

# The Nevada State Plan for the Support of Family Caregivers

January 2022 to December 2024

Nevada Lifespan Respite Care Coalition





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## Acknowledgements and Coalition Membership

This State Plan was developed by the Nevada Lifespan Respite Care Coalition, with input from family caregivers, service providers, and state agencies. We would like to thank our Nevada community for their dedication and support of this initiative.

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## Executive Summary

This State Plan was developed through various information gathering activities conducted by the Nevada Lifespan Respite Care Coalition (NLRCC) from October 2021 to December 2022. The recommendations outlined in this plan reflect the Nevada Lifespan Respite Care Coalition priorities for its monitoring and advocacy efforts for the next two years.

While information on informal and familial caregivers has been difficult to obtain, information has been derived from data available from reliable sources, including 2020 U.S. Census data and Behavioral Risk Factors Surveillance System survey (BRFSS) data from 2015-2017. However, as recommended below, future policy decisions would be better guided by current data that reflect the needs of family caregivers in the state of Nevada. In acknowledgement of the critical long-term services and support (LTSS) role performed by familiar caregivers, a priority needs to be placed on collecting family caregiver data and outcomes.

The efforts taken during the development of this plan have highlighted gaps in the LTSS infrastructure for the support of informal and familial caregivers, starting with the lack of information on caregivers. Nationally, the biggest factor driving improvements was the number of states conducting assessments of family caregivers for their own health needs and well-being. NLRCC wants to see caregiver assessments instituted in Nevada.

To address this, NLRCC gathered support rationale and federal initiatives for instituting caregiver assessments here in Nevada and presented a legislative recommendation for consideration. See Appendix B.

The plan will focus on an additional three critical areas: Collaboration, Funding, and Outreach.

These areas became central to our plan because, clearly, little attention has been paid to family caregivers who are a critical LTSS resource that Nevada needs to strengthen and support, before caregivers collapse under the weight of their overwhelming tasks and duties or are forced to resign their supportive role – for their own well-being and preservation!

### **Collaboration**

Goals for collaboration are meant to bring governmental program administrators, agency representatives, and community partners together in combined effort to attract, identify, refer for respite, and serve family caregivers as a team - to meet the unique needs of each caregiver - and implement data collection processes and tools so that future policy decisions can be tied to data that reflects the needs of caregivers in Nevada. This requires agreement around “sharing



caregivers” and establishing partnerships where cases can be triaged and supported together. Data collection efforts will need to be implemented and an accountability system developed for cross-system referrals that respite partners voluntarily participate in. Tied to these collaborative efforts, a state inventory of family caregiver programs and services could be gathered and placed on a user-friendly site for caregivers, not hidden behind supports and services designed for care recipients.

### **Funding**

Our goals for funding are to expand respite services and supports by including criteria in grant applications that encourage expansion of services to fill service gaps through partnerships or by stretching programming into new modalities or service areas. Ideally, grants for caregiver supports and services would be planned regionally, to assure better coverage of rural/underserved communities. Underserved communities lack the funding and infrastructure for respite services, so encouraging and supporting startups is necessary.

In addition to expansion of respite services, NLRCC would like respite services to be available for purchase through a sliding scale on income eligibility, so that all caregivers can purchase the service. Income criteria should not eliminate eligibility for respite or other caregiver supports. Some caregivers might need to blend funding sources, from VA caregiver programs, for example, Health Savings accounts and/or Flex Spending cards. Ultimately, families need more flexibility, choice, and control over how they receive respite, especially as low Medicaid reimbursement rates and higher wages for workers results in fewer hours of respite they can purchase.

### **Outreach**

Our system relies on family caregivers to self-identify for support, as most respite programs do not have a marketing plan. Unfortunately, caregivers are reluctant to ask for assistance until they reach a point of crisis. Language used in respite needs to “speak” to caregivers, especially where caregiving is so integrated into the culture. Caregivers need to be found/identified through public-private partnerships, and at logical points such as hospital discharge planning, where long-term care responsibilities are placed on caregivers, or through intake processes where a simple question could aid in caregiver identification. Not every caregiver is a legally or biologically related caregiver, so broader definitions must be used to include “families of choice.” Partnerships need to be developed between respite and organizations that have a stronger/trusted relationship with family caregivers.



## Measuring Success

NLRCC will be looking for the following improvements into our LTSS system for serving family caregivers:

- Evidence of self-direction and person-centered planning around primary caregivers
- Referral-to-respite process begins with identifying caregivers and promoting respite as a critical element of care.
- Barriers are identified through a program of respite accountability that captures reason(s) program is unable to provide respite to referred caregivers.
- Utilization of a standard Caregiver Assessment and Satisfaction Survey has expanded to more state and community partners.
- Nevada caregivers receive respite and other long-term services and supports through a trained and expanded workforce, that includes family and friends, with proof that the caregivers acknowledge that they trust/prefer the caregiving supports they receive.

Nevada will use this plan to shape policy recommendations and advocate for programming to support family caregivers. Efforts under this plan will be monitored and reported annually.

Family caregivers, people receiving care, advocates, and members of the public can use this document to work with legislators, program administrators, employers, and neighbors to adopt and administer person-centered and trauma-informed approaches that are based on caregivers' documented needs and preferences and grounded in their cultural realities.



## Background

The Nevada Lifespan Respite Care Coalition has been working to address gaps in respite services since 2007 as a non-profit organization. In 2021, the Coalition transitioned into a public advisory body under the Nevada Aging and Disability Services Division to increase their advocacy efforts for family caregivers in Nevada. The development of the State Plan for Support of Family Caregivers has been their priority since October 2021. This plan is meant to provide recommendations to Nevada leaders related to increasing awareness of respite and its benefits, reducing barriers to the access of respite services, improving the quality of respite services, and developing education and training resources for caregivers, and advocating for grants in support of family caregivers.

Respite provides the primary caregiver an occasional break or temporary relief from the day-to-day responsibilities of caring for their family member with a disability. Regular respite care for the caregiver helps sustain the health and well-being of the caregiver, helps avoid or delay costly out-of-home placements, and reduces the likelihood of abuse and neglect.

The NLRCC is comprised of representatives from the following constituencies:<sup>1</sup>

- Parents of minors who either have a disability or chronic health care condition.
- Family caregivers of adults over the age of 18 who either have a disability or chronic health care condition.
- Compound family caregivers, taking care of more than one person with special needs.
- Representatives of organizations that provide services to children with disabilities.
- Representatives of organizations that provide caregiver support services to family caregivers who care for someone over the age of 18.
- Representatives of organizations that provides caregiver relief such as palliative care, personal care, or other in-home services.
- State agency representatives who provide funding for respite and caregiver support services.
- Representatives of Nevada's No Wrong Door, Nevada Care Connection initiative.
- Representatives of organizations that provide services to veterans with long term care needs and/or their family caregivers.
- Direct service workers or volunteers, providing temporary respite services for family caregivers.

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<sup>1</sup>Nevada Lifespan Respite Care Coalition Bylaws, [Nevada Lifespan Respite Care Coalition Bylaws \(nv.gov\)](#)



On a national perspective, NLRCC strives to see Nevada in alignment with goals from the ACL RAISE Family Council and the RAISE Act Roadmap. This national strategy was developed by advisory councils established by the original RAISE (Recognize, Assist, Include, Support, and Engage) Family Caregivers Act and the Supporting Grandparents Raising Grandchildren Act, both of which had extensive input from family caregivers.

The Roadmap is meant to assist in efforts from the 2022 National Strategy to Support Family Caregivers, which highlights 350 actions the federal government can take and more than 150 actions that can be adopted at state and local levels of government across the private sector, all to support family caregivers.

NLRCC has adopted the following goals that align with those from the RAISE Family Council, such as:

- Family caregivers' physical, emotional, and financial well-being will meaningfully improve because of expanded awareness, outreach, and education.
- Increased public awareness and recognition of the diverse needs, issues, and challenges family caregivers face will result from an increased valuation and emphasis on recognizing family caregivers and supporting them in their role.
- Increasing family caregivers' self-identification, awareness of and access to information, services, and supports across a range of topics will strengthen their ability to perform a critical LTSS role and prevent both unnecessary institutionalization and caregiver fatigue or burnout.

In 2022, Aging & Disability Services Division also published the first "Caregiving in Nevada" report.<sup>2</sup> This report reflects the data on caregivers that could be collected through the existing data collection system. Increased participation in generating and collecting data on caregivers will be needed.

NLRCC has attempted to estimate numbers on familial caregivers from existing data and gather information about the experience of family caregivers in accessing and receiving services that were meant for their strength and preservation. The stark reality is that information or data on Nevada caregivers is very limited.

To gather more information on caregivers, NLRCC began a series of open forum meetings, called the Community for Respite, to invite discussion and perspectives on the status of caregiver supports and services, and gain input of strategies that have or may be implemented

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<sup>2</sup> [Caregiving In Nevada 2022 Report \(nv.gov\)](https://www.nv.gov/aging-disability-services-division/caregiving-in-nevada-2022-report)





to address barriers and challenges in delivering services and supports. The Community for Respite held 8 meetings From October 2021 to November 2022.

NLRCC also maintains a website, Facebook page, and YouTube channel as tools that could be used to reach family caregivers directly. During the development of this document, calls generated through the NVCaregivingRelief.org website increased, with most callers stating that NLRCC came up near the top of their Google searches in their quest for respite. Over 200 social media posts were created or shared through Facebook, and the YouTube channel hosts 27 videos that introduce visitors to the Coalition, the concept of respite, and self-care tips for caregivers. The first short video in a new YouTube series on the benefits of respite has been produced and 2 more videos are in development.

The NLRCC board also held a workgroup meeting in November 2022 to build consensus on identifying the strengths and weaknesses of the Coalition's role, addressing the availability and quality of respite care family caregiver supports in Nevada, the existing practices and policies related to problems with implementation, and what strategies should be adopted to move priorities along.

As a lack of data on informal and familial caregivers in Nevada was quickly identified, a recommendation was presented for legislative consideration. The NLRCC recommends that the State of Nevada Department of Health and Human Services (DHHS) engage family caregivers, use evidence-supported and culturally sensitive family caregiver assessments, and determine the willingness, ability, and needs of family caregivers to provide Long-Term Services and Supports (LTSS). Such assessments need to gather information on family caregivers' social determinants of health, specific risk factors related to stress and depression, and environmental and cultural barriers that put caregivers at risk. This recommendation has been submitted as a bill draft request by Assemblywoman Tracy Brown-May for the 2023 legislative session and is included as Appendix B to this State Plan.

In preparation for this plan, NLRCC gave presentations to other councils, commissions, advisory boards, taskforce groups, and tribal communities to explain the critical role of familial caregivers and what they need to be successful. While these other entities were focused on serving individuals with special healthcare needs or disabilities, they recognized the important role that family caregivers have in supporting and assisting those in need. Many of these groups expressed their interest in supporting Coalition efforts, as the results would be better care and supports for the individuals they represent.



## Profile on Caregivers in Nevada

Although family caregivers tend to be overlooked and taken for granted, to strengthen and support them as caregivers is a public health priority because they provide long, challenging hours of care to our most vulnerable populations. Without strong family caregivers, Nevada’s LTSS would drown in unmet needs faced by those who are disabled, chronically ill, injured, experiencing mental and emotional disorders, or encountering limitations as they age. Family caregivers often are relied upon as an essential, yet typically uncompensated, part of the health care system. Because caregiving is a public health issue of increasing importance as the U.S. population ages, the health status of caregivers warrants special attention.

“Family caregivers” include people of all ages, from youth to grandparents; people with and without disabilities; people providing care from a distance; and people meeting a wide variety of needs, such as supporting people with intellectual and developmental disabilities (ID/DD) across the lifespan, caring for people with serious and/or progressive illnesses like dementia and cancer, and assisting with daily tasks that can be challenging for older people and people with disabilities. The term also recognizes that a single person may receive care from multiple family caregivers. “Family” is used in the broadest possible sense.

In Figure 1, data from the Behavioral Risk Factor Surveillance System (BRFSS) highlights the available demographic characteristics of Nevada caregivers.

**Figure 1: Caregiver Demographics, 2015 – 2017**

Sex: Woman	57.4%
Race/Ethnicity: White	57.5%
Race/Ethnicity: Black	13.9%
Race/Ethnicity: Hispanic	13.3%
Race/Ethnicity: Other	15.3%
Age Group: under 45	46.2%
Age Group: 45-64	33.5%
Age Group: over 65	20.3%
Education: High School or Less	38%
Education: Some College or more	62%
Employment: Full/Part Time	57.7%
Marital Status: Married/Living with Partner	50.5%

*Source: Behavioral Risk Factor Surveillance System, United States, 2015-2017*

### How many caregivers are here in Nevada?

In determining the size of our constituency group – Nevada caregivers across disability and age groups - NLRCC estimates number of caregivers in Nevada ranges from 325,746 to 620,923.



On the high end of the range, data from the 2020 US Census and the Behavioral Risk Factor Surveillance System (BRFSS) collected from 2015-2017 was used. Based on the BRFSS data, 20.7% of respondents reported that they had provided care to a family member or friend who has a health problem or disability in the preceding 30 days and were classified as caregivers. Given Nevada’s population of 3,104,614, this would translate to 620,922 people providing care.

On the low end of the range, we balance the Nevada population of individuals with disabilities and special healthcare needs against studies that show how many caregivers support certain populations. Starting with the size of the population with disability status in Nevada totaling 405,952, the Under-18 age group was 29,558; the 18-64 age group numbered 202,739; and the 65-plus age group was 173,655.<sup>3</sup>

Unpaid caregivers were estimated from the following information:

- Most minors (99.9%) reside with family members or foster care families.
- Nearly 75% of Americans with disabilities live with a family caregiver, according to the Center on Developmental Disabilities at the University of Kansas.<sup>4</sup>
- Eighty-three percent of the help provided to older adults in the United States comes from family members, friends, or other unpaid caregivers.<sup>5</sup>

These estimated results are listed below (Figure 2) and represents 325,746 people providing care at the low end of the range.

**Figure 2: Estimated Number of Family Caregivers in Nevada**

Population, Type	Population Count	% Caregivers	# of Caregivers
<i>People with Disabilities, by Age (Low)</i>	405,952		325,746
People with Disabilities, under 18	29,558	99%	29,558
People with Disabilities, 18-64	202,739	75%	152,054
People with Disabilities, over 65	173,655	83%	144,134
<i>Total Nevada Population (High)</i>	3,104,614	20%	620,923

<sup>3</sup> Source: American Community Survey Data (census.gov) ; 2021: ACS 1-Year Estimates Data Profiles

<sup>4</sup>Source: Tanis, E.S., et al. (2022). The State of the States in Intellectual and Developmental Disabilities, Kansas University Center on Developmental Disabilities, The University of Kansas. <http://www.StateoftheStates.org>

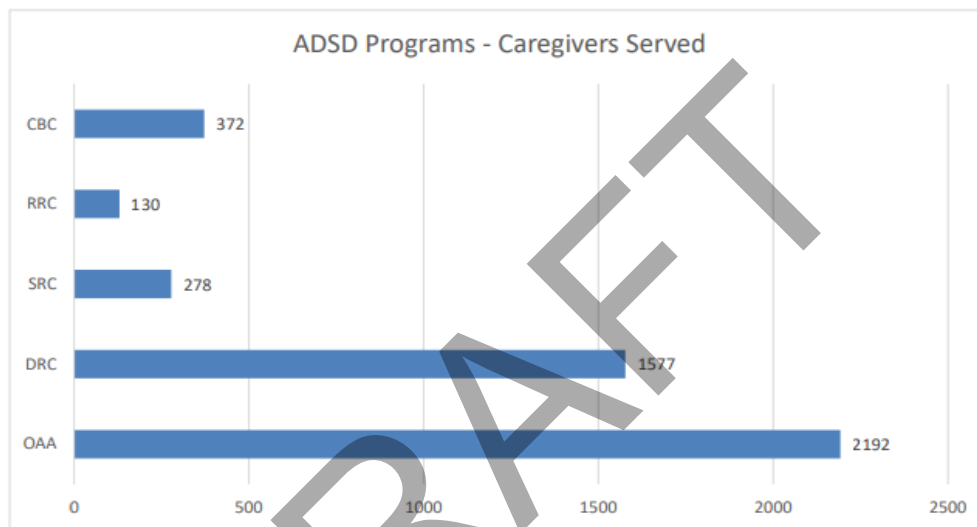
<sup>5</sup> Source: Friedman EM, Shih RA, Langa KM, Hurd MD. U.S. prevalence and predictors of informal caregiving for dementia. Health Aff 2015;34(10):1637-41.



## Respite and Caregiver Support Utilization

As reported in the Caregiving In Nevada 2022 Report, the number of caregivers served through Nevada Aging & Disabilities Programs account for a total of 4,549 caregivers (Figure 3) or only 0.7-1.4% of population estimates above. This data reflects the total number of recipients receiving various caregiver supportive services, including respite, adult day care, caregiver support groups/education, and caregiver information and referrals.

**Figure 1: ADSD Programs - Caregivers Served, SFY22**



*CBC = Community Based Care, RRC = Rural Regional Center, SRC = Sierra Regional Center  
DRC = Desert Regional Center, OAA = Older Americans Act programs*

### Do they know they are caregivers?

Some family caregivers assist others out of a wellspring of love and concern. Others provide care in response to tradition, culture, family expectations, or other factors.<sup>6</sup> More than half of all family caregivers (53%) feel they have no choice in taking on the role.<sup>7</sup> Often, some combination of these reasons causes a person to become a caregiver.

Many family caregivers assist others for years without realizing that their efforts extend beyond typical relationship expectations. By the time they realize that they are caregivers, they have often missed critical opportunities to learn family caregiving skills. Supports such as respite have not been offered to them.

Eager to get loved ones out of hospitals or to avoid institutionalized settings, family caregivers accept caregiving responsibilities without considering their own needs. Family caregivers do not

<sup>6</sup> Source: Zarzycki, Seddon, Bei, Dekel, & Morrison, 2022.

<sup>7</sup> AARP and National Alliance for Caregiving, 2020.



seek supports for themselves, but only more support for their loved ones. Too often, caregivers report only learning exactly how complex it is after finding themselves unexpectedly plunged into the role.

Family caregivers generally provide this support without a formal assessment of their needs or the needs of the person receiving support. That means they may have to take on tasks they do not know how to do, did not expect to have to do, or do not feel comfortable doing. They often have limited access to training or assistance that could enable success. They often face legal barriers to providing care, such as when a grandparent opens their home to a child but lacks legal custody or the authority to make decisions on behalf of the child. Over time, these hurdles can make an already complex task both stressful and exhausting and even drain financial resources, especially over time.<sup>8</sup>

### Problems with Self-Identification

Many individuals providing care to family members or others do not self-identify as caregivers. This is because they:

- a. Do not know they are caregivers or that they can receive respite.
- b. Did not anticipate their need for respite.
- c. Expected to “step up” to meet care needs.

Caregivers need to be empowered to identify the crucial role they play so that they can receive available training and assistance if, and when, they need it. Cultural and familial expectations of caregiving keep caregiving in a tight social circle, and family caregivers only seek outside help when in crisis. This is a matter of trust and will require focused and persistent efforts to overcome any mistrust of institutions, systems, and governments by using culturally competent approaches. Communications channels and methods must reflect the communities for which the message of support is intended.

When the challenges become overwhelming and family caregivers are unable to continue to provide support, the person they have been assisting is often left with no choice but to enter an institution. Institutional care also carries a tremendous financial cost – most of which is borne by Medicaid. The current U.S. system of long-term services and supports could not continue to function without the contributions of family caregivers. Ensuring family caregivers have the resources they need to continue to support older adults and disabled children and adults in the community is critical to containing the rising costs of health care.

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<sup>8</sup> Source: [2022 National Strategy to Support Family Caregivers \(acl.gov\)](#)



## Recommendations for Supporting Family Caregivers

The Nevada Lifespan Respite Care Coalition offers a total of 18 recommendations for supporting family caregivers in Nevada. These recommendations are grouped by three overarching themes that include: Collaboration, Funding and Outreach. The following sections identify the challenges and problems to be addressed by each theme, as well as goals and recommendations to address those challenges. Additional narrative and background regarding these recommendations are included in Appendix C.

### Collaboration

Several agencies and grant-funded programs have been identified as having a potential or known role in the field of respite and other caregiver supports, yet this information is not well-known or disseminated. Family caregivers cannot access services and supports that they are not aware of. These agencies and community partners need to better understand their important role in supporting family caregivers and actively participate in regular discussions about how to serve them better. See Appendix A.

#### Recommendations for Collaboration

Engage program administrators and agency representatives in a regular dialogue about caregivers and how they are served, to accomplish these several goals:

- Build agreements around sharing family caregivers who do not fit in one or another program by establishing partnerships where cases can be triaged and supported together.
- Compile a state inventory of family caregiver programs and services for those who are seeking information for themselves or those they serve and place them on a user-friendly site specifically for caregivers, not hidden behind supports and services designed for care recipients.
- Increase data collection efforts and cross-system referrals through an accountability system that respite partners voluntarily participate in.
- Leverage caregiver assessments, surveys, and tools to support identification, data collection, and service delivery so that future policy decisions can be tied to data that reflects the needs of caregivers in Nevada.
- Encourage state agencies and their community partners to streamline the process from application to deliver of respite services, as it takes months for respite to be achieved. Respect for the critical LTSS role of caregivers requires this recognition that time to result is important when caregivers do not ask for respite until they are in crisis.



## Funding

Because Nevada struggles to address the needs of care recipients first, the needs of caregivers for respite are largely ignored. In fact, caregivers encourage this by seeking to first receive all that the care recipient is entitled to before thinking of themselves. This makes caregivers' needs the last needs that are addressed.

Funding drives much of what is available for caregivers. Instead of just requesting more funding, NLRCC has tried to determine what more could be done with the funding levels we have – if only to gather information on the true needs and the most helpful strategies that caregivers hope they can soon rely on. NLRCC hopes to see funding used in the best ways that can serve the most families. That does not necessarily mean leaving things as they are.

## Recommendations for Funding

- Collect data on caregivers and base funding for respite on data collected. There cannot be an excuse for lack of data, especially among respite programs that have supposedly served caregivers for years.
- Fill service gaps in rural and underserved communities by outlining funding criteria that favors expansion of services through collaborative partnerships or through added modalities and/or service areas.
- Plan grants for caregiver supports and services regionally, not statewide, to assure better coverage of rural and other underserved communities.
- Utilize sliding income scale eligibility for respite, so that all caregivers can purchase the services, whether through vouchers or other funding mechanisms.
- Identify all sources for respite and caregiver supports, as additional support/funding may be available through other programs (i.e., VA caregiver programs, mental health supports).
- Conduct a review of Medicaid reimbursement rates, wages for PCA workers, and traditional agency-directed services against experience with caregiver self-directed model that provides more flexibility, choice, and control over respite services.
- Build infrastructure in underserved communities, especially in rural areas, by encouraging new respite programming through a process that has been simplified for startups.
- Determine if alternative options for funding respite, such as Health Savings Accounts and Flex Spending cards can be utilized for caregiver support.



## Outreach

Without healthcare professionals recommending respite or directing family caregivers to sources of support, family caregiver might not realize such programs and services even exist. The individuals providing support to others may not think of themselves as caregivers or may be reluctant to ask for assistance until they “reach a point of crisis.”

Our system relies on family caregivers to self-identify for support. Caregivers need to be found/identified through public-private partnerships, and at logical points such as hospital discharge planning, where long-term care responsibilities are placed on caregivers, or through intake processes where a simple question could aid in caregiver identification.

Language used in outreach efforts do not “speak” to informal caregivers and may completely miss caregivers in communities of color. Some cultures do not even have words, language, or terms to differentiate people who provide informal support to others, as caregiving is so integrated into their society. Partnerships need to be developed between respite and organizations that have a stronger/trusted relationship with family caregivers.

## Recommendations for Outreach

- Use language that is more inclusive and acceptable to all family caregivers so that messages of respite and caregiver support can reach them and will be recognized by them.
- Embed processes to identify family caregivers through state agencies and public-private partnerships, rather than waiting on family caregivers to self-identify.
- Establish a system of caregiver assessments to address the health and well-being of family caregivers, especially at logical points such as hospital discharge planning, where long-term care responsibilities are placed on caregivers.
- Develop caregiver accessible materials in other languages for outreach to minority caregivers and disseminate through partners with trusted relationships in minority communities.
- Raise the awareness and understanding of caregivers and their valuable community role by broadly sharing results of data collected from caregiver assessments.

## Measuring Success

The process of accessing respite services begins with identifying caregivers and promoting respite as a critical element of LTSS care. Are we developing policies and protocols around asking questions that identify caregivers? Are staff are trained to say, “are you calling about





yourself or for someone else?” to prompt a conversation and potentially identify a family caregiver?

Are we identifying and reducing barriers identified through a respite program accountability system that captures the reasons a program was unable to provide respite to a referred caregiver? Does the caregiver give up on the process because it takes so long or is not likely to meet their needs?

What do we know about caregivers through surveys, care plans, and assessments? Does data show we are making strides forward in serving underserved communities? Can we find evidence of person-centered planning around primary caregivers, not just the recipients of care?

Are there options in utilizing respite funding because there is more than one provider who will accept the funding available (in all geographic areas of Nevada), more than one modality for receiving respite, or options for self-direction?

NLRCC will be looking for the following improvements into our LTSS system for serving family caregivers:

- Evidence of self-direction and person-centered planning around primary caregivers.
- Referral-to-respite process begins with identifying caregivers and promoting respite as a critical element of care.
- Barriers are identified through a program of respite accountability that captures reason(s) program is unable to provide respite to referred caregivers.
- Utilization of a standard Caregiver Assessment and Satisfaction Survey that includes more state and community partners.
- Nevada caregivers receive respite and other long-term services and supports through a trained and expanded workforce, that includes family and friends, with proof that the caregivers acknowledge that they trust/prefer the caregiving supports they receive.

Nevada Aging & Disabilities Services Division, state DD Council, and other organizations in the aging and disability network can ensure that staff are aware of available family, kinship, and grandparent caregiver support programs and services and trained in the importance of proactive caregiver identification and referral.

Nevada will use this plan to shape policy recommendations and advocate for programming to support family caregivers. Efforts under this plan will be monitored and reported annually.



## Appendix A: Known & Potential Partners in Respite

The Department of Health and Human Services (DHHS) Director's Office oversees the Grants Management Unit that administers the Fund for a Health Nevada grant that includes respite services in its funding priorities. Funding for Respite Services is meant to improve access and coordination for respite services and supports. These services promote a person/family centered approach in care planning and caregiver support.

Another DHHS division, Child & Family Services (DCFS), also could have a role in respite through their Child Welfare Services and Children's Mental Health departments.

DHHS division Healthcare Financing and Policy (DHCFP) could have a role through Nevada Medicaid State Plan Services and 1915 Waivers for Frail Elderly, Physical Disability, and Intellectual/DD waivers.

Under Public & Behavioral Health, the Clinical Services Branch and Community Services Branch could also have a role. Community Services has the Maternal, Child and Adolescent Health program, the Chronic Disease Prevention and Health Promotion program, the Substance Abuse Prevention and Treatment Agency, and the HIV Prevention/Ryan White Part B program.

The Nevada Aging and Disability Services Division (ADSD) is one of 5 divisions under the Department of Health and Human Services and administers the Lifespan Respite Care Act grants that support the NLRCC Coalition. The Division is the designated state unit on aging and disability services and serves as the single area agency on aging. ADSD is comprised of several units which offer or potentially could offer respite or other caregiver supports:

**Nevada Early Intervention Services:** Services for families with children under the age of three. Individualized Family Services focused on the family's priorities and concerns.

**Autism Treatment Assistance Program:** Provides temporary assistance and funding to pay for evidenced based treatment such as Applied Behavior Analysis (ABA) for children on the Autism Spectrum, who are under the age of 20.

**Developmental Services:** Programs and services for individuals with intellectual and/or developmental disabilities of any age.

**Community Based Care:** Provides services to older adults and people with disabilities to remain in community-based settings of their choice.



**Planning, Advocacy and Community Services:** Responsible for strategic planning, councils & commissions, grant funded services and direct services for older adults, people with disabilities and family caregivers.

This list does not include other governmental entities, such as the VA or the Tribal Councils who may have programs for caregivers or a culture of care for elders, or other faith-based and community-based programs who intersect with caregivers.

During this reporting period, NLRCC gave public comment and presentations to other councils, commissions, advisory boards, taskforce groups, and tribal communities to explain the critical role of familial caregivers and what they need to be successful. While these other entities were appropriately focused on individuals with special healthcare needs or disabilities, they also recognized the important role that family caregivers have in supporting and assisting those in need. Many of these groups expressed their interest in supporting Coalition efforts, as the result would be better care and supports for the individuals these groups represent.

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## Appendix B: Compelled Caregiving Bill Draft

### Assembly Bill Draft Request AKA "Compelled Caregiving Bill"

**BDR Summary:** Establishes requirements related to programs for family caregivers.

#### **Background:**

In 2000, Congress established the National Family Caregiver Support Program (NFCSP) as part of the reauthorization of the Older Americans Act (OAA), marking the first federal recognition of the critical role families play in the nation's system of long-term services and supports. The estimates of the prevalence of informal caregiving make it clear that there is a great deal of reliance on family members to provide care to people living in the community.

Family caregivers have stepped into the role of caregiver to meet these long-term support needs without education, training, or an understanding of the sacrifices and tradeoffs they will be required to make. They are compelled by the desires of the recipient of care, family expectations, cultural expectations, social expectations, their own expectation of receiving familial and community support, and the lack of acceptable alternatives for care.

An extensive body of research documents the negative physical, emotional, and financial consequences that caregiving brings. The combination of loss, prolonged distress, the physical demands of caregiving, and any biological vulnerabilities of caregivers may compromise their physiological functioning and increase their own risk for physical health problems, even leading to increased mortality.

Currently, Nevada does not have a system of caregiver assessments to address the health and well-being of family caregivers, even at logical points such as hospital discharge planning, where long-term care responsibilities are placed on caregivers. Family caregivers are the critical link to ensuring that the instructions of medical providers are implemented outside of the physician's office or hospital.

Because of caregiving pressures and demands, family caregiver regularly need an intermittent break or short-term relief from the day-to-day responsibilities of care. Respite care for the caregiver helps sustain the health and well-being of the caregiver, helps avoid or delay costly out-of-home placements, and reduces the likelihood of abuse and neglect. Unfortunately, the link to respite is not made when it could provide protective and restorative benefits, because the needs of the caregiver are not assessed until the caregiver is in crisis.

In recognition of the pressures and demands of caregiving, there are several national initiatives that emphasize the importance of caregiver assessments.



First, the Centers for Medicaid and Medicare Services (CMS) final rule for section 1915(i) State Plan HCBS, states in § 441.662 (a)(4) a new requirement for a caregiver assessment. When caregivers are being relied upon to implement the person-centered service plan, it is important that a caregiver assessment be required, to acknowledge and support the needs of informal family caregivers. Caregivers provide critical care and support that enables individuals to live in their homes and communities. When there is a caregiver involved, an assessment of the caregiver's needs is essential to facilitate the individual's linkage to needed supports. The capacity of primary caregivers to provide for the individual's assessed needs is necessary, as natural supports often have declining capacity, and failing to take this into account leads to unrealistic plans. <https://www.federalregister.gov/d/2014-00487>

Secondly, caregiving issues were of particular interest to policymakers in the 2020 reauthorization of the Older Americans Act. P.L. 116-131 amends the National Family Caregiver Support Program (NFCSP) to include caregiver assessments, allowing Area Agencies on Aging (AAA) to utilize assessments in determination of services to be provided. Caregiver assessment refers to a systematic process of gathering information about a caregiving situation to identify the specific problems, needs, strengths, and resources of the family caregiver, as well as the caregiver's ability to contribute to the needs of the care recipient. Administration on Community Living (ACL) provides technical assistance on caregiver assessment, including *"tools and templates, comprehensive assessment protocols, and best practices concerning— (1) conducting caregiver assessments (including reassessments) as needed; (2) implementing such assessments that are consistent across a planning and service area, as appropriate; and (3) implementing caregiver support service plans, including conducting referrals to and coordination of activities with relevant State services."* [Public Law 116 - 131 - Supporting Older Americans Act of 2020 - Content Details - \(govinfo.gov\)](#)

Previous CMS guidance on the Balancing Incentives Program also acknowledged the importance of caregiver assessment. CMS recommended that family caregiver needs be considered as part of best practices, recognizing that *"families and/or caregivers often have needs outside the needs specific to the individual eligible for services. These needs are typically connected to caregiver stress, a need for information and referral, support groups and/or respite care. An assessment process that incorporates components tied to caregiver needs will result in a more well-rounded assessment of the service and support needs of the whole family."*

Since 2018, Medicare and Tricare have reimbursed clinicians for care planning services provided to individuals with cognitive impairment, including Alzheimer's disease and other dementias, mild cognitive impairment, and those individuals without a clinical diagnosis who, in the judgement of the clinician, are cognitively impaired. Under CPT code 99483, physicians, physician assistants, nurse practitioners, clinical nurse specialists, and certified nurse midwives can currently bill under this code every 180 days per



client. The code includes specific identification of caregiver(s), caregiver knowledge, caregiver needs, social supports, the willingness of caregiver to take on caregiving tasks, and the ability to provide care.

**Our recommendation** is to propose legislation that establishes a process for hospitals, Medicaid waiver programs, healthcare professionals, and agency programs for Long Term Services and Support (LTSS) that rely on a family caregiver to provide care and support for a person with a disability, terminal illness, cognitive impairment, or chronic healthcare condition (Inclusive of definitions in NRS 449A, NRS 426, and NRS 427A) to assess caregiver willingness, ability, and needs to provide that care long term, and provide data from the assessments to the Nevada Department of Health & Human Services (DHHS).

This legislation will emphasize caregiver engagement, including the use of evidence-support and culturally sensitive family caregiver assessments, to measure the extent, quality, value, or effect of family caregivers' social determinants of health, specific risk factors related to stress and depression, and environmental and cultural barriers that put caregivers at risk.

#### **Suggested NRS Provisions**

- DHHS to conduct an interim study of caregivers to include: 1) evidence-supported and culturally sensitive family caregiver assessments, to determine the willingness, ability, and needs of a family caregiver to provide long term services and supports to a person with a disability or special healthcare condition, 2) measuring the extent, quality, value, or effect of family caregivers' social determinants of health, specific risk factors related to stress and depression, and environmental and cultural barriers that put caregivers at risk, 3) the efficacy of referrals linking caregivers to local community resources, and 4) a process for gathering data from assessments for annual reporting.
- Implement a pilot program of the caregiver assessment tools and process developed in the interim study, expanded, based on recommendations from the study, to include other target populations, with an emphasis on strategies to address unmet demand for community resources.
- Report results of the study and pilot program to the Nevada Lifespan Respite Care Coalition, the Commission on Aging, the State Independent Living Council, and the Commission on Services for People with Disabilities annually throughout the biennium.
- DHHS will develop a system for all programs, including subrecipients, to report caregiver assessment data, and require participation as part of grant awards.
- DHHS will publish an annual report of caregiver data to include family caregivers' willingness, ability, and needs to provide long term services and supports, social determinants of health, specific risk factors related to stress and depression, and environmental and cultural barriers that put caregivers at risk.



**Additional Items for Consideration/Research**

- Conduct an interim study on the expansion of NRS 449A.324 to include a caregiver assessment, upon hospital discharge, of the caregiver’s capacity to provide all necessary aftercare, including any ADLs and IADLs.
  - Require hospitals to report data to DHHS Office of Data Analytics
- Conduct an interim study on the use of CPT Code 99483 to analyze its usage for caregiver assessments in Nevada, specifically identifying caregiver knowledge, caregiver needs, social supports, the willingness of caregiver to take on caregiving tasks, and the ability to provide care.
  - Require practitioners to report data to DHHS Office of Data Analytics

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## Appendix C: Expanded Recommendation Narrative

### Recommendations for Collaboration

Family caregivers must navigate systems of healthcare, social services, insurance, military benefits, employment, and much more to support a loved one. But those systems are not required to understand each other or coordinate on behalf of families in need. Left on their own, family caregivers do not receive any of their own case management because their support is generally hidden behind supports and services designed for care recipients.

Families are not able to access respite, not typically due to eligibility, funding, or even workforce capacity, but because they need support that does not fit the modality used or the restrictions/limitations placed on relief workers. A companionship program may not meet the complex needs of a care recipient during respite, or a compound caregiver is supporting more than one person/age group/diagnosis with special needs. Something about the care situation makes it impossible to benefit from the respite offered. When a family fails to access respite, there is no place to help triage the situation and no group working to overcome the difficulties that the programs themselves create for caregivers.

Some families might qualify for additional/different supports from other governmental silos - like the U.S. Department of Veteran Affairs (VA) - that have no communication/coordination with state systems (like Medicaid). There needs to be a relationship between agencies (like the VA) to get information on providers (like Medicaid) outside of their own silo to share with their clients.

Respite Voucher Programs should meet regularly as a committee, to know each other and who can serve which caregivers. As a respite committee, together they can find the right respite program and get caregiver where they need to be – by navigating the system for them.

All programs are collecting data, but these collection efforts have not focused on caregivers. ASD should lead the effort to implement data collection strategies on caregivers, to leverage caregiver assessments and surveys, and build an accountability system to handle cross-system referrals to document reasons why a program cannot serve a caregiver through its regular modality. A collaborative partnership will encourage respite partners to voluntarily participate in these efforts. ASD cannot seek to fix systemic problems until they know what they are.

To assist family caregivers, ASD should compile a state inventory of family caregiver programs and services for those who are seeking information for themselves or those they serve. This resource list should be easy to find online and easy to have printed out for caregivers. This inventory should provide more information than a directory – and define the eligibility, service





area, service modality, skill level required of employees, and average wait until services received. Place this state inventory on a user-friendly site specifically for caregivers, not hidden behind sites designed for care recipients. ADSD should implement a caregiver support dashboard on the site with information on classes/clinics, and special events. Marketing this site to other agencies and providers will help engage the whole field of respite and caregiver supports in collaborative outreach activities. This information can then be shared in agency updates and newsletters through all providers to the families they serve.

Being aware of each other's programs, service population, and service areas would be a good start towards more collaboration and joint ownership of the problems of access to and the availability of respite. This group can also be a place to triage the "difficult to serve" cases where a caregiver cannot access respite that fits their needs, to derive solutions/alternatives that one provider cannot meet alone, like embedding companionship respite in a facility-based unit where skilled care support would be utilized only if needed.

### Recommendations for Funding

Because state agencies and respite providers do not have data-driven programs, they are not always aware of service gaps, nor do they hold themselves responsible to help address them. These programs don't collaborate, triage cases, or offer any creative solutions to caregivers who do not fit a specific mold. It is difficult to advocate against a system that is not responsive to the growing/changing needs of caregivers. Services stay the same, offered the way they always have been, available to only those who can benefit from traditional offerings from governmental programs.

One path given is no path at all if the family needs are divergent from the siloed approach that exists. This is inherently discriminatory because not all families are the same, nor are their needs met in just the same way.

Each program targets its respite resources to certain service modalities and/or prescribes eligibility for respite so narrowly that service gaps naturally occur – and there is no rationale available on why certain policies and regulations or reimbursement rates were determined, especially when they serve to stymie some caregivers from accessing respite.

Some funding for respite and other caregiver supports is underutilized, and some funding quickly runs out. Funding levels are not clearly defined by the number of caregivers in the service population or the cost of care. Funding agencies are less concerned with the difficulties of securing services, as they administer programs but do not navigate the challenges of helping caregivers find direct care workers. Issues with funding have led providers to exit the field of respite or require significant out-of-pocket commitments from caregivers. Staff shortages are



also tied to funding issues, as programs cannot attract workers in a competitive market when funding limits the hourly rate that can be paid.

Even though family caregivers are often managing complex medical care for their loved ones with minimal training, respite programs restrict who can give them temporary relief - limiting their respite workers to hands-off, non-medical care or requiring more expensive Personal Care Aides to be hired when only companionship is needed for respite. Respite services need to deliver a level of trust and skill “good enough” to replace the caregiver temporarily, and not be tangled in regulations and liability restrictions that generate more barriers than relief. Caregivers have repeatedly stated, “if I can do it, I can train someone else to do it.” Why have programs not explored the use of liability waivers, used so often in other states?

Since the pandemic caused programs to re-evaluate how to deliver services, self-directed care is more available in Nevada statewide. Self-directed care is well designed for family caregivers who want to hire friends and family, and who will accept the responsibility to hire, train, schedule, supervise, and dismiss their relief workers if necessary. The family caregiver maintains control over how and when care is provided, given the approved tasks and hours on the agreed upon care plan.<sup>9</sup> While legally responsible individuals (i.e., spouses or parents of children under the age of 18) cannot be hired for relief work in Nevada, one estimate shows that about 70 percent of providers in self-directed programs are family members or friends.<sup>10</sup>

When respite provider agencies struggle to attract and retain a workforce to meet the needs of their current clientele, self-direction opens respite work to a wide array of workers who would not be interested in helping, except in support of the friend or family member they care about. Greater stability can be maintained in the care relationship through self-direction – and more caregivers will accept care relief - especially when they can pay workers who are employed on an intermittent basis.

Wages and benefits for respite relief workers have been a point of contention for workers, their employers, and the funding agencies who negotiate reimbursement rates. Studies to examine the difference in Medicaid reimbursement rates and the wages for personal care aides have been conducted, most notably in the Guinn Center Report.<sup>11</sup> The Medicaid reimbursement rate

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<sup>9</sup> Source: Nevada Medicaid. “Nevada Medicaid’s PCS Program Offers Distinct Choices for In-Home Care.” <https://www.leg.state.nv.us/App/InterimCommittee/REL/Document/2586>

<sup>10</sup> Source: Kezia Scales, Jodi M. Sturgeon, Robert Espinoza, Stephen Campbell, and Allison Cook. 2019. “Envisioning the Future of Home Care: Trends and Opportunities in Workforce Policy and Practice.” PHI. Available: <https://phinational.org/wp-content/uploads/2019/10/The-Future-of-Home-Care-2019-PHI.pdf>.

<sup>11</sup> [Guinn-Center-Helping-Hands-PCAs-Nevada.pdf \(guinncenter.org\)](#).



for respite of \$9.75 an hour is well below the competitive wages paid to PCA staff (around \$12/hour), and completely unacceptable once Governor Sisolak announced a historic increase in home care funding and a \$15 minimum wage for workers.<sup>12</sup> However, no consideration was given to the impact this would have on family caregivers who have not seen their respite funding increase. Higher rates for services translate into fewer hours of respite for them. Agencies have demanded that family caregivers pay for additional hours of service out-of-pocket to remain on active clientele lists or have refused to accept respite vouchers anymore. As NLRCC has tried to determine, the LTSS workforce of unpaid familial caregivers is multiples the size of Nevada's 13,000 home care workers and weakening family caregivers further by effectively reducing their respite relief would be counterproductive.

Also, according to initial news reports, under the Governor's proposed budget, Medicaid reimbursement rates – which have remained unchanged for decades – would increase from \$17.56 to \$25 an hour and shore up a home care workforce and provider network that has been weakening over many years. What change, if any, in the respite funding rates or what changes might be made to the Medicaid recommended budget when it is handed off to Governor-elect Lombardo needs to be examined closely.

Communities too often lack the funding and infrastructure to address caregiver needs, especially in rural areas. The process and path forward to become a provider of respite and other caregiving services needs to be outlined, promoted, and the smallest startup supported. It needs to become easier to exist in this field.

Collect data on caregivers and base funding for respite on data collected. Respite voucher programs fund respite but do not base the funding on any data collected, even among respite programs that have supposedly served caregivers for years. Where there is no data, it is harder to advocate for family caregivers.

Expand services to fill service gaps by including funding criteria for grantees to partner with collaborators on filling service gaps or to stretch programming into new modalities or service areas. Encourage the state agencies that grant funds for respite and caregivers supports to include criteria for expanding services to fill service gaps, and favor applications where an applicant has partnered with collaborators who can help them address gap needs (instead of competing against each other for funding) and will stretch programming into new modalities or service areas.

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<sup>12</sup> [Sisolak proposes raise for state employees, increased K-12 funding in 2023-24 budget | Las Vegas Review-Journal \(reviewjournal.com\)](https://www.reviewjournal.com/news/sisolak-proposes-raise-for-state-employees-increased-k-12-funding-in-2023-24-budget/)



Plan grants for caregiver supports and services regionally, not statewide, to assure better coverage of rural and other underserved communities.

Utilize sliding income scale eligibility for respite, so that all caregivers can purchase the services, whether through vouchers or out-of-pocket. Income criteria should not eliminate eligibility for respite or other caregiver supports.

Assume responsibility for role in referring caregivers to additional support through other programs (i.e., VA caregiver programs, mental health supports). Some families are eligible for support through other programs (i.e., VA caregiver programs) and they need to be referred to all funding sources for caregiver supports. How are we helping to identify military families and connect them to the VA? Are there other connections we need to make for caregivers (i.e., Mental health supports)?

Examine the difference in Medicaid reimbursement and wages for PCA workers, in understanding the barrier this creates for family caregivers seeking respite and compare traditional agency-directed services with a self-directed model that would give caregivers more flexibility, choice, and control over receiving respite.

Underserved communities often lack the funding and infrastructure to address caregiver needs, especially in rural areas. Where is the process to become a provider of respite outlined, promoted, and the smallest startup supported on a path forward? It needs to become easier to exist in this field. While the recommendation above is about encouraging expansion of service, this recommendation is about encouraging new startups.

Determine the utilization of alternative options for funding respite. Are respite services eligible for coverage by Health Savings Accounts and Flex Spending cards?

### Recommendations for Outreach

Nevada needs a system of caregiver assessments to address the health and well-being of family caregivers, especially at logical points such as hospital discharge planning, where long-term care responsibilities are placed on caregivers. Numerous studies have shown that talking with caregivers directly to better understand their needs, problems, resources, and strengths, as early as possible in their caregiving journey, helps them to maintain their health and sustain their ability to provide care. This needs to happen routinely throughout their caregiving journey.

While some respite programs have established ties to medical professionals who make referrals, healthcare professionals rarely assess the support needs of family caregivers or



consider them a critical part of the LTSS team towards achieving the best outcomes for the recipient of care. Without healthcare professionals recommending respite or directing family caregivers to sources of support, family caregiver might not realize such programs and services even exist.

Our system relies on informal family caregivers to self-identify for support. There is no ADSD-funded marketing campaign or outreach effort to find them. Most of the respite programs do not have an outreach or marketing plan and rely primarily on referrals from resource navigators.

Caregivers who represent unserved, underserved, and/or marginalized communities frequently experience greater physical, emotional, and financial challenges associated with caregiving. The individuals providing support to others may not think of themselves as caregivers or may be reluctant to ask for assistance. They may feel discrimination and are distrustful of service providers, making them less likely to seek assistance until they “reach a point of crisis.”

Language used in outreach efforts do not “speak” to informal caregivers and may completely miss caregivers in communities of color. Some cultures do not even have words, language, or terms to differentiate people who provide informal support to others, as caregiving is so integrated into their society.

The first step would be to develop simple family caregiver self-identification tools that can be widely adopted. This could be a consistent question embedded in an existing intake such as “do you help someone with shopping or daily activities?” Embed processes to identify family caregivers through state agencies and public-private partnerships, rather than waiting on family caregivers to self-identify. Identify and utilize new outlets, like the VA Homemaker program Freedom Care and the Patriot Angels Community awareness activities and/or resource fairs.

Use language that is more inclusive and acceptable to all family caregivers so that messages of respite and caregiver support can reach them and will be recognized by them. Words like “respite” and “caregiver” are not common in our vernacular and are easily ascribed to paid direct care workers. The term “caregiver” is used regularly in the social service field, and while many people like the term “caregiver,” others prefer to use terms like “care partner” to describe the person who helps others.

Pay attention to messaging and avoid the word “caregiver” and instead use phrases that describe caregiving. Different stakeholder groups prefer different terms to describe the tasks



performed by familial caregivers to be “care,” while others use “support,” “assistance,” or simply, “help.”

Developing broader eligibility definitions among respite programs that include a range of caregivers from families of choice, such as non-legally or non-biologically related caregivers, grandparents raising children, neighbors, and friends, can ensure that more types of unpaid caregivers receive support.

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