



# Nebraska Lifespan Respite Subsidy 2015 Evaluation Report September 2015

Department of Health & Human Services



# Nebraska Lifespan Respite Services

## Annual Evaluation

2014-2015

Department of Health & Human Services



Report

### Overview of Lifespan Respite Subsidy Services

Part of the overall Nebraska Lifespan Respite Services Program, the Lifespan Respite Subsidy Program provides funding for family caregivers to use for obtaining respite care services. The program provides a subsidy of up to \$125.00 per month to purchase respite care services. Those respite care services are designed to provide a break for family caregivers of a person with special needs. Special needs includes: developmental disabilities, physical disabilities, individuals with a cognitive impairment (such as Alzheimer's disease or dementia), emotional or mental disorders requiring supervision, chronic health conditions, individuals with physical disabilities and those at-risk for abuse and/or neglect. Families are able to select the respite caregiver, determine rate of pay, location of respite services and the schedule for those services. One recent addition to the program is crisis respite support which allows program eligible families to request additional respite support. Crisis Respite Eligibility criteria must be met to be considered for funding. A crisis situation is defined as "an unforeseen circumstance or unplanned event that calls for immediate action or an urgent need for short-term assistance or relief to substitute for the Caregiver in the absence of any other funding source." If crisis respite eligibility criteria are met, up to \$1,000.00 of supplemental respite funds for crisis support per program eligibility year for eligible clients is available. This addition was incorporated into the program during fiscal year 2014 (FY14).

### Evaluation Overview for 2014-15

The evaluation model selected for this evaluation is based on Patton's Utilization-Focused Evaluation model (Patton, 2012) with the purpose for the year being exploration and the goal towards program improvement.



The evaluation process for 2014-15 year focused on the Lifespan Respite Subsidy program. A subsection of the evaluation was the Employee Engagement pilot program implemented by the Department of Health and Human Services, the University of Nebraska Medical Center and Nebraska Medicine. The overall evaluation plan can be broken down into five general areas: Need, Access, Caregiver Outcomes, System Outcomes and Cost-Effectiveness of the system. While the components overlap, each has data that contribute to the overall picture. Two main questions will drive evaluation: (1) What is the current state of the respite care system? (2) What are the outcomes of the services provided within the system? By answering those questions, the goal would be to provide results on cross-agency collaboration and outcomes for caregivers.

The evaluation for year one focuses mainly on analyzing data that are already collected as part of the process. Of the five program areas, the evaluation will be focused primarily on need and access to respite care services as well as satisfaction with those services. Information on caregiver outcomes and new programs, such as REST (Respite Education & Support Tools) an evidenced-based national respite provider training model utilized statewide in Nebraska, will also be collected and included in the annual report for 2015.

As 2014-15 is a pilot year for the evaluation, changes may be made to the evaluation plan for the next two years as questions arise that need to be answered. One area of particular focus for the 2016-2018 is the collaboration between agencies and funding sources in providing respite care services. Additionally, information collected for the 2014-15 year may impact how data are collected from paid and unpaid family care providers and other stakeholders in the following two years.

Below are the questions from the three year evaluation plan broken down by each evaluation area. For 2014-15, some of the evaluation questions from each of the first three sections (need, access and

caregiver outcomes) are addressed. Systems outcomes will be addressed in years two and three. Cost effectiveness has preliminary findings and will carry into years two and three.

***Need: What is the need for respite services?***

1. Who needs respite services?
2. Who needs respite services but are not able to access them? For what reasons?
3. What is the projected need for respite care services over the next five years?
4. Is there a need for an increase in the number of providers? How does this vary by state region?
5. What is the perception of caregivers on their needs for respite in regards to number of hours and frequency of respite care?
  - a. By funding source
  - b. By program

***Access: What is the access level to respite care services?***

1. Who is accessing respite care services? Are there differences in the groups?
  - a. State regions
  - b. Disability categories
  - c. Age of family caregiver(s)
  - d. Age of care recipient
  - e. Income level(s)
  - f. Ethnicity of family caregiver
2. What is the frequency of access? Are there differences across groups?
  - a. State regions
  - b. Disability categories
  - c. Age of family caregiver
  - d. Age of care recipient
  - e. Income level(s)
  - f. Ethnicity of family caregiver
3. What are the formal and informal supports accessed by families?
4. How do waivers and subsidies affect access to respite care services?
5. What is the monthly average out of pocket expense for respite services?
6. What are the barriers to accessing respite care services?

***Caregiver Outcomes: What are caregiver outcomes related to: (1) satisfaction with services; (2) stress level; (3) relationships; (4) employment; (5) finances; (6) health?***

1. Are family caregivers satisfied with respite services?
2. Are stress levels impacted by receiving respite services?

3. How are relationships with significant others, family members, and the care recipient impacted by respite care services?
4. Is employment affected by access to respite care services?
5. Is health of the caregiver impacted by caring for the identified recipient? How does receipt of respite care services affect caregiver health outcomes?

#### **System Outcomes: What are the systems level outcomes?**

1. What is the level of agency collaboration statewide?
2. How effective is the centrality of data collection?
3. What are examples of effective sustainability efforts?
4. Do participant outcomes differ depending on the waiver program(s) they qualify for?
5. What are the outcomes from the Employer Engagement Pilot?
6. What is the effectiveness of the REST training?

#### **Cost Effectiveness**

1. What is the cost effectiveness in providing respite care services?
2. How are employers affected?

## **Methods**

Data were collected from multiple sources but all of the data are from families receiving the Lifespan Respite Care Subsidy funds. Data were gathered from the DHHS CONNECT client eligibility system, Lifespan Respite Network eLifespan Respite system, targeted focus groups and an online survey.

### **Focus Groups**

Focus groups were conducted in three Nebraska regions (Omaha, Lincoln and Loup City). Regional Respite Coordinators extended invitations to recipients of the Nebraska Lifespan Subsidy Program. Across the three groups, a total of nine family caregivers participated. Focus group participants were asked about their overall experience with the respite care system, the benefits of receiving respite care services, challenges within the system, and possible improvements. The focus groups expanded on some of the survey items around family caregiver outcomes particularly in the areas of stress, health symptoms, and use of time during respite care services and finances. Some items were adapted from pre-existing surveys (Kosberg & Cairl, 1986; Pearlin, et al., 1990). Each of the groups lasted approximately one hour. Some caregivers were unable to attend the group and a phone interview using the same questions was conducted instead. These participants received a \$25 gift card for their participation.

### **Lifespan Respite Subsidy Survey**

An online survey was sent out to family caregivers qualifying for the Lifespan Respite Subsidy program. Prior to the survey being sent out, a letter explaining the rationale for the survey and the overall evaluation was sent to family caregivers currently enrolled in the Lifespan Respite Subsidy Program. One week after the letter was sent via email, the online survey and survey link were emailed to enrollees. The 16 item survey addressed family caregiver satisfaction with services, respite hours received, the need for hours and multiple caregiver outcomes including health, relationships with others, stress levels and finances. Items for the survey were adapted from multiple pre-existing survey instruments (ARCH National Survey; George & Gwyther, 1986; Pearlin, et al., 1990). ARCH is “Access to Respite Care and Help”, the national respite technical assistance center for states funded by the Administration on Aging/Administration for Community Living. Invitations to complete the survey were sent to 93 participants (those with valid email addresses in the CONNECT system) with 26 participants completing the survey for a return rate of 28%. Participants received two reminder emails over the course of three weeks to complete the survey. No incentive was provided to participants for completing the survey.

## Findings

The following section discusses the findings as they pertain to the evaluation questions using data gathered from the online survey, focus groups and intake information provided to DHHS. The findings are organized around questions rather than the data source.

### Survey Respondent Information

Of the 26 family caregivers completing the survey, 30% have received respite care services for less than one year, 54 % have received services between 1-5 years and 16% have received services for more than 5 years.

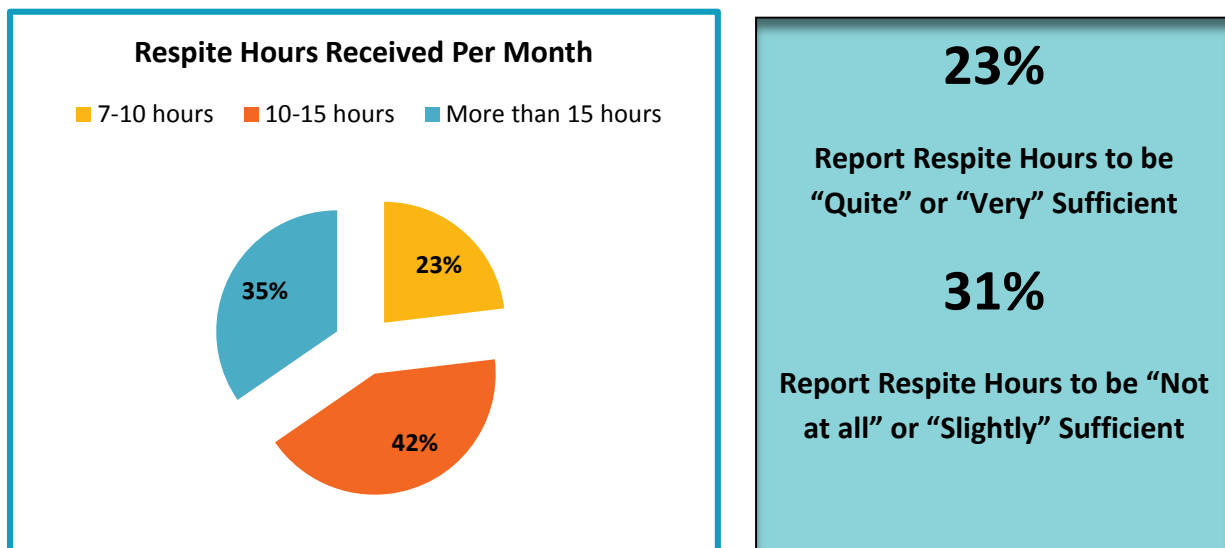
## Satisfaction with Respite Care Services

I am satisfied with...	Strongly Disagree	Disagree	Agree	Strongly Agree
The overall level of respite care services I have received.	4%	16%	40%	40%
With the ease of finding a respite care provider.	20%	24%	32%	24%
With the care provided to the care recipient.	4%	0%	50%	46%
With the number of hours of respite care received per month.	19%	12%	46%	23%

Overall, family caregiver satisfaction was high with both the overall level of services and with the care provided to the recipient. Eighty percent of the survey respondents gave the overall respite services a satisfactory rating while nearly all (96%) were satisfied with the care provided to the recipient. Responses from focus group participants echoed the survey findings with feeling at least satisfied with the respite care providers. One family caregiver stated, “We are lucky and blessed to have respite care.” All focus group participants receiving respite care services talked about how respite care had improved their quality of life in a number of areas. For those families, “Respite care is not gravy. It is something we need to continue being good parents.”

Satisfaction levels decreased when asked about the ease finding a care provider (56% agreed or strongly agreed) and when asked about the number of hours received per month (69% agreed or strongly agreed). It should be noted that for this program, families determine the number of hours of respite care services received. The Lifespan Respite Subsidy program authorizes funds for use. Family caregivers set the pay rate and determine the respite care provider. Focus group participants discussed at length the difficulty of finding respite care providers. Many stated it added to their stress levels when they were either unable to find a care provider or when the care provider canceled leaving them without a needed break.

## Respite Hour Use



Survey respondents all reported receiving at least 7-10 hours of respite per month with most of the sample receiving 10-15 hours and over one third receiving more than 15 hours of respite per month. When asked about unpaid respite hours (volunteers, family members, etc.), 54% of the respondents indicated receiving unpaid respite services ranging from 3-102 hours per month with the median amount of unpaid hours being 15 hours per month for those family caregivers. Family caregivers were asked how many respite hours would be ideal to receive per month. The responses varied considerably

for this question ranging from 15-160 hours of respite care per month with the median response being 40 hours per month. As with the focus group participants, some of the survey respondents reported a need to be gone overnight or for a weekend.

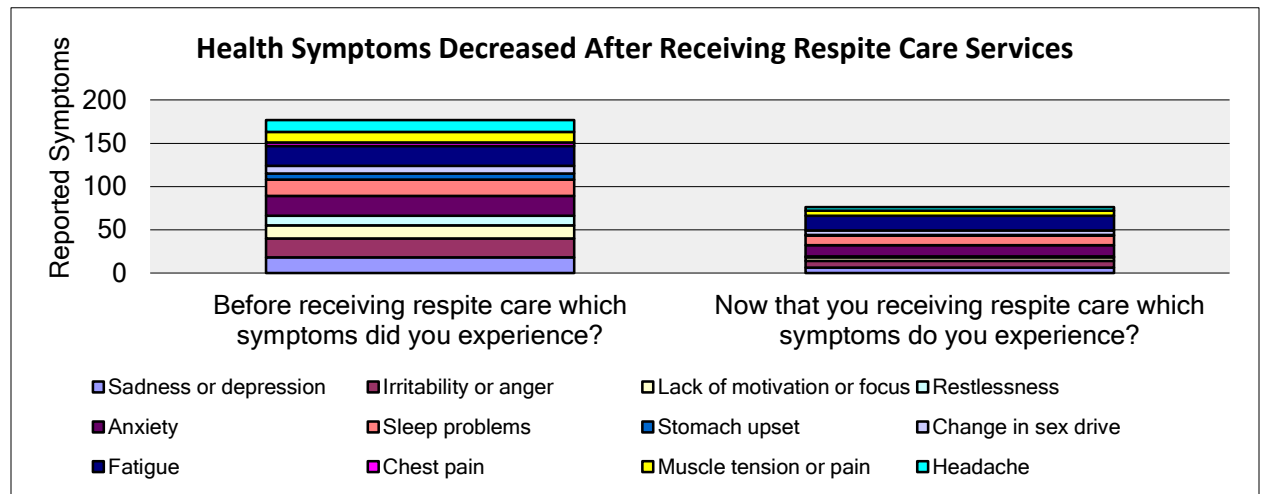
## Family Caregiver Outcomes

Family caregivers are those providing ongoing care for a family member unable to care for him/herself. Reinhard, Feinberg, Choula & Houser (2015) estimated that there are 40 million family caregivers in the country providing ongoing care for an adult. This number is higher when taking into account those families providing ongoing care for a minor with special needs. For this evaluation, the family caregivers were from families eligible for the Lifespan Respite Subsidy Program, meaning they provide care for an individual of any age with special needs.

Due to the focus on family caregiver and what is happening in the state of Nebraska, the majority of the survey items focused on family caregiver outcomes. Questions were asked on family caregivers' health, stress levels, relationships with others and the care recipient and finances. To gauge the impact of respite care, the items were asked to see how family caregivers functioned prior to respite, now that they receive respite care services and for them to predict what would happen should respite care services end for their family.

In addition, the focus groups sought to delve more deeply in the day to day stresses and challenges with being a family care provider as well as to gain a sense of what is working for them with the respite care services being provided. Family caregivers discussed possible improvements to the respite care system in addition to the positives it brought to their families.

## Family Caregiver Health and Stress Outcomes





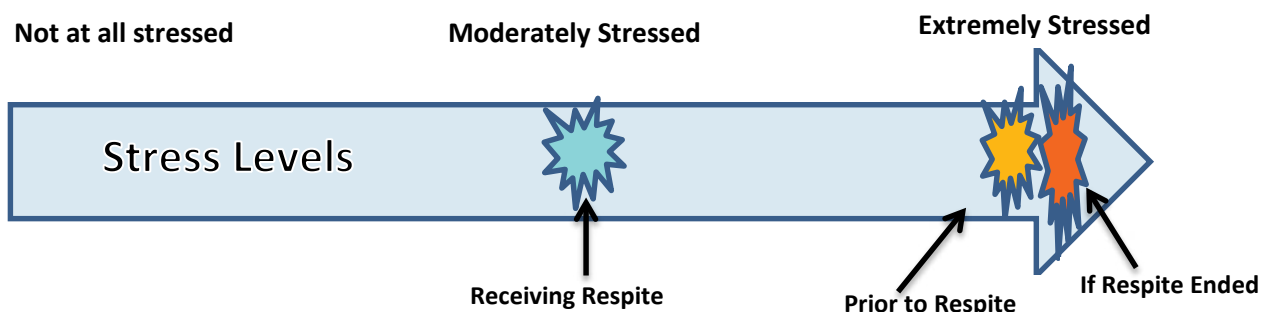
Survey participants reported a decrease in health symptoms across all categories after receiving respite care. The most commonly reported health symptoms prior to receiving respite were anxiety (88%), fatigue (88%) and irritability/anger (85%). After receiving respite care, the number reporting those symptoms decreased dramatically for anxiety (88% down to 54%) and irritability/anger (85% down to 33%) with fatigue decreasing less (88% down to 71%). Some symptoms decreased completely or almost completely for participants such as chest pain (15% down to 0%) and restlessness (42% down to 4%). For more detailed information on all pre/post health symptom patterns see Appendix 1.

A second question asked about the relationship between caregiving responsibilities and health problems. Prior to receiving respite care, 69% said caregiving responsibilities greatly or extremely contributed to their health problems. That percentage dropped to 15% when receiving respite care services.

The survey results were consistent with the focus group input. The family caregivers in the focus group talked about having far fewer stress related health issues when receiving respite care services. Participants discussed how it helped to ease frustration and anxiety knowing that a break was on the way. One participant remarked that, “It’s probably kept me alive. I’ve had so many illnesses that have been stress related or stress aggravated.” While another participant said respite care services helped get her through her last pregnancy safely because of the support provided. All participants agreed feeling less anxious and less stressed since receiving respite care.

## Family Caregivers and Stress

Related to the health symptoms are the reported stress levels of the family caregivers. Caregivers were asked to rate their stress levels before respite care, now that they are receiving respite care services and if respite services were to end. Caregivers rated their stress on a five point scale with *1=Not at all stressed to 5= Extremely Stressed*.



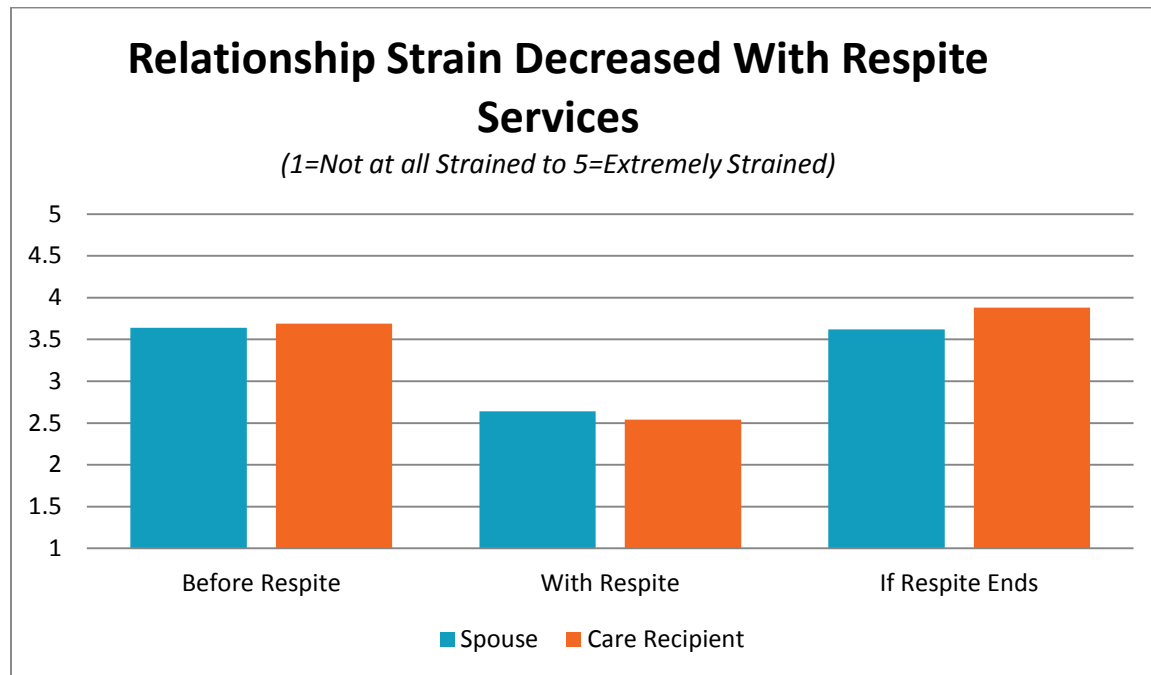
Family Caregivers rated their stress levels in the extremely stressed range prior to respite ( $M=4.62$ ) and predicted even higher stress levels were respite to end ( $M=4.92$ ). Impressively, the reported stress levels for family caregivers dropped to the moderately stressed range ( $M=2.92$ ) upon receiving respite care services.

Stress was a common theme with the focus group participants across all three regions. Participants discussed feeling relief when they knew someone was coming in to give them a break. If a caregiver failed to show up, it caused the caregivers even more stress as they had mentally planned on getting a break.

Many family caregivers stated that alleviating some of the stress of continual caregiving helped to relieve some health symptoms, allowed them extra rest opportunities and helped them to reconnect and maintain relationships with others, particularly their spouses. One participant stated, “It can be the difference between being a parent who just can’t keep going to being a parent who can hang in there.”

## Relationships with Others

The online survey asked questions about the family caregiver’s relationships with others, in particular with his/her spouse and with the care recipient. Relationships can suffer due to the demands of providing care on an ongoing basis. The questions asked family caregivers to rate the strain on their relationships prior to respite care, now that they’re receiving respite care and what would happen without respite care.



Respite services led to family caregivers feeling less strain in their relationships, both with their spouses and with the care recipient. Average strain prior to respite care was in the moderately to very strained

range for both types of relationships but then dropped to being in the slightly strained range once respite care was provided. Focus groups provided insight into the survey results.

## Opportunities Outside of the Home

Sufficient opportunities to engage in social/recreational activities....	Not at All	Slightly	Moderately	Very	Extremely
Before Respite	58%	15%	12%	4%	12%
Receiving Respite	12%	35%	39%	15%	0%
If Respite Ended	62%	15%	4%	0%	19%

Answers to this survey item ( $n=26$ ) varied considerably. The general trend of the data indicates that family caregivers experience more opportunities to participate in social and recreational activities when provided with respite care services. However given the decrease in the “Extremely” sufficient category from before respite to receiving respite, the question may have been confusing to some of the survey respondents.

A similar question was asked of the focus group participants. They were asked to name the top three activities they do when they have respite care. The top areas from the family caregivers in the focus groups were: Rest, Errands, Recreation, Personal Care and Time with Family. When asked about using it to attend a support group, the caregivers indicated that care is usually provided at support groups, so they would not use their respite care for that purpose. Two of the participants expressed disappointment in not being able to use respite for furthering their education. One noted, “I could use respite to take a knitting class but not for a class towards my Master’s degree. That was disappointing.” Yet another appreciated the break that respite gave her to volunteer and have, “a chance to use my adult brain.” A common theme amongst the participants was the need to maintain a part of their individual identity and have time for self. The most frequent answers for how family care providers spent their time when provided with respite were rest, a chance to get fit, be away from their caregiving responsibilities and an opportunity to reconnect with other family members.

## Cost Effectiveness Analysis

### Costs

The cost effectiveness analysis (CEA) was conducted for Fiscal Year 2015 (FY15) to examine the program efficiency of the Lifespan Respite Subsidy Program. Total costs of the Subsidy, excluding regular DHHS operating expenses, were provided by the Division of Children and Family Services at the Nebraska Department of Health and Human Services, hereafter the Division. The two cost categories for the Program were from Salaries and Subsidy and totaled \$43,819 and \$372,283, respectively. There were no start-up costs for the Subsidy in FY15 as the Subsidy was in its 9<sup>th</sup> year. Most of the costs for the program, capital expenditures, maintenance costs, materials and supplies, etc. had not additional

marginal costs as these costs were already covered by the Division budget (for a complete description of all costs see Appendix 2).

Nebraska Respite Subsidy Cost Table

Costs (to NE/DHHS)	FY15	Notes
Startup costs	\$0	NA, not first year of program
Capital costs	\$0	Costs absorbed into Division administrative budget.
Salaries	\$43,819	Paid UNL/CCFL contract for eLR/NRRS-respite site
Maintenance	\$0	Costs absorbed into Division administrative budget.
Materials and Supplies	\$0	Costs absorbed into Division administrative budget.
Travel	\$0	Costs absorbed into Division administrative budget.
Overhead	\$0	Costs absorbed into Division administrative budget.
Subsidy	\$372,283	Direct aid/respite services
<b>Total Costs</b>	<b>\$416,102</b>	
<b>Cost Effectiveness Ratio</b>	<b>\$5,013</b>	<b>Per Out-of-Home Placement Prevented (n=83)</b>

Notes: *Division* refers to Division of Children and Family Services under the Department of Health and Human Services. *Number of institutionalized care recipients prevented* is based on a 20% decrease in respondents considering out-of-home placement for their care recipient before and during participation in respite subsidy, extrapolated to total number of Subsidy users.

### Outcome measure

The median annual cost of care for out-of-home placement in Nebraska ranges from \$43,500 for assisted-living facilities to \$79,500 for a nursing home (Genworth Financial, 2015). Given that these high costs are many times shouldered by Medicaid and Medicare (Kaye, Harrington, and LaPlante, 2010), programs such as the Subsidy are important in helping unpaid family caregivers receive the respite the need in order to keep their care recipients in the community. As a measure of effectiveness, the number of prevented out-of-home placements was calculated. This outcome measure was calculated using the data from the Internet Survey responses to questions regarding participants' considerations of out-of-home placement for their care recipient before receiving the Subsidy and "now" after having received the subsidy. Before receiving the subsidy 40% of caregivers were considering out-of-home placement for the caregivers. This fell significantly to 20% after participant received the subsidy.<sup>1</sup> The 20% rate of participants still considering out-of-home placement was used to calculate the number of prevented out-of-home placements within the current Subsidy enrollment (n = 413). The total number of out-of-home placements prevented in FY15 was 83 care recipients.

### Cost-Effectiveness Ratio

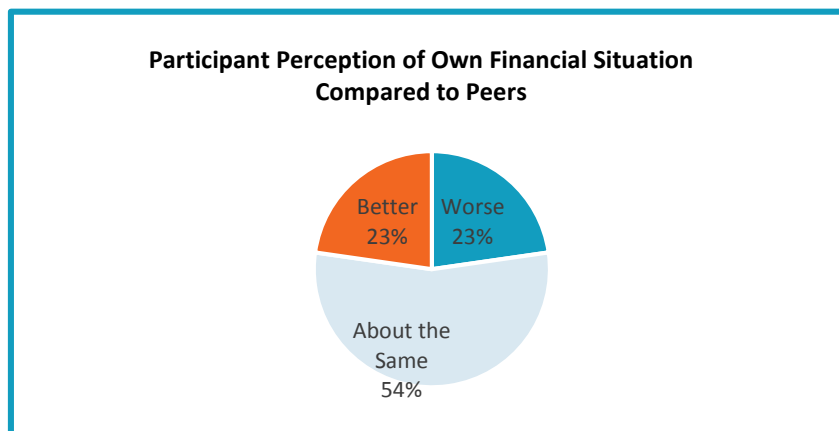
<sup>1</sup> In a follow up question asking if the participant would consider out-of-home placement for their care recipient if the Subsidy were to end, 32% of participants indicated that they would consider out-of-home placement. This is a 60% increase from the proportion of participants who indicate they are considering out-of-home placement while currently receiving the Subsidy.

Based on the total marginal costs of the Subsidy program, the cost-effectiveness ratio for the program in FY15 is \$5,013 per out-of-home placement prevented. This cost is 8.6 to 15.9 times lower than the cost care recipient placement in an assisted living facility or nursing home, respectively. No longitudinal data on costs were provided, thus no analysis on the changes in program efficiency over time cannot be made. The total Legislative budget for the Subsidy program in FY15 was \$810,000; therefore, assuming that no new personnel would be needed to increase salary costs, the program has capacity to add another 252 full-year caregivers (total = 675).

### **Economic Perceptions of Subsidy Participants**

In addition to the CEA, the evaluation efforts attempted to capture participant perceptions about their financial status and the impact the Subsidy has had on their families' financial situation. This data was captured with the online survey described in the Methods section of the report. Participants were asked to respond to their perceptions of their financial status compared to their peers, the change in their standard of living, and their personal finances. In addition, participants were asked about their monthly costs for respite and total caregiving expenses. The median cost monthly respite costs were \$200 (min = \$125, max = \$1,013). Not surprisingly the minimum was equal to the maximum of the respite subsidy (n = 6). However, most respondents spent over the monthly subsidy amount on respite services. Excluding respite costs, the median monthly costs of caregiving was \$369 (min = \$50, max = \$2250). The wide range of monthly caregiving costs is likely due to the severity of health care recipient health problems; however, no in-depth data was collected.

The goal of the Subsidy program is to assist caregivers with the fatigue, social isolation, and other negative externalities that occur amongst caregivers. While the Subsidy is not aimed to change the financial situation of caregivers, its purpose is to help alleviate some of the financial burden that may keep caregivers from allowing themselves to take advantage of respite care services due to cost. As such, participants' perceptions of their financial situations is of interest. A little over half (54%) of the participants perceive their financial situations to be comparable to their peers, and the



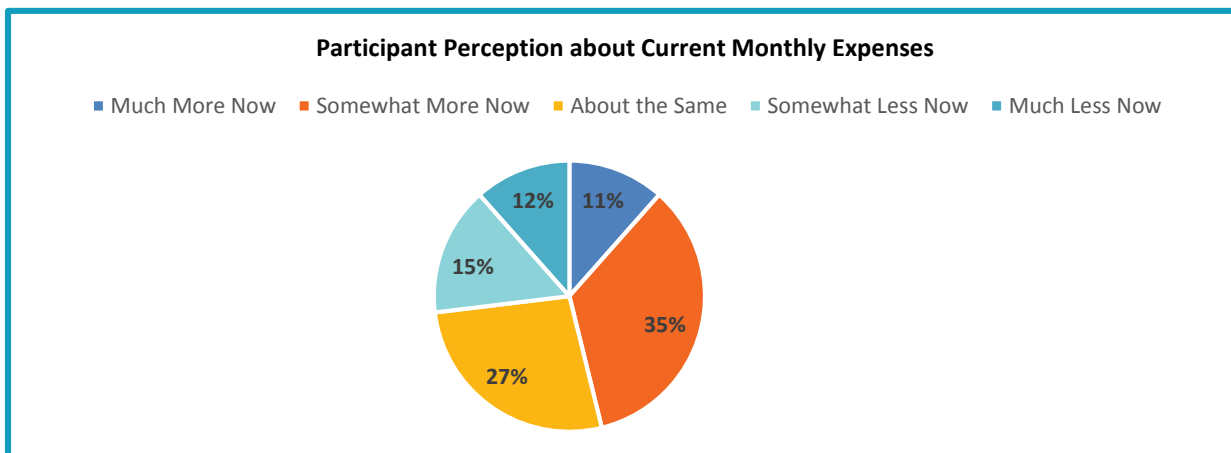
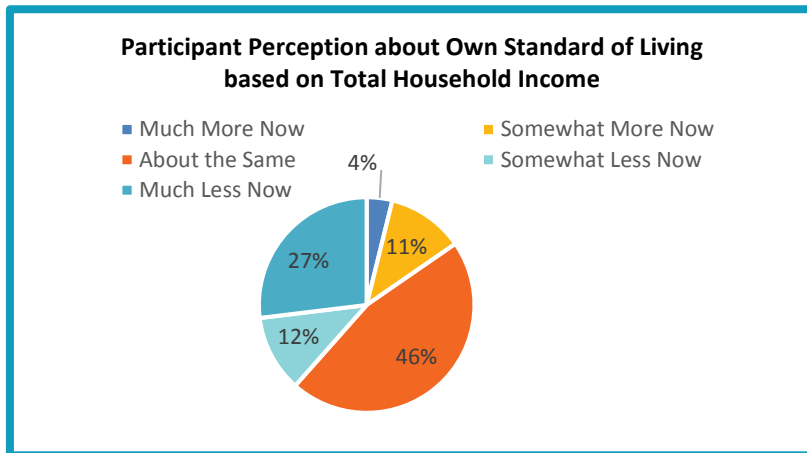
remaining respondents were split in half (23% each) perceiving their financial situation to be better or worse than their peers. Questions were also asked regarding participant financial situations before the start of participation in the Subsidy program and show that 28% perceived their financial situation to be

improved, which is a significant increase in the perception of participants regarding their financial situation ( $p = 0.007$ ). Conversely, when asked how their financial situation would change if Respite were

to end, significant portion of respondents (40%,  $p = 0.001$ ) would perceive their financial status to be worsen compared to their peers.

The preceding 2 charts show the breakdown of respondent perception regarding their total household income and monthly expenses before and after starting to provide care. Figure 2 indicates that almost half (46%) of

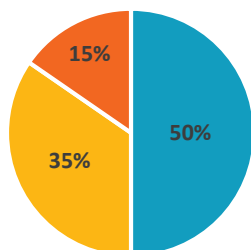
respondents see their household income to be the same while 39% state their household incomes as being lower after caregiving compared to 15% who report higher household incomes after caregiving.



With respect to expenses, only about a quarter (27%) see stated their expenses have remained the same. In contrast to changes in household income, 46% indicated their expenses were somewhat to much higher after providing care, while 27% indicated lower expenses. Finally, Figure 4 shows responses to how participants see their family finances at the end of the month. Roughly half indicated that their financials situation is not enough to make ends meet while only 15% responded to having money left over at the end of the month. The Internet Survey did not ask about general household spending, thus it cannot be assumed that the caregiving costs are the sole reason attributed to financial strain, but are likely a contributing factor.

**Figure 4. Perception about Personal Finances**

■ Not enough to make ends meet   ■ Just enough to make ends meet   ■ Some money left over



The focus groups discussed financial issues in depth. Family caregivers were concerned with making ends meet, having enough funds for respite care services and qualifying for the respite subsidy program. The graphic below shows responses to statements about their financial situations.

### Focus Group and Finances

The following statements were read to the focus group participants (*n*=8 family caregivers). They were asked to rate each statement on a five point scale (1=Strongly Agree to 5=Strongly Disagree).

■ Neutral   ■ Agree   ■ Strongly Agree

***I feel that caring for my relative is causing me (will cause me) to dip into savings meant for other things.***



***I feel that my family and I must give up (will have to give up) necessities because of the expense to care for my relative.***



***I feel that my family and I cannot (will not be able to) afford those little extras because of the expense of care for my relative.***



*I feel that caring for my relative is (will be) too expensive.*



Multiple financial challenges were discussed during the focus groups. Many of the participants talked about having little to no savings, needing to stop funding college accounts and worrying about dipping into any retirement accounts. Most family caregivers said that they could not see retirement in their future. One participant remarked, “I’ll need to work until I die. I don’t see any way I will be able to retire.” That sentiment was echoed over and over by multiple caregivers. Of those participating in the focus groups, 5 of the 8 caregivers had high levels of education (Master’s degree or above) and had at one point had held a professional position. However, due to caregiving responsibilities most could not continue to work in their chosen profession. Some worked part-time but were underemployed given their education status and work experience. Not only is the caregiving exhausting financial resources but the family caregivers are not able to access their full earning capacity.

## Challenges and Possible Improvements

The challenge heard most frequently across focus groups was lack of knowledge about respite services. Several of the participants had been providing care for more than a year before finding out about the possibility of services. This was particularly challenging for families moving into the state who had been provided more extensive respite services from their previous state. The participants stated that information about respite services often depended on the person or director who you worked with and not all of them had the same knowledge or understanding of respite services.

Another challenge was finding a respite care provider. Multiple participants had been approved for the Lifespan Respite Subsidy program but could not find a respite care provider. Not being able to find someone to provide respite care was seen as frustrating and stressful for the family care providers. Finding providers for children with significant behaviors and for adults was seen as a huge challenge. Some participants had qualified for the subsidy but had been unsuccessful in finding a provider willing to handle the challenges of the care recipient.

Participants from the focus groups found the paperwork part of the Lifespan Respite Subsidy program to be challenging and a possible barrier for other families. Participants had questions about the income levels, why respite couldn’t be used for their own education and how to complete the paperwork overall. One comment was, “We look ok on paper but financially we are struggling.” Others felt, too, like they had to exhaust their retirement, saving and college accounts in order to qualify for assistance.

Some felt that certain programs and social workers were adept at handling their paperwork questions and others were less helpful with that part of the process. One participant had asked hospice repeatedly



about possible options but they didn't know about respite services. A possible improvement would be to disseminate more information about the respite services available.

One improvement that emerged across multiple focus groups was to provide subsidy dollars and respite hours based on the needs of the care recipient. An example was given of a person with terminal cancer needing full-time care for all daily living activities. The caregiver in that instance may need more hours (for a shorter duration) than someone with fewer overall needs. In some states, hours and money is based on a ranking system of disability and need. For a care recipient with intense needs, respite care may be need at least once per week.

Another suggestion was to provide an allotment of hours at the beginning of each year or when the family was approved for the subsidy. With this arrangement, families could have overnights or a weekend away and still have hours to spread out over the months. Most participants agreed that \$125.00 per month didn't allow for an extended break or an overnight break. "Banking" of respite funds is available to provide the level of flexibility referred to by respondents. Banking policy allows clients to "bank" 2 plus months for paying respite care needed for an extended period such as out of state travel for family caregivers, special needs camps, hospitalization with follow-up t of family caregiver, etc.

## Employee Engagement Project

The employee engagement project is a three year pilot collaboration between the Department of Health and Human Services (DHHS) and the University of Nebraska Medical Center (UNMC). The goal for the project is that the University of Nebraska Medical Center will develop a replicable model of incorporating information about respite resources into workplace wellness and human resource supports. Data collected throughout the pilot project includes information on referrals made to the local respite network, dissemination activities, materials developed and a cost savings analysis. For this first year, baseline data on knowledge and referrals were collected.

### Activities

Activities for the Employee Engagement Pilot for 2014-15 included meeting with the directors of Human Resources at UNMC and Nebraska Medicine, attending new employee orientation and distributing information about both respite care services and how to become a respite care provider and collecting baseline data from the human resources, employee assistance and wellness programs. The team will continue to work over the next two years to disseminate information on the Nebraska Lifespan Respite Program.

### Baseline Information

Three questions were sent to the Human Resources, Cultural Diversity, Employee Assistance and Wellness personnel for the University of Nebraska Medical Center and Nebraska Medicine to attain a baseline level of understanding and knowledge about respite care services available in Nebraska. The three questions were: 1) What is your current understanding of Respite Care?; 2) What respite

information are you currently providing to UNMC/Nebraska Medicine employees?; 3) Approximately how many Respite referrals have you made in the past year and to what organization do you send referrals?

Of the five personnel to respond, four out of the five had a basic understanding of respite care in that it provided a break for family members who were caring for a family member with special needs or a disability. Current information on respite care is provided to employees through the Employee Assistance program but is limited and not all respondents knew of the practice. Finally, there are no methods to collect data on the number of referrals made to respite care.

## **REST (Respite Education & Support Tools) training**

A train-the-trainer REST workshop was provided to 21 participants during April 2015. The training was held at the University of Nebraska at Omaha Community Engagement Center and was a joint effort between UNMC staff -, DHHS and the national REST organization in Chicago, IL. The training was seen as highly valuable with the overall mean ( $N=21$ ,  $M=4.67$ ) being in the Excellent to Outstanding range. A follow up survey will be sent to the same participants during the 2015-16 evaluation to determine how many have become respite care providers or provided respite training for other interested individuals.

## **Key Findings**

Respite care services provided by the Lifespan Respite Subsidy Program are overall seen as a positive and necessary resource. Each of the outcomes examined for family caregivers showed a change in the desired direction from before respite services to receiving respite services. Stress levels decreased with respite as did the number of health symptoms experienced by the family caregivers. As stress levels and health symptoms decreased, relationships with others (spouse and care recipient) became less strained. However, while the caregiver outcomes were positive, many family caregivers reported that the number of respite hours received per month were inadequate.

Baseline information from the Employee Engagement Pilot program affirmed the need for greater knowledge among employers and the need for an increase in the dissemination of information on respite care. Anecdotal information from the new employee orientation found an interest in respite care services not only from family caregivers but from medical care providers who felt they could pass along the information to their patients.

Information from the focus groups provided a rich context about the stress of providing ongoing care for a family member. The caregivers confirmed the need to have respite care services available and stressed how respite care services provided benefits for the entire family. The benefits of respite care include better relationships with a spouse, helping the family caregiver with his/her own health, reduction in stress levels and in being a better parent. The “break” from caregiving was viewed as necessary in order to be emotionally and physically healthy and to continue providing care for a family member.

## Recommendations

Possible recommendations for the 2015-16 evaluation include:

1. Incorporate other respite funding sources into the evaluation to determine if family caregivers experience a difference in services and/or outcomes depending on the program(s) they qualify for.
2. Survey the family caregivers across the programs using the same tool. It provided excellent data on caregivers. For 2015-16, it will need to be linked to each federal and state-funded program authorizing respite care.
3. Partner with Charlie Lewis, Project Director/UNL Center for Children, Families and the Law, on the data they are collecting for annual reports. Data collected by the center would allow for disaggregation of the data and outcomes. One of the evaluation questions needing to be answered is who is not being served by the current system.
4. The focus group information suggested a missing link between family caregivers and finding a provider. This was particularly the case for families with children with significant needs and challenging behaviors. The management team for respite may want to consider how to ease the burden on families in finding respite providers.
5. Continue tracking the progress of the Employee Engagement Pilot program.
6. Consider including information on respite care providers. The evaluation has focused on family caregivers but it could be helpful to gain understanding from paid and unpaid care providers.
7. Evaluate effectiveness of REST Provider Training on building the capacity of Respite Providers across the state.
8. For 2015-17, collaboration between agencies providing respite care services will be examined more formally. This could help identify possible gaps as well as strengths that already exist within the system.

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Appendix 1. Health Symptoms Reported.

Health Symptom	Percent Reporting Each Symptom	
	Before receiving respite...	Now that you are receiving respite...
Headache	54%	17%
Muscle tension or pain	46%	25%
Chest pain	15%	0%
Fatigue	88%	71%
Change in sex drive	35%	21%
Stomach upset	27%	4%
Sleep Problems	73%	46%
Anxiety	89%	54%
Restlessness	42%	4%
Lack of motivation or focus	58%	17%
Irritability or anger	85%	33%
Sadness or depression	69%	25%

## Appendix 2. Types of Costs

<b>Type of Cost</b>	<b>Examples</b>
Start-up costs	Use of consultants, computer database development, costs associated with setting up the program, etc.
Capital expenses	Purchase of materials with use longer than one year – computers, office equipment, etc.
Salaries	Full-time, part-time, contract employees. Include DHHS employees, outside case managers, etc.
Maintenance	Extra costs of maintaining facilities; may include energy cost, janitorial, maintenance, <i>website maintenance</i> , etc. These are marginal costs incurred over the costs that would not have been incurred without the program.
Materials and Supplies	Office supplies, brochures, etc.
Travel	Not employees getting to and from work, but travel on behalf of the program, (e.g. case workers meeting with respite provides).
Overhead	Administrative, insurance, etc.
Subsidy	Total Amount Subsidy paid to program participants (total paid each fiscal year)

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