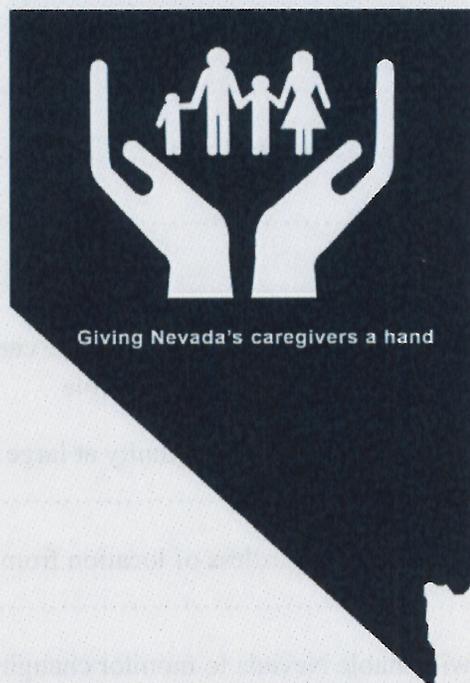


Lifespan Respite Program



State of Nevada
Aging and Disability
Services Division

January 1, 2014

To

January 1, 2019

Five Year
Strategic Plan

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Project Contact Information

Grantee Contact Person:	Vicki Kemp, Program Manager
Telephone Number:	(775) 687-0561 or (775) 400-0073
Email Address:	vkkemp@adsd.nv.gov
State Name and Division:	Lifespan Respite Care Program - Nevada Aging and Disability Services Division

Participants in the Statewide Plan Development of Nevada Lifespan Respite

Name and Title	Division/Unit	Email Address
Laura Valentine - Chief of Disability Services	Disability Services	jdkotchevar@adsd.nv.gov
Cheyenne Pasquale- ADRC Project Manager	Resource Development	cpasquale@adsd.nv.gov
Gabriela Villafuerte- Lifespan Respite Coordinator	Contractor	gnvillafuerte@adsd.nv.gov
Jeff Doucet- Management Analyst II	Resource Development	jsdoucet@adsd.nv.gov

Nevada Lifespan Respite Care Program Mission Statement

The mission of the Nevada Lifespan Respite Program is to expand quality respite services throughout the age spectrum, statewide. Our goal is to promote and assist in the development of these services so caregivers can continue to provide long-term care of their loved one.

Nevada Lifespan Respite Care Program Vision Statement

Our vision is to educate all Nevadans about respite and its necessity in our state, and to increase the accessibility and availability of respite services to all family caregivers regardless of age, location or condition.

Nevada's Definition of Respite

Respite is planned or emergency care provided to a child or adult with special needs in order to provide temporary relief to family caregivers who are caring for that child or adult.

ARCH National Respite Network and Resource Center

The mission of the ARCH National Respite Network and Resource Center is to assist and promote the development of quality respite and crisis care programs in the United States; to help families locate respite and crisis care services in their communities; and to serve as a strong voice for respite in all forums.

The ARCH National Respite Network includes the *National Respite Locator*, a service to help caregivers and professionals locate respite services in their community, the *National Respite Coalition*, a service that advocates for preserving and promoting respite in policy and programs at the national, state, and local levels, and the *Lifespan Respite Technical Assistance Center* which is funded by the Administration for Community Living, *Administration on Aging (AoA)* in the US Department of Health and Human Services.
<http://archrespite.org>

The Aging and Disability Resource Center program (ADRC)

The Aging and Disability Resource Center program (ADRC) is a collaborative effort of the *Administration on Aging (AoA)* and the *Centers for Medicare & Medicaid Services (CMS)* to provide information and access to long term supports and services. The ADRC program serves as a single point of entry into the long-term support system for seniors, people with disabilities and caregivers. ADRCs are sometimes also referred to as a “one stop shop” or “no wrong door” system. ADRCs benefit consumers by helping to identify needs, gathering information and resources to meet those needs and reducing the stress of navigating benefits.

Nevada's Care Connection:ADRC program was established in 2006 and helps consumers become aware of their choices, empowers them to make informed decisions and easily access public and private long term supports and service programs. This website as well as local ADRC sites throughout the state are the first stop for Nevadans who are seeking information and assistance about long term supports and services. The success of Nevada's Care Connection is strengthened through a wide range of partners and collaborative efforts among service providers within our state. We strive to provide friendly, welcoming places where anyone can come for information and assistance regarding public benefit programs and other services available to plan for long-term care needs.

Learn more about why it's important to transform long-term supports and services.

The ADRC is jointly funded by the Administration on Aging and Centers for Medicare and Medicaid. It is administered by the state of Nevada Aging and Disability Services Division (ADSD). For a complete list of ADSD offices, click [here](#).

Visit www.nvaging.net to learn more about the Aging and Disability Services Division.

History

Respite services offer tremendous benefits to family caregivers, care recipients, and all of those affected by disabilities and/or aging. These services also have a significant impact to the communities in which they are imbedded. Due to the impact and the benefits of respite, Nevada has joined other states in the quest of making quality respite services accessible and available regardless of age, condition or location. Nevada is very unique in regards to its population distribution, diversity, and rapid growth rates that make accomplishing its mission on service delivery more difficult. Over the last couple of years Nevada has implemented innovative ideas, by utilizing data collection/analysis and technology, and has dedicated much effort in the areas of public awareness, service accessibility, direct service voucher programs, and training so Nevada's caregivers can continue their efforts in caring for their loved ones.

According to the National Respite Coalition family caregivers encounter many challenges that affect them physically, emotionally, and financially. Research continuously indicates that many of these problems can be addressed or relived by offering caregivers a break from their care giving responsibilities. Respite services help caregivers and care recipients sustain their health, wellbeing, and overall stability. Respite assists in avoiding or delaying costly out-of-home placements, enhances the ability for families to cope, and reduces the likelihood of abuse and neglect (ARCH National Respite Network, 2007; Cowen, 1998; Jackson, 2001). It also helps with avoiding crises as the caregiver is able to take a break from the potentially stressful situations that occur in families, and is among the most frequently requested family support services (Evercare & National Alliance for Caregiving, 2006). Unfortunately, even with all the research that supports respite, quality respite care is still often too costly and difficult to find for many family caregivers in need of the service in Nevada.

Nevada is a very unique state with unique challenges when it comes to making respite accessible and available. It is the seventh largest state in the nation but the 35th least populated, with a total population of 2,700,551, according to the 2010 U.S. Census. Most of its population is concentrated in three urban counties

and the rest is dispersed throughout 14 rural and frontier counties. According to the 2010 U.S Census data, 89.9% of its population resides in Clark, Washoe and Carson City, the remaining 14 counties comprise approximately 87% of Nevada's land mass with an average population of 2.9 persons per square mile. Nevada has also been the fastest growing state in the nation for the last five decades. The rapid growth rate has brought an expansion in diversity in terms of race, ethnicity, and cultural characteristics seen mainly, but not limited to, the most populated areas of the state. Numerous barriers exist to providing year-round services to many parts of the state, including remoteness, geographic obstacles, weather conditions and communication. However, over the last couple of years, these distinct and complex barriers have been addressed aggressively with multiple strategies, and the battle to overcome these factors is ongoing.

In December of 2006 respite was signed into law by congress as the Lifespan Respite Care Act of 2006. The goal of the act was to improve the delivery and quality of respite services by establishing coordinated respite systems throughout the country. The law seeks to accomplish the following:

- *to expand and enhance respite care services to family caregivers*
- *to improve the statewide dissemination and coordination of respite care*
- *and to provide, supplement, or improve access and quality of respite care services to family caregivers, thereby reducing family caregiver strain* (Administration on Aging Lifespan Respite Care Program, 2011)

The act set new standards and new hope for this much needed service. This new law authorizes for: “planned and emergency respite for family caregivers, training/recruitment of respite workers and volunteers, provision of information to caregivers about respite/support services, assistance for caregivers in gaining access to such services, establishment of a National Resource Center on Lifespan Respite Care” (American Psychological Association The Lifespan Respite Care Act, 2013). There were initially 12 states that joined in the efforts set out the by the national government, and Nevada was one of those first states to take the initiative. Today, there are 29 states and the District of Columbia who have received grant money for this purpose, and since FY 2009

Congress has granted \$2.5 million per year for respite services (Administration on Aging Lifespan Respite Care Program, 2011). Nevada, as a recipient of those funds, has accomplished many goals and has begun closing the gaps in respite services with the help of this money. However, there is still much need and work to be done, and in 2013 the act will have to be reauthorized to continue in its mission of delivering quality respite services.

In September of 2009, Nevada was awarded \$288,550 in Lifespan Respite grant funds for a three year project to improve access to respite services and to develop a network of services, including training for caregivers and service providers through collaboration, outreach and by effectively utilizing volunteers. Aging and Disability Services Division (ADSD) in collaboration with project partners—the Cleveland Clinic Lou Ruvo Center for Brain Health (CCLRCBH), the Alzheimer’s Association-Northern Nevada and Northern California Chapter, the Alzheimer’s Association of Desert Southwest, the Aging and Disability Resource Centers (ADRCs) and the Nevada Lifespan Respite Care Coalition— have worked together to develop a coordinated, comprehensive system of information dissemination and service delivery called the Nevada Lifespan Respite Care Program.

In September of 2011, Nevada was additionally awarded a \$172,015 Lifespan Respite expansion grant to build upon work already begun to improve access to respite services. This project focused on providing direct Lifespan Respite services to fill an identified gap in service delivery and address the unmet respite needs of family caregivers. 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. Much information was obtained from those served under this grant including: need, impact and demographics. The data gathered yielded valuable

information about caregivers in Nevada, and the report was praised by the Administration on Aging.

(Appendix)

In August of 2012, Nevada was once again awarded funds to continue working and expand on what had been accomplished with the past grants. A total of \$333,425 was awarded for the Lifespan Respite Care Program. This grant is to complete projects that were started including the ARDC web portal, training modules, increase resources, develop a care provider classification system and develop tools that will provide demographics and demonstrate need and impact in order to better serve and allocate resources in the state. This grant cycle will run from August 2012-January 2014, and will also have a direct service voucher component to it targeting Hispanic families, rural residents, and individuals between the ages of 18-64 through the Lifespan Respite Integration and Sustainability (LRIS) Grant voucher program. The goal of the Lifespan Respite Care Program is to complete these projects that will increase public awareness, increase the number of care providers, increase the number of family caregivers who access respite, and overall make respite accessible and available throughout the state.

Nevada has implemented a number of programs and strategies throughout the years to help address obstacles and meet the established goals. To help resolve issues related to service delivery a number of different approaches have been taken, and many are still underway with the new grant. They are as follows:

- The Nevada ADRC sites are designed to be a true one-stop-shop and a system of support, in which individuals are able to access multiple resources and a variety of public benefit programs from one place or source. These sites are located throughout Nevada, and can assist family caregivers locate providers, guides, find information, funding, etc... In connection with the ADRC sites, the ADRC web portal uses the same concept of assisting individuals in getting connected with available resources and services, and makes this information readily and easily available online for anyone to access at anytime. The ADRC Portal is envisioned as the main connection point to available services for individuals and provider

agencies across the state. Those who have online capability and know-how can connect directly to the ADRC Portal for available services and information.

- The Nevada Lifespan Respite Care Coalition (NVLRC) is a collection of numerous, passionate representatives volunteering their time and resources from various stakeholder agencies across Nevada. Membership is continuously open for representatives to join and be a part of the coalition, but approximately 25 individuals routinely attend the various meetings. The coalition is a non-profit organization and meets monthly via videoconference in three locations across the state: Las Vegas, Reno, and Elko. Nevada is planning to expand representation on the NVLRC to include family caregivers and representation in rural and underserved areas. The coalition works closely with the state's Lifespan Respite Care Program. NVLRC contributes valuable ideas, resources, and overall support to the goals and mission of the Lifespan Respite Care Program. They continuously lend their expertise in many forms including the formation of sub-committees to work on particular projects that will help make respite services more available and accessible in Nevada.
- A measuring tool known as the Minimum Data Set was developed to capture impact, community need, and gaps in services across the age spectrum statewide. The information obtained will come from both private and subsidized respite service providers. Similar information that proved to be very valuable was obtained from participants of the LRBI voucher program grant, but the minimum data set that was developed will help obtain information throughout the state, from multiple care providers and on a larger scale. This will assist the state with addressing needs by allocating resources and funds in a more efficient and effective manner.
- Another measuring tool, the Satisfaction Survey was developed to provide feedback and input as far as services received and the overall impact that respite had on the family caregiver. This tool will be utilized to improve services throughout Nevada as well as identify gaps.

- One of the goals of the Nevada Lifespan Respite Program is to raise awareness and spread the word about respite benefits and services. Outreach activities are taking place in nonprofit organizations, local governments, senior centers, community centers, universities, the private sector, and many others. The goal is to make respite a public concern for all constituents, help family caregivers recognize themselves as such, and guide them on whom to contact and/or where to go regarding services and information.
- The Nevada Lifespan Respite Program has also put together a Caregiver Handbook. The purpose of this handbook is to assist caregivers, care recipients, providers, and anyone interested in respite locate available resources in Nevada, and provide them with tools and a basic introduction to what respite is.

On June 29, 2012 Aging and Disability Services Division (ADSD) and ARCH National Respite Coalition held Nevada's first Respite Summit. There was a total 102 participants who attended, including family caregivers, providers, professionals, government representatives and advocates from different parts of the state and country. (Appendix) The summit was held and viewed throughout the state including: Las Vegas, Reno and Elko. The summit was very successful in bringing stakeholders together, sharing information, and providing a networking opportunity to participants. ARCH's perspective was that Nevada had an incredibly successful, highly prepared and well organized summit. Our national guests were impressed by the level of commitment, engagement and energy that emerged at the end of the day among participants.

The summit provided a good beginning, and helped establish a course for future activities. Many valuable ideas were generated, and needs and gaps were identified during the summit. Priorities were also developed and established according to the needs of each region of the state, but the emphasis for the future is to develop a statewide, lifespan approach to these priorities. There were also certain themes identified by all three regions as being areas of concerns during the summit including public awareness, education, funding, and service accessibility. The following are the priorities from the three regions (Please note that some have been combined, but the region of where it originated is identified):

1. Recruitment and Training of Providers (Elko)
2. Expansion of Coalition – emphasis on rural/underserved populations (Elko, Las Vegas)
3. Communication and Education about Respite-including a statewide marketing plan (Las Vegas, Reno)
4. Legislative Advocacy (Las Vegas)
5. Diversify Funding sources for Respite (Las Vegas)
6. Expand Services to 19-64 year olds (Las Vegas)

7. Expand access to Respite providers-comprehensive Resource Database (Las Vegas/Reno)

Goal #1

Family caregivers will be supported in making informed decisions regarding respite care options and providers as well as supportive service options for care recipients to ease the caregiving role.

In an effort for family caregivers to make informed decisions, ADSD will:

Objective: Inform and promote caregivers of utilizing their family and friends as respite providers.

Objective: Inform and promote caregivers of the *Models of Respite* for care options.

Objective: Promote the training available for care providers on the portal.

Strategy: Develop a statewide marketing campaign to educate and motivate caregivers, care providers and the public at large regarding the types of respite care and training.

Strategy: Train ADRC sites across the state on the use of the Respite Assistant as part of the Options Counseling to help caregivers identify care providers and plan financially for future respite needs.

Performance Measure: Track the number of trainings completed on the portal.

Performance Measure: Track the number of resources on the portal

Performance Measure: Track the number of caregivers provided with Options Counseling.

Barriers

- Continuous resource growth to support ADRC's mission in offering support for everything respite.
- Caregivers reluctant to self-identify and/or accept respite services.
- Not too many people interested or afraid of becoming a provider due to the responsibility/liability of caring for someone with a disability or elderly

Aging and Disability plans to address the barriers as follows

- Offer training through the portal on multiple health conditions and basic care giving to remove that fear.

- Use outreach to spread awareness about who can be a provider i.e. family member or trusted friend, and use this outreach as recruitment.

Goal #2

Family caregivers, care recipients, legislators, stakeholders and the community at large are educated in the need for respite, and are aware of the value in supporting family caregivers.

In an effort for family caregivers, care recipients, legislators, stakeholders and the community at large to be educated about respite, ADSD will:

Objective: Perform outreach activities throughout the state

Objective: Utilize data collected locally and nationally to advocate for the caregiver throughout Nevada

Strategy: Locate existing caregiver advocates and unite with their efforts.

Strategy: Spread ARCH's definition of respite.

Strategy: Develop an advocacy campaign and demonstrate the value of the unpaid family caregiver by utilizing statistics and research.

Performance Measure: Track utilization of the portal

Performance Measure: Demonstrate an increase in available funding for respite and caregiver supportive services.

Barriers

- Reaching underserved (i.e., Hispanic) and rural communities
- Lack of technology in rural areas of the state
- Available staff to perform data analysis

Aging and Disability plans to address the barriers as follows

- Establish who are the key agencies and community leaders in these populations so they can assist with outreach and advocacy.

- Locate computer centers and/or anywhere they are available in rural areas to indicate to clients where to go.

Goal #3

Respite services are available to families across the lifespan regardless of location from a variety of providers throughout the state.

In an effort to make respite available across the lifespan throughout Nevada, ADSD will:

Objective: Perform outreach targeted to minorities and rural areas in the state.

Objective: Assist caregivers in recognizing themselves as caregivers.

Objective: Promote innovative sustainable solutions for respite, such as volunteer programs.

Strategy: Develop training for caregivers to increase their awareness on the subject and guide them where to go for services.

Strategy: Identify best practices in regards to successful volunteer programs and encourage organizations to replicate them locally.

Strategy: Properly train the ADRC sites to assist caregivers with their needs.

Performance Measure: Track the results from the Minimum Data Set to measure what populations and from what part of the state are utilizing respite services.

Performance Measure: Track Service Delivery Topics from ADRC sites.

Performance Measure: Pilot of at least one volunteer program in the state.

Barriers

- Availability of resources.
- Local organization may not be inclined to pilot a volunteer program.

Aging and Disability plans to address the barriers as follows

- Utilize encouraging and appealing data on pilot volunteer programs to present to these organizations.
- Promote the use of the training available on the ADRC portal so friends and family members of the caregiver can learn basic care and become available care providers.
- Email and newsletter campaign.

Goal #4

Ongoing data collection and program evaluation will enable Nevada to monitor changing trends in order to respond to family caregiver needs in an efficient and effective manner.

In an effort to respond to changing trends efficiently and allocate resources accordingly and appropriately, ADSD will:

Objective: Make Satisfaction Survey tool universal among state funded providers to measure to what extent the services provided to the family caregiver met their needs and how it benefited them and the care recipient.

Objective: Encourage the private and public sectors to utilize the Minimum Data Set tool to quantify the need and impact of respite in Nevada.

Strategy: Perform analysis on the data collected from the Satisfaction Survey and use it to identify areas of growth.

Strategy: Perform analysis on the data collected from the Minimum Data Set to determine gaps in services and add needs.

Performance Measure: Track the Satisfaction Survey results to measure satisfaction and quality (each year).

Performance Measure: Track the Minimum Data Set results in regards to caregivers receiving respite services (each year).

Barriers

- Lack of motivation from non-funded providers to collect needed information/data
- Each provider has tools already in place.

Aging and Disability plans to address the barriers as follows

- Appeal to their business side as they will be listed on the ADRC portal which could be seen as free propaganda.

- They can use the ADRC portal as their own database.
- They too can benefit from this data to see areas of need and that need improvement.
- Advise them that this could open the door to possible funding opportunities.

Goal #5

Family caregivers, care recipients, providers and stakeholders have access to resources and information regarding respite through a coordinated network of providers including public agencies and Nevada’s Care Connection program.

In an effort for family caregivers, care recipients, providers and stakeholders to have access to respite resources and information, ADSD will:

Objective: Promote the use of the ADRC portal and sites for respite resources and information.

Objective: Remain up-to-date and a reliable source for everything related to respite.

Strategy: Gather and centralize all funding opportunity information for caregivers throughout the state, and make it available on the ADRC portal and sites.

Strategy: Continuously update the resource directory, funding and reading materials on the portal and for the sites.

Strategy: Strengthen the referral network with 211.

Performance Measure: Track the number of people that use the Respite Assistant.

Performance Measure: Track the number of referrals and phone calls from the ADRC sites relating to respite.

Performance Measure: Track page hits on ADRC portal.

Barriers

- Not enough ADRC sites
- Limited internet use for underserved and rural Nevada

Aging and Disability plans to address the barriers as follows

- Continuously add more sites and expand service accessibility.
- Utilize computer access in these areas to obtain the information.

Plan and Resources to Sustain Efforts

Respite is a much needed service with very little resources available to those who need and require it. The benefits that the caregiver and the community at large receive are priceless. Unfortunately obtaining respite service can be very expensive and/or burdensome to some families, and others may not be able to access it at all. With these efforts we plan to achieve uninterrupted respite services for years to come through outreach, education, partnerships and by reaching out to the legislative body for future funding opportunities and consideration. The following is the plan the state of Nevada and Aging and Disability Services Division (ADSD) will implement for the next five years in regards to sustaining respite services in the state.

ADRC- Options Counseling and preparing sites to address respite needs

Aging and Disability Services Division will be adding a respite component to the Aging and Disability Resource Center's (ADRC) Options Counseling. Through Options Counseling families at risk of not having or having inadequate respite services will have an opportunity to recognize their need, find providers in their area, identify and locate funding opportunities, obtain pertinent reading material and develop a financial plan for future respite needs. This process will also help identify benefits that the care recipient may be eligible for, and the benefit the family as a whole. Caregivers will be referred to the ADRC web portal and will be provided with a guide on the navigation process so they can obtain information on their own for future needs, if they so please. Through this process families in Nevada will be better informed of what services may be available to them and their care recipient, and be better prepared to address and manage their own future respite needs.

The Lifespan Respite Care Program is an important component of the Aging and Disability Resource Centers, and as part of their site trainings, respite material will be included. The purpose of this is to better equip the sites so they will be able to serve and guide citizens who contact them in need of respite services. They will be trained to advise on available funding opportunities, reading material, locating respite providers based on the need of the caregivers and care recipient and helping them financially plan for respite in the future.

Cultivate- Outreach and education for Nevada

As part of our efforts in sustaining respite in the state of Nevada we plan to continue participating in outreach activities and educating citizens. We will promote the use of our tools that have been developed including the Caregiver Handbook, caregiver satisfaction survey, training materials, Models of Respite and all the resources available on the ADRC web portal and sites to assist Nevada's caregivers obtain services and information. The information obtained from these tools will also be utilized to address the legislation with data from Nevada's caregivers, and bring more dollars to the program. Respite information and brochures will continue to be distributed and disbursed in events that become available through the Aging and Disability Services Division, as well as events that the agency is invited to through its different programs. We will continue to spread the word and raise awareness on the importance of the caregiver and the benefits of respite services.

Coalition- Continue ADSD representation in the Nevada Lifespan Respite Coalition

ADSD will continue to support the Nevada Lifespan Respite Coalition, and participate in the monthly meetings and activities. ADSD will continue to provide support and ideas for the purpose of furthering the coalition's mission in helping Nevada's caregivers.

Funding- Inform the public of available funding sources in the state

Funding for direct respite services will continue to be available through Nevada's Health and Human Services (HHS) Grants Management Unit and Aging and Disability Services Division. The ADRC sites will be informed of the grants available so they can better assist and inform those who call wanting and needing respite.

Staff from Nevada's HHS divisions will meet to review each area's funding process and scope of work to better develop a coordinated infrastructure.