Nevada Lifespan Respite Care Program
Data on Caregivers 2012

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

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

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

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

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

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

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

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

DEMOGRAPHIC DATA

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

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

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

N=230

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

Clark County = 169

Washoe County = 40

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

The following chart also illustrates the applicant response from around the state. It also reflects that the LRBI program made significant efforts to reach caregivers around the state. The LRBI grant had a target of 13% rural representation of caregivers. The number of rural participants is 20 families, which represents 11.5% of all the caregivers in the program. However, only RAVE was charged with outreach
in rural counties. Of the 58 vouchers that RAVE awarded, these 20 families represent 34.5% of the voucher recipients.

![Counts](image)

**Ethnicity**
This data comes from the LRBI application form.

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

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

N= 250

- Hispanic = 97 or 39%
- Multi-Racial = 9 or 3.5%
- African American = 32 or 13%
- Asian = 3 or 1%
- Native American = 4 or 1.5%
- Other (Hawaiian-1, IndoEuropean-2) = 3 or 1%
- Caucasian = 102 or 41%
**Household Income Levels**
This data comes from the LRBI application form.

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

N = 160

Under $25K = 135

$25K-$50K = 17

$50K-$75K = 3

$75K-$100K = 2

Over $100K = 3
Caregivers Data
This data comes from the LRBI application form.
Care Recipient Data
This data comes from the LRBI application form.

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

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

The ages of care recipients were grouped into four categories. Minor children are eligible for different respite funding and resources, as are seniors. The adult population was split at age 50 to see changes in the identified disabling condition. Concerns that care recipients with early onset dementia or other age-related conditions are not old enough to qualify for respite programming that serves seniors. This data attempts to recognize those care recipients and conditions.
Child (0-17 yrs) = 95  Range of Supports Needed =1-13; Avg. = 6
Young Adult (18-49 yrs) = 21  Range of Supports Needed =1-13; Avg. = 7.7
Adult (50-64 yrs) = 15  Range of Supports Needed =4-12; Avg. = 9.2
Senior (65+ yrs) = 100  Range of Supports Needed =1-13; Avg. = 8

**Care Recipients**

**Range & Average of Support Needs**

- Children: 6
- Young Adult: 7.7
- Adult: 9.2
- Senior: 8

- Children (0-17 yrs)
- Young Adult (18-49 yrs)
- Adult (50-64 yrs)
- Senior (65+ yrs)
Note: Applicants were able to select more than one response on both disabling condition and the assistance and supervision needed. There were 16 choices of condition, and 13 choices for assistance and supervision.

**Disability**

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

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

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

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

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

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

Seniors: Intell= 4, Mental=3, Neuro= 82, DD=2, Medical= 34, Sensory= 31, Ortho=41
Assistance/Supervision Needed: 129= eating/feeding, 191= bathing & hygiene, 148= toileting, bowel & bladder care, 177=dressing & grooming, 96=transferring, 78=standing & walking, 128=medication reminders, 138=transportation, 151=meal preparation, 121=necessity shopping, 112=light housekeeping, 101=medical escort, 84=communication, other (please specify) 10=Safety, 16=Other
Living with Caregiver? Y=224   N=6

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

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

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

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

Sandwich of Children & Adults (18-64) =13, Sandwich of Children & Seniors=19
Pre-Respite Data
Families who applied for the LRBI voucher program were asked to complete a survey prior to receiving and using their voucher awards. The questions and responses are given below. The charts are labeled from 2.1 to 2.19.

Were you aware of respite or respite services prior to making this contact?       YES         NO
Aware of Respite?       Yes=125       No=104       Inconclusive=2

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

![Graph of Compounding of Care](chart.png)

![Graph of Awareness of Respite](chart2.png)

![Graph of Have Used Respite](chart3.png)
If Yes, Used Respite? Of the Aware group of 125, 84 had used respite previously=67%. Of the Aware group, 41 had not used respite before = 33%.

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

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

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

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

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

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

Of total (n= 83=23+52+8) Prompted Use responses: Break=9+15=24, Friend/Family=1+7=8, Aware =1+12=13, Agency/Social Worker=2+1+6=9, Provider/Service Org=3+6+10=19, Emergency= 1+2=3, No Citizenship=6, Easier to Find Provider=1.
All Referrals N=6+7+23=36 came from: Agency/social worker=2+1+6=9, Provider=3+6+10=19, Friend/Family=1+7=8

2. Do you have concerns about receiving respite services? (Check all that apply)
24=Care recipient is reluctant to accept outside help
43=Uncomfortable with having people we do not know in the home
32=No one else can provide care as well as I do
10=Other -(Breakdown of Other is not available – Data Collection Tool neglected to capture)
141=No concerns at this time

3. Is there anyone you can call on in an emergency to fill in for you as a caregiver?
Yes=125 or 54%  No=44 or 19%  Maybe=61 or 27%

4. If care recipient has a chronic disease or condition, how knowledgeable do you feel about this
disease or condition?
VERY= 135 or 60%  SOMEWHA= 75 or 33%  NOT AT ALL = 5 or 2%
NOT APPLICABLE= 12 or 5%

Note: This data reflects the experience and preparation that caregivers had prior to seeking respite through the
LRBI program. When data was analyzed for differences in awareness of respite or prior use of respite, the results
did not change the percentages significantly from the group as a whole.
5. Do you need information, education and/or training about any of the following? (Check all that apply)

83=In-home support services
80=Legal and financial issues, powers of attorney, living will
64=How to care for yourself while caring for others
63=How to get other family members to help
59=Support groups
50=Long-term care options (insurance and/or other benefits)
49=Home safety and/or home modifications, or equipment
45=Short-term respite care in a facility
38=More information about care recipient’s disease/condition
34=Individual counseling options
33=On-line information and supports
25=Choosing a long-term care facility
23=How to provide care to an aging individual or a person with a disability
17=Hands-on skill training for personal care tasks (bathing, grooming, toileting etc.)
4=Other (Please describe) - DNR Orders, Diabetes Class, Caregiver, None Given
6. Do you find care-giving to be stressful?  
   YES=204 or 90%  
   NO=24 or 10%  
   No Response=2

Rate your current stress level:  
   LOW  
   MODERATE  
   HIGH  

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

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

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

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

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

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

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

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

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

Burnout results when caregivers reach a point of exhaustion, when they no longer have the physical or emotional strength to continue. Damage has likely occurred within the family unit by then, with divorce, substance abuse, domestic violence, abuse & neglect reflecting the impact of un-relieved caregiving on these familial relationships.
Note: Questions 8 and 9 have been interchanged for the purposes of this report. The numbers are for reference to the document they were taken from.

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

NEVER RARELY SOMETIMES FREQUENTLY NEARLY ALWAYS

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

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

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

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

Note: Some funding of respite has been tied to at-risk behaviors. This data attempts to see whether caregiving stress leads to at-risk behavior.
8. What do you do to cope with the stress related to giving care? Please Describe ________________

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

Yes Stress Group: Religion/Prayer=24+1+12=37, Exercise/Self-Care=20+1+9+1=31, Sleep/Rest/Relax/Time for Self=4+2+2+13+8+1=30, Be Understanding/Put Up With It=12+1+1+2=16, Movies/TV/Computer=3+6+7=16, Music/Reading=8+8=16, Hobbies/Interests=1+1+1+1+1+2+2+1+1+3=14, Cry/Yell/Breathe=10+2+1=13, Social/Friends/Family=11+1+1=12, Get Out/Get Away/Outdoors=3+3+3+1=10, Sing/Dance=4+1=5, Smoke/Eat=1+3=4, Therapy/Prescription=2+2=4, Nothing=1+1+1+1=4 (Write in: “Nothing, Not sure what to do, Don’t know how, Having a hard time”)
10. I feel …. (Check all that apply) n=230

Positives:

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

135 or 59%=Confident about providing care

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

Negatives:

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

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

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

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

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

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

Note: This question asks about the caregiver’s commitment to care. Keeping caregivers committed to providing care is why respite has become a top priority for Nevada. Alternatives to care when the caregiver’s commitment...
to continuing care wanes (due to stress, health, finances, burnout, etc.) are expensive, and difficult to provide everywhere they are needed.

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

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

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

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

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

YES=36      NO=40      No Response=5
12. Have your care-giving responsibilities contributed to ANY health problems you may have?

YES   NO   NOT SURE

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

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

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

Note: Interesting to see that caregivers who said they had no health problems indicated that caregiving contributed to health problems. Those caregivers who had health conditions strongly see that caregiving contributes to their health problems.
13. How often have you been able to spend time in the various activities that you enjoy (e.g., going to religious services, socializing with others, going out for a meal) or spending time on hobbies or activities you like to enjoy alone (e.g., reading or gardening)?

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

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

14. Do you feel that if you are able to access respite, it would make a positive difference for you and your family?

YES = 219 or 95%  NO = 4 or 2%  No Response = 8 or 3%

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

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

No Response = 3 or 1.5%

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

YES = 168 or 73%  NO = 30 or 13%  MAYBE = 26 or 11%  No Response = 7 or 3%
Note: Seventy-three percent of Caregivers who applied for the LRBI vouchers already had potential respite caregivers identified. This counters speculation that finding a respite caregiver is a barrier to respite. This data should be compared to LRBI Post-Respite Survey data about the ease/difficulty of finding respite caregivers.

17. I feel .... (Check all that apply)

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

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

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

**RX Diagnosis: Caregiver Assessment**

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

Note: This document gathered information on relationship between caregivers and care recipients, length of time in caregiving, employment status of caregivers, language barriers, and other information that potentially has bearing on the access and use of respite services. The document also uses a modified Zarit Burden Interview in Question 7. Studies have demonstrated that the Zarit Burden Interview is a valid and reliable instrument for measuring the burden of caregivers.
1. A friend or family member may already depend on you for help or assistance, or to respond when needs arise. Please select the choice that best reflects your role.

220=Yes, I provide care regularly.

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

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

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

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

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

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

37=a=Spouse/Significant Other

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

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

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

6=e=Grandchild(ren)

3=f=Friend/Non-Relative

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

1= No Response
3. How long have you been giving extra care and assistance to the person identified above? Give an approximate length of time.

6 or 3%=a=One month or less
13 or 6%=b=Less than 1 year
95 or 41%=c=1-5 years
60 or 26%=d=5-10 years
53 or 23%=e=More than 10 years
No Response=2 or 1%

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

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

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

110=ages 17 or younger
13=ages 18-21
6=ages 22-35
8=ages 36-49
3.4

Caring for More Than One Care Recipient

<table>
<thead>
<tr>
<th>Age Category</th>
<th>Number of Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children Only</td>
<td>21</td>
</tr>
<tr>
<td>Child + Adult</td>
<td>6</td>
</tr>
<tr>
<td>Child + Senior</td>
<td>6</td>
</tr>
<tr>
<td>Senior Only</td>
<td>6</td>
</tr>
<tr>
<td>Adult Only</td>
<td>1</td>
</tr>
</tbody>
</table>

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

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

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

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

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

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

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

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

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

None of the Above= 8, with Reasons Given: Student=1, Can’t make enough money to pay someone else to stay with Mom=1, Unspecified “unable to work”=1, Terminated=1, None Given=4)
6. Please read each statement and indicate if any apply to you.

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

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

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

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

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

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

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

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

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

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

5=None of the above
Note: Question 7 below is the modified Zarit Burden Interview. This information is not captured in any other tool used by the LRBI Respite Expansion grant. Compare to Question 10 in the Pre-Respite Survey.

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

19=That you are asked to give more care than is really needed.

162=That time spent in care giving leaves little time for yourself.

110=Stretched between demands as a caregiver and demands from work and family.

31=Embarrassed/scared by behavior from person you provide care to.

33=Sometimes angry when you have to provide care.

54=Care giving for one person is negatively affecting your relationship with others.

139=Afraid of what the future will be like for the person you provide care for.

163=That the person you provide care for is dependent upon you.

39=Strained in your relationship with the person you provide care for.

34=Uncomfortable about having other people over when you are care giving.

89=Like you are expected to provide care because no one else can be depended on.
163=That there is not enough money for the extra care needed.
36=Unsure about your ability to continue to provide care much longer.
63=A loss of control over your life.
36=Wishful about leaving care giving in someone else's hands.
24=Uncertain about knowing what to do for the person needing care.
30=You should be doing more.
31=You could do a better job of care giving.
85=Burdened by care giving.
104=Your own health has suffered because of the demands of care giving.
95=A loss of privacy because of care giving.
163=A loss of a social life because of care giving.
6=None of the above.

**Zarit Burden Interview**

![Zarit Burden Interview Chart](chart.png)
Note: The results above may also be important to awareness campaigns and marketing of respite. Helping caregivers recognize the sacrifices they make in providing care is an important part of getting them to accept respite.

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

112=Good information about resources and services available.
52=Advice from other caregivers, gathered from their experiences.
187=Regular or temporary breaks from care giving role.
137=Extra assistance or help so you can provide the care needed.
35=Training so you can provide better care.
64=Strategies to make your care giving easier.
12=Other (please specify) 1=Money, 10=Unspecified, 1=Time

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

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

184=Extremely likely
25=Very likely
8=Moderately likely
7=Slightly likely
5=Not at all likely

If not, why not? __________________________________________________________

10. Where do you live?

City/Town: ________________      ZIP: ________________

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

**Voucher Claims & Use**

As the LRBI grant has recently closed, voucher claim updates are still coming in. The data available on August 31, 2012, form the basis for the information and the illustrations below. Contact the Aging & Disability Services Division for the final report. The charts are labeled from 4.1 to 4.5.
Under the LRBI Respite Expansion grant, 174 Vouchers of $600 each were to be awarded, totaling $104,400. As of the most recent reports from GAB and RAVE, $103,184 had been awarded – leaving $1,216 yet to be awarded.

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

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

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

GAB voucher claims of $58,074.51 represent 5674.75 hours of respite, at an average cost of $10.23/hour. The range of hourly rates is between $1.76 - $35.42/hour.
RAVE voucher claims of $26,225 represent 3392 hours of respite, at an average cost of $7.73/hour. The range of hourly rates is between $2.27 - $24.00/hour.

Breakdown:

- $1.00-9.99 = 26
- $10.00-14.99 = 46
- $15.00-19.99 = 19
- $20.00-24.99 = 8
- $25.00+ = 3

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

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

<table>
<thead>
<tr>
<th>Month</th>
<th>GAB</th>
<th>RAVE</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>OCT</td>
<td>5</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>NOV</td>
<td>0</td>
<td>48</td>
<td>48</td>
</tr>
<tr>
<td>DEC</td>
<td>60</td>
<td>125</td>
<td>185</td>
</tr>
<tr>
<td>JAN</td>
<td>282</td>
<td>408</td>
<td>690</td>
</tr>
<tr>
<td>FEB</td>
<td>855.75</td>
<td>373</td>
<td>1228.75</td>
</tr>
<tr>
<td>MAR</td>
<td>732</td>
<td>811</td>
<td>1543</td>
</tr>
<tr>
<td>APR</td>
<td>785.5</td>
<td>598</td>
<td>1383.5</td>
</tr>
<tr>
<td>MAY</td>
<td>654.5</td>
<td>309</td>
<td>963</td>
</tr>
<tr>
<td>JUN</td>
<td>687</td>
<td>513</td>
<td>1200</td>
</tr>
<tr>
<td>JUL</td>
<td>556</td>
<td>207</td>
<td>763</td>
</tr>
<tr>
<td>AUG</td>
<td>769</td>
<td>0</td>
<td>769</td>
</tr>
<tr>
<td>SEP</td>
<td>310.5</td>
<td>0</td>
<td>310.5</td>
</tr>
</tbody>
</table>
Below is the chart of how many voucher awards were made each month. Note: GAB made efforts to re-assign partial and unused vouchers, but RAVE’s data updates end July 31st, and does not contain information about whether or not RAVE re-assigned any vouchers.

**Vouchers Awarded Per Month**

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

The processing of application and awarding vouchers took at average of 28.22 days. GAB data shows an average time differential of 28.99 days; RAVE’s data was only 53% complete for application dates, but the data available shows an average time differential of 25.29 days.
Respite Time Used For
GAB Data: Travel = 14, Time Alone = 70, Time with Others=67, Health=38, Religious =11, Chores =20, Work = 5
RAVE Data: Travel = 10, Time Alone = 70, Time with Others =32, Health=27, Religious=4, Chores =15, Work =3

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

1. Who were the people or programs who delivered respite to you under this grant? (Check all that apply)
   ○ Family & Friends
   ○ Neighbors & Community Members, including Volunteers from Faith-Based, Social or Service Organizations
   ○ Volunteers/Employees from an In-Home Respite Program
   ○ Volunteers/Employees from a Facility-Based Respite Program
2. Who would you prefer to use for respite services in the future, if the option is available? (Select One Only)

- Family & Friends
- Neighbors & Community Members, including Volunteers from Faith-Based, Social or Service Organizations
- Volunteers/Employees from an In-Home Respite Program
- Volunteers/Employees from a Facility-Based Respite Program
- Professional Care Providers from a Home Healthcare or Personal Care Service Program
- Professional Care Providers from a Day Care Program, Assisted Living, or Nursing Home Program
- Other (Please Describe) ____________________________

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

- More comfortable accepting help from others
- More comfortable having respite workers provide support at home
- More comfortable with respite support outside of home
- That respite workers have provided competent care
- That I should have used respite supports earlier
- Other (Please Describe) ____________________________

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

- Identifying potential respite worker/provider
- Selecting a respite worker/provider
- Hiring a respite worker/provider
- Training a respite worker/provider
- Planning/Scheduling with a respite worker/provider
- Getting respite reimbursement paperwork completed/submitted
5. Do you now have someone you know you can call on in an emergency to fill in for you as a caregiver?

YES     NO     MAYBE

6. Have you felt a reduction in care-giving stress?

YES     NO

Rate your current stress level:
LOW     MODERATE     HIGH

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

__________________________________________________________________________________

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

NEVER     RARELY     SOMETIMES     FREQUENTLY     NEARLY ALWAYS

9. I feel .... (Check all that apply)

○ A sense of relief that someone else is available to provide care

○ More confident about asking for help or assistance with care

○ More balance in my life in giving care and also trying to take care of myself

○ I have regained some enjoyable activities I had lost in caregiving

○ I am taking better care of my own health (physically and emotionally) through respite

○ Getting respite breaks was worth my time and effort in arranging them

○ The quality of the care during respite was competent and adequate for our needs

○ I am able to continue in my caregiving role for the foreseeable future

○ That the care recipient has benefited from the interaction with the respite worker/provider

○ More confident about finding/identifying/selecting a respite provider

○ More confident about preparing/training a respite provider to give care

○ More confident about how to use respite breaks effectively

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

NOT AT ALL  A LITTLE  A LOT

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

12. How much benefit came from receiving respite services?

NOT AT ALL  A LITTLE  A LOT

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

NOT AT ALL  A LITTLE  A LOT

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

If YES, what would that be?  Please Describe ________________________________