application have been completed and submitted:
 - a.** Coordinator reviews the documents to identify service gaps and respite needs. Caregiver and care recipient both need to be Nevada residents.
 - b.** Coordinator contacts caregiver to conduct Pre-Respite Survey, confirm information on application & referral, and describe how Respite Rx program works. Coordinator will make 3 attempts to contact caregiver from application & referral materials. Typically, the attempts are by a) phone, b) email, and c) a mailed request for reply. If the caregiver does not respond, the application is denied, and the referring agency notified. If the caregiver does respond, step one is completed, and a respite design session is scheduled for the upcoming week and contact numbers confirmed.

- c. Letter of acceptance (or denial) into the program is sent to caregiver and referring agency.
- 2. **Respite Design Session & Job Description-** The respite design appointment is to learn about the caregiver, care recipient, and discuss the supports they need or have in place by using the My LifeCourse template. This helps family caregivers create a plan to access respite services within and outside the formal services system. This typically takes about an hour.
 - a. Person-centered counseling on fitting respite into their lives.
 - b. Benefits sought from respite identified.
 - c. Strategy on how caregiver will use their respite and execute their plan, including recruitment strategies, discussed.
 - d. Draft job description for respite worker.
 - e. Provide evidence that respite is the service wanted/needed and document if the caregiver and/or the recipient are willing to utilize the Respite Rx program.
- 3. **Recruitment & Dissemination-** If needed, the coordinator works with the caregiver to create a job posting they can share within their network or post on social media or post on employment sites. The job posting must receive the caregiver's approval before used for recruitment. Handouts for interviewing/selecting respite workers is provided, if needed. After the posting is disseminated; the caregiver awaits responses, begins to interview individuals interested in the position, and determines who they would like to hire. This takes the most time as it is difficult for caregivers to find a respite worker when they do not have anyone already identified for the position. Recruitment and job posting dissemination strategies utilized have had inconsistent results. Caregivers can request background checks on their employees.
- 4. **Employer/Employee Paperwork-** This is a paperwork-intensive step in the process, and all parts must initially be submitted together.
 - a. **Fiscal Management Service (FMS) Paperwork & Review-** The coordinator sends via email, mail, or fax the documentation needed to enroll an Employer-of-Record and the Vendor or Employee hired for the respite position. A caregiver may hire up to two different vendors/workers under their contract, either to split the contract hours between them or designate one as a backup. An additional appointment with the caregiver/worker(s) is scheduled to go over the paperwork and answer questions to mitigate any delays with FMS. The Employer of Record forms are completed once; the vendor/worker forms may need to be completed multiple times if caregivers make changes to the contract.
 - b. **Spending Plan-** The ADSD Respite Rx Spending Plan is also developed to authorize the FMS to accept ADSD payment on behalf of the employer and worker. Requests for background checks are also included on the spending plan. The spending plan may need to be completed multiple times if caregivers make changes to the contract.

5. **Actively Receiving Respite-** The caregiver schedules respite sessions with worker/vendor and signs off on the respite worker's timesheet in a timely manner to submit/receive payment on a bimonthly payroll schedule. Timesheets & vendor invoices are submitted directly to the FMS for payment. Coordinator may need to facilitate communication between FMS & caregivers/workers and intervene when errors or delays create non-payment issues. Communication on when background checks are complete, enrollment paperwork has been processed, or when missing items or warning flags are identified is important in allowing caregivers to start respite sessions.

Nevada Lifespan Respite Rx Pilot Program

Caregiver Handbook 2019



Important Phone Numbers

Nevada Care Connection Resource Centers (NCCRCs)

Identifies eligible caregivers and assists in the application process.

Northern Nevada

Access to Healthcare Network (877) 861-1893

Servicing Washoe, Carson, Douglas, Storey, Mineral, Elko, Eureka, Humboldt, Lander, and White Pine counties

William Pennington Life Center (775) 423-7096

Servicing Churchill and Mineral counties

Lyon County Human Services (775) 577-5009

Servicing Lyon county

Southern Nevada

Nevada Senior Services (844) 850-5113

Servicing Clark, Lincoln, Nye, and Esmeralda counties

Nevada Aging and Disability Services Division

Provides program oversight, administration, and processes payment for FMS service.

Planning, Advocacy, and Community Services Unit

Jamie Ahumada (775) 684-5881 | JAhumada@adsd.nv.gov

Autumn Blattman (775) 687-0973 | ABlattman@adsd.nv.gov

PALCO-Financial Management Services

Website: www.PaLCOFirst.com

1-(866) 710-0456

Respite Rx Program Coordinator

Approves applications from eligible caregivers, assists in designing respite services, and prepares spending plans.

Cheryl Dinnell (775) 401-4163 | CDinnell.contractor@adsd.nv.gov

Introduction to the Respite Rx Program

Caregivers have gone from being completely invisible to starting to be recognized as the largest long-term care workforce in this country. Caregivers are finally being seen as critical members of the long-term care team. Whether the care is for a child with Down syndrome, a younger adult with traumatic brain injury, a spouse with multiple sclerosis or a parent with Alzheimer’s disease, more attention is now being paid to caregivers' key role in helping them to live fully and successfully in the community. For younger adults and for rural families, access to respite “programs” is almost non-existent. Younger adults do not qualify for programs for children or seniors. Rural families can be isolated. But every family has connections – through work, church, neighbors, family relations, community organizations, and agencies. Together, we work with the caregiver to identify sources for respite that can be built through those connections. This expands the access of respite beyond traditional respite programs.



Respite Rx is a caregiver-directed service program. The program is administered through the State of Nevada Aging and Disability Services Division (ADSD), in partnership with the Nevada Care Connection Resource Centers (NCCRCs). Funding is provided by the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS). Respite Rx is a federal grant-funded opportunity and will end on August 31st, 2020.

Welcome to the Respite Rx program. This program is a caregiver-directed approach to providing respite support to eligible caregivers. As a participant in the Respite Rx program, you will direct the spending of your annual respite budget. This program gives you the **CHOICE, CONTROL,** and **FLEXIBILITY** in how you spend your monthly budget to meet your respite needs. This allows caregivers to have the flexibility to hire respite providers they feel comfortable with through an established service plan.

Prior to your first appointment with the Program Coordinator, feel free to read through this handbook and write down any questions you may have. You can also review it with the Program Coordinator during your enrollment period.

Who Qualifies for the Program?

To be eligible for the Respite Rx program, a caregiver must meet the following criteria:

1. Be an unpaid caregiver for an individual with disabilities, special health care needs, or condition related to aging
2. Recognize respite as a valuable resource that the caregiver will use to achieve or maintain the caregiver's optimal level of functioning, comfort, and independence

Before you can recognize that respite is a valuable resource, you must first acknowledge that: a) you face important challenges daily, and b) the stress response they cause has a direct effect on your body and mind. Even though picking up after another person or helping someone around the house may seem like small things, they add up. These responsibilities also keep you from doing the things you would normally do to stay well and happy.

Respite Rx is a pilot program, which means that the participants in the program will have up to one year to receive Respite Rx services. However, participation in the Respite Rx program helps Nevada learn about what kinds of services are needed for caregivers and what the benefits and challenges are of a program like Respite Rx.

What are the Goals of the Respite Rx Program?

The Respite Rx program's primary goal is help you design respite with your needs in mind. The Respite Rx program aims to help:

1. Enhance caregiver control over decision-making and use of service
2. Enhance flexibility in services to match caregiver circumstances and preferences
3. Enhance convenient access to respite
4. Enhance affordability of respite
5. View respite as a multi-component service (time to engage in other activities/services)

The Respite Rx program empowers you to have autonomy over the services you receive.



We work with caregivers to design a respite voucher that will work best for them. The caregiver decides the when/how/where/who & cost of the respite provision, and selects a provider of choice, not only from professional providers, but from friends, family, neighbors, and community members as well.

Instead of offering a respite program with limits on how respite is delivered, we offer the flexibility to arrange respite whenever it meets caregiver's need – any time, including after hours, overnight, weekends, in smaller or larger blocks of time, or at secondary sources of respite, such as camps. We also offer strategies for addressing emergency and future planned needs.

Caregivers value their resources of time & money and, in gaining these respite resources, will be motivated to be good stewards of the program funding. Through careful use and allocation, funding can be leveraged to gain the most time & most beneficial respite. Research shows that respite provision can usually be purchased for under \$15/hour. We also recognize the affordability concerns that any skilled care needed during respite could be much more expensive. As the employer of record, the caregiver negotiates the rate of pay, and secures respite at whatever rate is necessary to allow the caregiver to get respite.

Getting caregivers to accept respite and use it is an important goal in itself, but we also want caregivers to benefit from that respite. Caregiver dissatisfaction with the use of their respite time can be very high. We need to help them see respite not only as a break from caregiving, but an opportunity to do something meaningful to them. What caregivers do during respite can significantly affect their health and well-being. In effective respite programs, respite time cannot be misspent or wasted time.

Partner Roles

The Respite Rx program is a partnership between the Caregiver, Program Coordinator, PALCO, and ADSD. While you have the primary responsibility of managing your services and monthly budget, each partner plays a supporting role.

What are the Responsibilities of the Caregiver?

You are responsible for recruiting, hiring, training, and supervising employees. You are also responsible for the ongoing monitoring of services performed, verification of timesheets submitted for payroll, reviewing your respite provider's services, and the possible termination of the caregiver as appropriate.

If you approve respite services that are not a part of your Spending Plan, you will be responsible in paying for those services out of your own pocket. These actions may also be reason for disenrollment in the program.

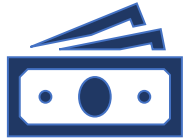
What are the Program Coordinator's Responsibilities?

The Program Coordinator will support you in assessing your needs and goals, developing your service plan and initiating services. The Program Coordinator is available to you for support throughout your time in the program. The Program Coordinator is also responsible for monitoring your activities as an employer and can help you troubleshoot or identify any potential concerns.

The Program Coordinator will be available by telephone and email to you on an as-needed basis but ADSD staff will check in with you at least once each quarter. You are encouraged to call your Program Coordinator anytime adjustments to your care plan are needed.

Who is the Fiscal Intermediary, and What are their Responsibilities?

ADSD has designated fiscal responsibilities to PALCO. Enrollment paperwork will be provided to you by the Program Coordinator.



The PALCO customer service department will assist you or your respite worker with any enrollment paperwork questions. The Program Coordinator can also assist with questions or concerns.

Timesheets will be submitted to the fiscal intermediary directly for payroll services twice a month. Respite services must be provided by the enrolled respite worker(s) you select, and according to the approved Spending Plan.

How is this Program Monitored?

Part of your responsibility as the employer is to monitor the respite services being provided to you. You are also responsible to verify the timesheets claim hours of actual services provided. Any falsification of your verification may result in recoupment of wages previously issued, as well as termination from the Respite Rx program. You should also complete an annual quality review of your employee(s).

Your Program Coordinator and/or ADSD staff will make frequent contact to provide guidance, training, ongoing status, and assist with payroll and billing duties as needed. ADSD Staff will also be conducting pre, quarterly, and post surveys to ensure that our program is meeting your needs in the best way that we can, and to see what we can improve on as a program.

Respite Rx Allowable Services

The Respite Rx program gives you the choice on how to spend your monthly budget. Your Respite Rx Spending Plan will include the respite services you desire from individual providers or agencies, and an emergency and planned savings fund.

A primary respite service would include those services where the specific intent is to provide the caregiver relief from caregiving. Secondary services include those where the purpose is to meet the needs of the individual with special needs, and respite occurs as a by-product, for example, when a child attends a summer day camp program.

A second aspect of respite service is the duration of the provided respite care. Short-term respite usually provides relief for a couple of hours or a larger block of time to allow the caregiver to attend to other family needs, enjoy an activity, or simply have a rest.



Caregivers want access to a wide variety of respite care options that can meet the needs of their care recipient and family. The needs and preferences vary between families and within families across time, as circumstances change. Having a positive, enriched and supportive environment

for the care recipient consistently is placed ahead of a caregiver's need for respite. Preference is also for services that a caregiver can trust.

In-home services appear to be the option preferred by the majority of caregivers, as they are seen to be least disruptive to the care recipient and family, and caregivers are able to monitor the quality of care provided.

Emergency respite services and/or longer-term respite may need to be provided outside of the home. Still the preference at these times is that the out-of-home service still be provided in a "home-like" setting in the community, as much as possible.

Caregivers with medically fragile care recipients have a need for more intensive services and require more highly trained respite workers.

Paid Respite Workers

The potential respite worker must be at least 18 years of age with a satisfactory criminal background history. A satisfactory criminal background history does not contain guilty convictions for crimes such as theft, assault, sexual assault, and alcohol or drug related offenses. A positive criminal history check will be discussed with you to determine if the worker can be employed.

A respite worker can be a relative or a friend, if not currently living in the same house as the care recipient. The individual you select must be capable of providing the care you need and be approved by the Program Coordinator before billing for services. The respite worker(s) you select must complete PALCO's *Worker Packet* as part of the hiring process.

What are the Responsibilities of the Paid Respite Worker?



All individual respite workers must meet the minimum criteria:

1. At least 18 years of age or older
2. Legally eligible to work in the United States

Family members are eligible to be hired by the caregiver as long as they meet the minimum criteria listed above.

Individual respite workers are employees of the caregiver and have the same responsibilities they would for any job. This can include, but is not limited to:

1. Working according to their designated schedule.

2. Providing enough notice if they are unable to work.
3. Respecting the caregiver and the care recipient.
4. Completing training as directed by the caregiver.
5. Submitting timesheets in a timely manner.
6. Reporting care incidents to the Respite Rx Program Coordinator

Individual respite workers and caregivers are each liable for any negligent or wrongful acts or omissions in which either party personally participates. At the back of this handbook, we have provided a sample “Employment Agreement” you may wish to have your respite workers sign upon hire. (*Sample located on page 26*)

Emergency and Planned Savings

In an event of an unplanned circumstance that results your unavoidable absence as a primary caregiver, there are emergency funds that will provide you the ability to quickly find your care recipient care during this short term. You will have the ability to select a provider of choice, not only from professional providers, but from your own identified support system such as family, friends, neighbors, community members, etc.

Referral forms will be provided to the ADSD staff from a variety of organizations or from caregivers currently participating in Respite Rx, and if approved, a caregiver can receive up to \$1,500 for their emergency situation. If denied, the Program Coordinator or other ADSD staff will provide education and information of respite services to the caregiver, and, if in need of more assistance, will make a referral to the caregiver’s local Nevada Care Connection Resource Center.

Employer and Employee Rights and Responsibilities

In thinking about employment, it is good to look again at the rights and responsibilities of both the employee and the employer. The Program Coordinator will cover the Caregiver Responsibility Agreement and a copy will be provided to the caregiver.

Employees have the right to:

1. Be treated with dignity and respect.
2. Express reasonable concerns regarding work conditions.
3. Not be treated as a servant.
4. Express their feelings about work expectations.
5. Be paid for services rendered.



Employees have the responsibility to:

1. Perform all agreed upon duties in a thorough and caring manner.
2. Communicate clearly and honestly about feelings, needs and routines.
3. Treat all information learned about their employer in a confidential manner
 - a. Refrain from talking about employer outside of job.
 - b. Check with employer before answering any questions about him/her - even from family. Politely tell the person asking, "I cannot answer that but feel free to contact my employer."
4. Be dependable in the work relationship.

Employers have the right to:

1. Be treated with dignity and respect.
2. Make informed decisions about self, care-recipient and employee(s).
3. Experience success and failure.
4. Determine their own lifestyle and house rules.
5. Voice grievances and voluntarily withdraw from this program.

Employers have the responsibility to:

1. Respect their employee's privacy and needs.
2. Communicate clearly and honestly about feelings, needs and expectations, routine, and schedules.
3. Treat all information learned from the employee in a confidential and respectful manner
4. Utilize your Program Coordinator when necessary.
5. Be dependable in the work relationship.

Respite Rx Program Policies

Complaint Policy

It is the policy of ADSD that all complaints are addressed in a timely manner to ensure the health and safety of individuals receiving respite services administered by Respite Rx.

1. Complaints should be brought to the attention of the Program Coordinator, in writing or verbally.

2. The caregiver and Program Coordinator can set up a meeting to discuss the complaint and the caregiver can choose to have an ADSD supervisor, the employed respite worker, or other representation available, if appropriate.
3. If the complaint cannot be resolved through discussion with the Program Coordinator, the ADSD staff will be asked to review the complaint and help both parties come to a resolution.



Disenrollment Policy

Enrollment in the Respite Rx program is voluntary and determined by the Program Coordinator and caregiver.

1. Voluntary disenrollment can occur at any time the caregiver decides that he/she no longer wants to be in the Respite Rx program. The Program Coordinator will use the *Communication Form* to work with the caregiver and make a referral to the appropriate ADRC to set up alternative long-term supports, if necessary.
2. Involuntary disenrollment may occur for the following reasons:
 - You are unable to direct your services and manage the service plan, even with help from the Program Coordinator.
 - Factors occur which jeopardize your health, welfare, and safety of others.
 - You become ineligible for caregiver benefits (i.e., death of care recipient).
 - Care recipient is admitted to a long-term care facility.
 - Misuse of funding, or the availability of other funding sources that meets respite needs.
 - You are unable to complete program requirements, such as responding to the Program Coordinator, not completing required surveys, or are unable to find a respite worker within a reasonable amount of time.

Disenrollment will be documented and communicated to the Program Coordinator, and the caregiver will be transitioned to the appropriate long-term care services.

Risk Mitigation Policy



The health and safety of both the caregiver and care recipient are paramount for this program. ADSD shall identify and reduce potential risks to individuals enrolled in Respite Rx. Risk and liability will be reduced by evaluating risk and conducting prevention activities. The Program Coordinator will assist the caregiver with decision making through informed consent to mitigate risks.

For the purposes of the Respite Rx program, risk mitigation will entail:

- Service plans which reflect self-directed planning.
- Policies and procedures to assist the caregiver and Program Coordinator with risk evaluation, managing risk, and dealing with risk-related incidents.
- Defined roles and responsibilities for the caregiver, Program Coordinator, and employee
- Available criminal history background check for all employees.
- Backup plans in case employee cannot work.

- Changes to service plan when necessary and request to change provided by caregiver verbally or written in a timely manner.

Respite Rx Questions to Consider

Have you thought about what you would do in case there is an emergency, such as staff not showing up for their shift (because of a sudden illness, family emergency, or other situation)? Please identify any back up or emergency plans:

What concerns or questions do you have about the Respite Rx Program?

Employer Tools

The following tools are designed to help you with the hiring, training, and managing of respite workers. The included tools include:

1. Assessing My Lifestyle
2. Job Description
3. Advertising for a Caregiver
4. Interviewing a Prospective Caregiver
5. Reference Check for Employment
6. Back Up Planning
7. How to Train a Caregiver
8. How to be an Effective Employer

Additional tools can be provided by your Program Coordinator or the Financial Management Service, PALCO.

Assessing My Lifestyle

This worksheet is to help you in evaluating your unique lifestyle. It may assist you in deciding what types of things you want to include when training the respite worker. Think about what things in your lifestyle are important, that you want this person to be aware of, and agreeable to,

in working with you and your care recipient. It may be helpful to mention some of these things when you interview the person.

Food and Eating Arrangements

1. What kind of foods do I usually eat? Where do I like to eat? What assistance with eating do I need?

2. Do I eat at regular times or when I feel like it?

Personal Preferences

1. Do I like things very, very neat or am I not particular?

2. Do I like to keep to a definite routine, or would I prefer to be flexible?

Personal Care

1. How often do I need to bathe?

2. Is my personal appearance important to me?

Personal Habits, Etc.

1. Do I smoke?

2. Do I drink alcohol?

3. Do I like to sleep late in the morning or get up early?

4. What time do I usually go to bed at night?

5. Do I go out to visit friends and to participate in other social activities?

6. Will I want to entertain friends and family in my home?

7. Do I usually like activities well planned or do I like them to be spontaneous?

8. What do I like to do for entertainment?

9. Do I like to listen to music? What kind? What volume?

10. Do I like a quiet atmosphere?

11. Do I like to watch TV? What do I like to watch?

12. What hobbies do I have?

13. Do I consider myself a flexible person? Example:

14. How do I react if I have to change my plans at the last minute?

15. Is there a spiritual aspect to my life which is important?

Job Description

Now that you have clearly defined your needs and examined your lifestyle you are ready to make a formal job description. The following are some reasons why it is important to create a job description.

1. In the process of developing a job description, you develop a realistic picture of your own, and your care recipient's, limitations and lifestyle.
2. This can be used as an opportunity to identify what criteria are critical to meet your requirements for a respite caregiver (i.e.: non-smoker, caregiver needing to have a car, not wearing perfume, etc.).
3. It can be used as a guideline for more in-depth questions in the interview process.
4. It will give a prospective employee some idea of what the position requires.
5. After an individual has been hired, the job description can serve as a checklist of duties and responsibilities of the position.
6. You, the employer, can use it as an evaluation tool for the Caregiver's performance on the job.
7. It can be used by your respite worker, so you do not make excessive demands. It can be used if there are disagreements between you and the respite worker, as to what his/her duties are.

Job Description Planning

Bathing:

Dressing:

Helping-to-Bathroom:

Toileting:

Type-of-Transfer:

Exercise:

Preparation-of-Meals:

Housekeeping:

Laundry:

Grocery Shopping:

Correspondence, Finances:

Other needs: school, social, job, occasional assistance to achieve a skill to increase independence:

Transportation:

Advertising for a Caregiver

This recruitment section is a helpful tool and possibly critical if the caregiver does not have family or friends that they already know and would like to hire. As you advertise this information be sure to frequently refer to the job description created above.

Places to Advertise

- Local Newspapers, Advertisers, and College Newspapers
- Local Newsletters (i.e., community groups, special interest groups, church groups, etc.)
- Job Service or Employment Office
- Financial Aid Office (college, university, technical school or other similar institutions)
- Bulletin Boards in Apartments, Grocery Stores, Libraries, Churches
- Word of Mouth
- Social Service Agencies

Sample Ads

CAREGIVER NEEDED!

Part-time Respite Caregiver needed for help with disabled female. Assist with personal care, transfers in/out of seats, and light housekeeping. Flexible schedule. Call

Part-time Caregiver needed for frail senior, flexible, 8 a.m.-12 p.m. weekdays. Help with personal care, companionship, meals.
Call _____.

Young physically disabled adult (male) needs Caregiver to maintain independence a few hours/week. Centrally located, near University. Call _____ after 9:30 a.m.

Telephone Screening

It will be to your advantage to carefully screen calls from prospective caregivers who are calling in response to your advertising. By discussing important aspects of the job and also finding out something about the prospective Caregiver, you may be able to determine that a person would not be appropriate for this job and thereby save time for both of you.

1. It is important when talking on the phone to be friendly and pleasant. If you are looking for a come-in respite worker, you will want to know if they have transportation.
2. Also, you need to find out what kind of hours and pay they are interested in. If they want more pay than you can afford or will receive, or if they cannot work the hours you need, you do not have to interview the person.
3. If the person's hours, pay, and transportation needs are not a problem, you may want to give a brief description of your job, hours, and salary.
4. If the person is still interested in the job, you should now set up a time to conduct a formal, personal interview, away from home.

5. The purpose of this face-to face personal interview is to learn as much as you can about this person who is applying for a job with you, and to give them as much information about you and your care recipient as you can, so that both of you have enough information to make a good decision.

Interviewing a Prospective Respite Worker

Through your telephone screening, you have arranged to interview only those applicants who are good candidates for the job. You may want to have another person present for the in-person interviews. Your Program Coordinator may be able to assist you. You may consider conducting the interviews away from your home for safety. These interviews will give you a much better idea of who will be the best person for you, and it is important that you be as thorough as possible. You will be working with this person very closely and hopefully for a year, so it is important that you learn as much about him/her as you can. Also, it is important for the prospective respite worker to ask questions about you, so encourage this.

It is very important to check work references of a prospective respite worker, as sometimes this is the only way to find out if they have had work problems in the past. With the applicant's permission, you can call their previous employers and explain the job the person is applying for, and ask questions regarding that person's dependability, honesty, and ability to relate well to others. If the applicant is unwilling to give permission to contact previous employers, then you probably do not want to hire them. There may be other questions you wish to ask. However, you will also need to be flexible because not everyone will have work references or sometimes a person will have a negative reference, he/she feels is unfair. Under these circumstances you may want to consult someone else before making a decision.

Effective Interviewing Techniques

1. Try to make your prospective caregiver feel comfortable.
2. Explain your or your care recipient's disability if you feel comfortable doing so.
3. Give the job description to him/her to read.
4. After giving the prospective respite worker the job description, you may want to ask these questions:
 - Do you feel uncomfortable about performing any of these duties and responsibilities?*
 - Do you have any questions?*
5. Ask the prospective respite worker about jobs he/she has had in the past.
For example:
 - What jobs have you held in the past?*
 - How do you feel about those jobs – what did you like, what did you not like?*
6. Ask for at least two (2) work references.
7. Ask the prospective respite worker why he/she wants this kind of work.
8. Talk about how you will evaluate his/her performance. Let him/her know that you want feedback about how things are going for them too.
9. Ask about hourly rate of pay.
10. Use questions from "Questions to Think About When You Interview a Respite Worker" that are appropriate – try to get to know something about this person's dislikes and habits.

Questions to Think About When You Interview a Respite Worker

As part of the interview you will want to ask questions from this questionnaire, especially if you are planning respite at home. Use these questions to hire someone that you feel comfortable with (i.e. someone who does not wear perfume if you are bothered by strong scents).

These questions will help you learn more about his/her personal habits and lifestyle. Hopefully, the prospective respite worker will want to know some of these things about you, too.

After the interview, it is a good idea to write down your impressions, noting special considerations. If you interview several people, it can be hard to recall things you liked or disliked. It is also helpful to list and rank in order the characteristics you feel are important in a respite worker. Then, after each interview, you can determine which of these characteristics the prospective respite worker has.

During the interview, keep in mind the qualities that you like in other people. This person does not have to become your best friend but should be someone you can like and respect. The following questions may help you discover if you and the respite worker would be compatible, but do not limit yourself to only these questions.

Questions to Think About When You Interview a Caregiver

Food and Eating Arrangements

1. What kinds of foods do you usually eat?
2. Are you a good cook?
3. Where do you shop for groceries?
4. Do you eat at regular times or when you feel like it?
5. How do you feel about eating together?
6. How do you feel about taking cooking instructions from me?
7. If you like different foods than I do, will you be willing to prepare my meals and yours?

Transportation

1. Can you drive?
2. Do you have a valid (State) driver's license?
3. How do you feel about accompanying me on errands?
4. Do you have a car, insurance?

Housekeeping

1. Have you had experience with housekeeping and laundry?
2. Do you like things very, very neat or are you not particular?
3. How do you feel about taking cleaning instructions from me?
4. Do you like a definite schedule for cleaning and laundry (i.e., vacuum on Monday, scrub floors on Tuesday, etc.). Do you prefer to be more flexible?

Personal Care

1. Do you think it would bother you to help me with toileting, catheter irrigations or suppositories, if necessary?
2. Will you be able to bathe me, if necessary?
3. Is there any aspect of personal care that you feel uncomfortable with?
4. Lifting?

Personal Habits, Etc.

1. Do you smoke?
2. Do you sleep late in the morning or get up early?
3. What time do you usually go to bed at night?
4. Are you a light sleeper?
5. Do you go out to see your friends?
6. Will you expect to entertain your friends in my home? All the time? Some of the time? Never?
7. Might you ever want a friend to stay overnight?
8. Do you usually like activities well planned or do you like to do things on the spur of the moment?
9. What do you like to do for entertainment?
10. Do you like to listen to music? What kind? At what volume?
11. Do you like quiet surroundings?
12. Do you like to watch TV?
13. What hobbies do you have?
14. Do you consider yourself a flexible person? What examples can you give?
15. How do you react if you have to change your plans at the last minute?
16. Describe your personality!
17. What do you personally expect to give to this job?
18. Do you have any emotional problems that might interfere with your work?
19. How long do you anticipate keeping this job?
20. Do you have personal health insurance?
21. What rate of pay do you feel is acceptable?

Interviewer's Comments:

Reference Check for Employment

I _____, authorize all current and former employer(s) to release information concerning my work record to _____, for the purpose of an employment reference check.

You need to complete the same employee information for ADSD and PALCO for each potential emergency/backup respite worker in order for them to be paid by the Respite Rx program for the hours they work. It is important that the total time worked by all caregivers does not exceed the hours are authorized to receive, or you will be responsible for compensating them for the extra time. When using a home health agency for backup, the Program Coordinator must be notified first due to increased cost.

How to Train a Respite Worker

Now that you have interviewed and selected a respite worker to work for you, you will be focusing on training. What you teach that person to do depends on what your special circumstances are.

- A. Begin interview by explaining the disability in as much detail as you are comfortable sharing.
- B. Explain any technical words that you use – be as descriptive as you can.
- C. Be sure to emphasize anything relating to safety or emergencies.
- D. When giving instructions involving a procedure like transferring, include each step as you go – describe why it is important to you that something be done a certain way.
- E. Do not take for granted that they know what you meant – ask for them to explain back to you what they understood you have said/demonstrated.
- F. Be patient – your respite worker may not get everything right the first or second time.
- G. Try to be aware of your respite worker’s feelings as you train – put yourself in his/her shoes.
- H. Use others to help train, i.e., previous respite workers, nursing home staff, and family members.

Employment Agreement

This agreement is entered into between _____, who is the Caregiver/Employer of Record, and _____, who is the Respite Worker.

The Care Provider agrees to the following:

1. I am employed by the Caregiver/Employer of Record
2. I agree to perform all training and tasks as assigned by the Caregiver in the attached Job Description.
3. I agree that the total numbers of hours I am authorized to work for the Caregiver is _____ hours per month.
4. I agree to complete my timesheet bi-weekly in a manner that accurately reflects the number of hours of service delivered to the Caregiver. The Caregiver will approve all timesheets.
5. I understand PALCO – FMS is the Fiscal Intermediary for the Caregiver and PALCO is responsible for processing my payroll.
6. I agree to be on time, to call the Caregiver if I will be late or if I am unable to work at a scheduled time.
7. I agree to communicate with the Caregiver or his/her Representative about all work-related issues.
8. I agree to a rate of pay of \$_____ per hour.

Weekly Schedule

Day	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Start Time							
End Time							

Caregiver/Representative Signature:

Respite Worker Printed Name/ Signature:

How to Be an Effective Employer

Note: Throughout this guide, you will find a strong emphasis on communication. Learning good communication skills and using those skills are the keys to working effectively with a respite worker.

Good Work Environment

It is a fact that respite work is usually not well paid and offers few, if any, fringe benefits. Therefore, those who do this kind of job often do it because it has other rewards, such as personal satisfaction or a chance to work closely with other people. That makes the work environment a most important factor in keeping your respite worker.

Good employers create a work environment that will bring out the best a respite worker has to offer. You will want your respite worker to have good morale, be happy and satisfied with his/her work and therefore be a productive employee. Good communication between you and your respite worker can help do this. To create a good work environment:

1. Reward respite workers for the work they are doing by praising them frequently. Everyone wants to feel appreciated, needed, and important.

For example, your respite worker has transferred your loved one with special needs very smoothly from the bed to the wheelchair. You might say, "That was a really smooth transfer. You do it very well and very safe." You have communicated your appreciation in a very concrete way and your respite worker will know that he/she has performed this task well.

When you must criticize something your respite worker has or has not done, it is important to be open and honest and to criticize the action, not the person.

For example, your respite worker has come an hour later than planned. He/she did not call to explain, and you are angry. You might say, "You said you would be home an hour ago. I feel frustrated and angry when people are late. In the future I would appreciate it if you would call me and let me know you will be late." Do not say, "You idiot – you are always late! I do

not know what I am going to do with you.” This will only make your respite worker defensive and angry and you will not resolve anything.

2. Do not let small irritations build up until an angry explosion occurs. Anger vented in these explosions often is expressed in a hurtful and destructive way. If you feel irritated about something that is happening, talk about it as soon as possible. This may happen daily, especially if you have just begun to work together.
3. Respect your respite worker. He/she is a human being and should be treated accordingly. Use the Golden Rule and treat your employee as you would like to be treated. Be honest, fair, kind, respectful and patient.
4. Respite workers have their own lives too. It is important to be sure to respect their privacy, leave them alone during their time off and realize that unexpected events sometimes disrupt schedules. Although your respite worker has responsibilities to you, you should not attempt to control his/her life. Flexibility and compromise are important qualities for both of you; remember the respite worker is only responsible for agreed upon paid time.
5. Ask your respite worker how he/she feels about their work and about you as an employer. Set up a regular time to share feelings about your relationship. Then, both of you be open to making changes in the routine, in attitude and in anything else that can correct a problem.
6. When things just do not work out even after repeated attempts, it is time to terminate the agreement. There are good and poor ways to do this as well.
 - Do state your reasons clearly without attacking him/her personally.
 - Do give a period of notice, usually two weeks. This allows time for him/her to find a new job and you to find a replacement.
 - Do not withhold payment of wages even if you are not satisfied with his/her work. Just give notice and terminate the agreement.

To summarize: you, as the employer, have the opportunity to provide a positive work environment for your respite worker. This in turn helps him/her to be happy, productive and motivated to work for you. Good communication between the two of you is the key to this interdependent relationship. A respite worker who is happy in his/her work will stay with you longer and do a better job, which will benefit both of you.

If you are interested in learning more about communication skills, check with your local social service organization, colleges, universities, or technical schools for classes in assertiveness, conflict management or basic communication skills.

Giving Criticism/Praise

- Give the criticism as soon as possible after the situation that you dislike occurs.
- Criticize only one incident at a time.
- Do not bring up things from the past. Stick to the present.
- Criticize the person's actions, not the person.

- Keep the criticism brief and to the point.

Use constructive criticism as a tool for sharing information with your respite worker that will help his/her do the job more effectively.

Three steps for giving criticism

1. Describe the situation or event that you disliked.
2. Tell what you were feeling when the incident happened.
3. State how it could be done better the next time (Suggestion).

Praise

1. Always be sincere. Do not say something you do not really mean.
2. Give compliments often.

Two steps for giving compliments

1. Describe the situation or event which you liked.
2. Tell what you were feeling when it happened.