

# Nebraska Lifespan Respite Network: Producing Positive Outcomes for Families

**2015-2017**

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## **Nebraska Lifespan Respite Network Evaluation**

Respite is providing a short-term break to those caring for family members with special needs. Multiple programs provide support and funding for respite services in Nebraska. The following is a list of programs with a respite service component: 1) Lifespan Respite Subsidy; 2) SSI/DCP (Disabled Children's Program); 3) Subsidized Adoption; 4) Developmental Disabilities Medicaid Waivers; 5) Aged & Disabled Medicaid Waiver; 6) Title III of Older Americans Act (National Family Caregiver Support Program); 7) Foster Care/Child Care Protective Services; 8) Medicaid through Personal Assistance Services and Skilled Nursing Care Services; 9) Adult Protective Services (Title XX); 10) Alternative Response; and 11) U.S. Air Force (USAF) Exceptional Family Member Program (EFMP).

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 were 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.

The purpose of the evaluation was to gather as much comprehensive information about respite services in Nebraska and how those services were both provided and received. Family caregiver outcomes related to stress levels, health, mental health, employment, relationships and finances were all explored and evaluated. In addition, respite care providers provided information about service provision, training and challenges in the field. Additionally, system outcomes were addressed as need for respite services and access to those services continues to be misaligned across the state. Finally, a preliminary investigation into cost-effectiveness provided insight into the potential cost-saving attributes of a statewide respite system.

In reading this report, the reader will notice data displayed in terms of year collected and when appropriate in aggregate form across all three years. Some data were collected only in one year of the evaluation and yet, it is important to include in the final report for the reader to gauge the full picture of the respite care system. Different methods and different populations were used and evaluated and thus are part of the final report. Conclusions and key findings from each year are shared along with a final summary.

Finally, multiple activities were planned, developed and implemented throughout the evaluation. The activities coordinated and planned by the UNMC/MMI team are included in the final report along with future directions for these activities.

## Nebraska Lifespan Respite Evaluation Model and Guiding Questions

The evaluation model selected for this evaluation was based on Patton’s Utilization-Focused Evaluation model (Patton, 2012) with the purpose being exploration, program improvement and improved outcomes for program participants. The logic model and evaluation questions were developed in collaboration with a variety of stakeholders and were adapted throughout the course of the evaluation. Stakeholders involved in the process were the Nebraska Department of Health and Human Services (DHHS), the Nebraska Lifespan Respite Network (NLRN), regional respite coordinators, community agencies, respite care providers and family caregivers. The majority of the evaluation focused on who was served by the Lifespan Respite Network and the outcomes associated with those family caregivers.

The evaluations from the first two years led the management team to develop new strategies, make programmatic changes and form additional partnerships within the state.



### *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 is 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 For 2015 (Year 1)

Data were collected from multiple sources but all of the data were from eligible families receiving 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. Across the three groups, 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, 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 to family caregivers qualifying for the Lifespan Respite Subsidy program. Prior to the survey being sent, 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.

## Key Findings from 2015 Evaluation

Respite care services provided by the Department of Health and Human Services (DHHS) Lifespan Respite Subsidy Program were overall viewed 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) were less strained. However, while the caregiver outcomes were positive, many family caregivers reported that the number of respite hours received per month was inadequate.

Baseline information from the UNMC-MMI Employer Engagement Pilot project 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 also 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.

## Methods For 2016

For the FY 2016 evaluation, multiple methods of obtaining data were used. During this evaluation period, data were collected across multiple respite programs throughout Nebraska rather than being targeted to those participants eligible for the Lifespan Respite Subsidy. Therefore, for the family caregivers, data do not reflect a particular respite program or funding source. Rather they reflect the aggregate experiences of respite services. Demographic data and numbers were accessed using the NLRN online, secure data collection and worksite, known as eLifespan. eLifespan tracks and monitors data from family caregivers and providers. Three surveys were distributed to capture the experiences and perspectives of family caregivers, respite providers and participants completing Respite Education and Support Tools (REST) training. Distribution of surveys occurred using multiple distribution points: surveys were emailed, links were posted in newsletters and on social media and paper copies were distributed at conferences, by regional coordinators and at other respite events. Finally, individual phone interviews were completed with the six local network respite coordinators.

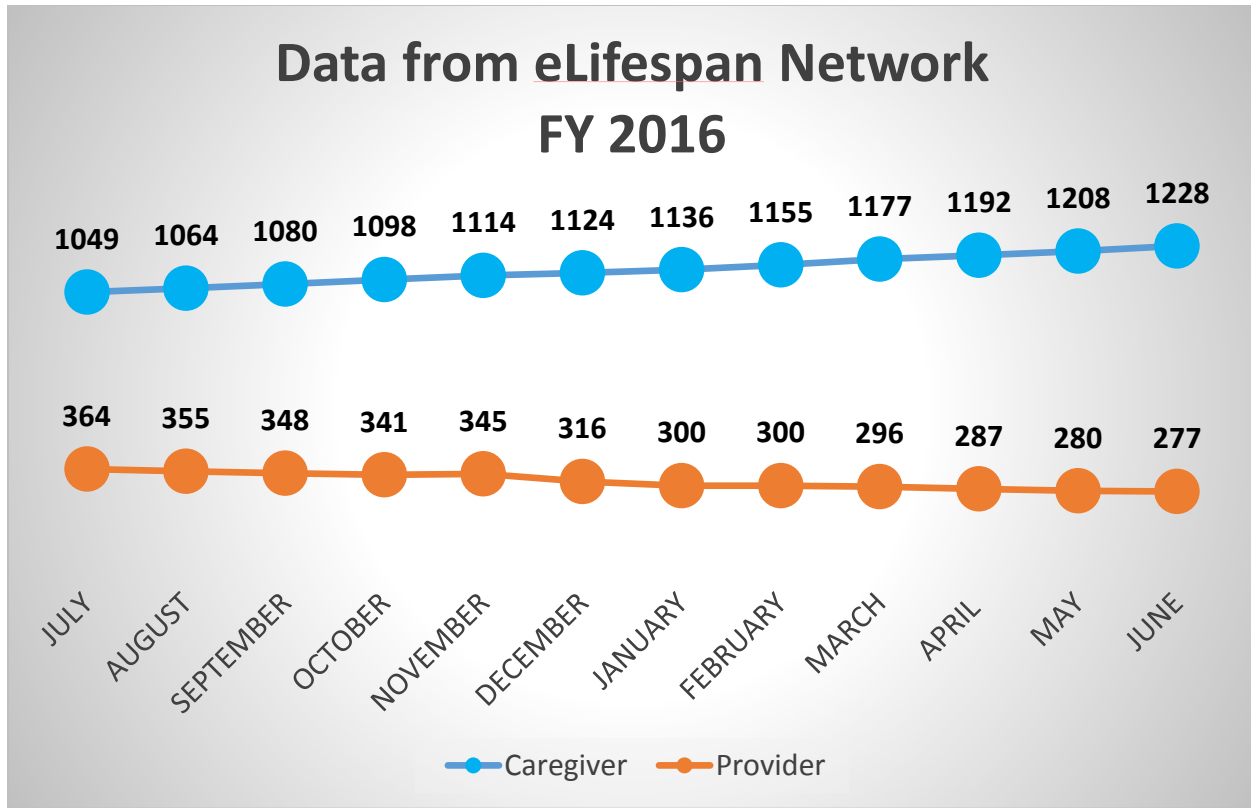
## Methods for 2017

For the 2017 evaluation, the decision was made to focus primarily on the DHHS Lifespan Respite Subsidy Program. The family caregiver survey was shortened and edited from the original version and mailed to each recipient or authorized representative of Lifespan Respite Subsidy funds. Additionally, brief telephone interviews were conducted to gather more data on mental health and employment. Interviews were conducted by respite coordinators and the evaluation team. Finally an evaluation plan was developed to evaluate the college curriculum pilot facilitated by UNMC-MMI.

## Family Caregivers and Respite Providers

The most recently reported numbers as found in the Nebraska Lifespan Respite Network database (August 2017) indicated that there were 1800 caregivers statewide serving over 1400 care recipients.

To provide broad information about respite statewide, information was obtained from the eLifespan system. eLifespan gathers data from respite coordinators on both family caregivers and respite providers. The system is dependent on the respite coordinators connecting with caregivers and providers and then upon them entering the data and information into the system.



The above chart shows the difference in the numbers of family caregivers and respite providers who had contact with one of the six regional coordinators during the year. While it is only one program, it provides a snapshot look at why family caregivers report dissatisfaction with being able to find a respite provider.

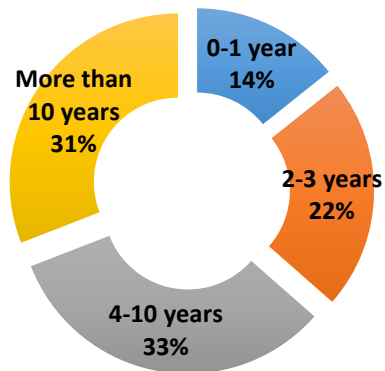
### Demographics of the Lifespan Respite Network

The eLifespan system provides snapshots in time of family caregivers, respite providers and care recipients. The following data are reported as percentages of the populations recorded into the eLifespan system during July 2016. The data provide a snapshot of the different populations involved within the Lifespan Respite Network. What follows are graphs and charts displaying information on total numbers, demographics and to whom services are provided. It is not meant to be representative of all respite programs but to provide some context to the nature of respite statewide.

Family caregivers also provided the number of years being a caregiver. The chart below shows the percentage of family caregivers in across the ranges and shows that most family caregivers have been in that role for at least 4 years (64%).



## Years as a Family Caregiver



As illustrated, most family caregivers involved with the Nebraska Lifespan Respite Network have had the responsibility of caring for a loved one for multiple years. Only 14% of family caregivers in the system reported being a caregiver for one year or less while 31% reported being in the caregiving role from more than 10 years.

Below is table listing the most frequent reported medical conditions of care recipients by family caregivers. While other conditions are listed on enrollment forms the table below is a listing of the most frequently selected.

### Top Ten Most Frequent Medical Categories of the Care Recipients (2016)

Category	Percentage	Category	Percentage
Intellectual Disability/Developmental Delay	11%	Visual Impairment	8%
Alzheimer's /Dementia	10%	Hearing Impairment/Hearing Aids	6%
Autism/Autism Spectrum Disorder	9%	Breathing Problems: Asthma, COPD and Cystic Fibrosis	6%
Arthritis/Other Joint Problems	8%	Heart Problems	6%
Speech-Language Delayed	8%	Diabetes	4%

When examining the medical categories for care recipients, cognitive impairments were the most frequently identified by the family caregiver. For some of the medical conditions, Alzheimer's and Autism Spectrum Disorder specifically, behavior and emotional symptoms are frequent hallmarks of the disability and therefore it is not surprising to see those symptoms ranked frequently for behavioral/emotional conditions.

## Most Frequent Behavioral/Emotional Conditions

Behavioral/Emotional Condition	Percentage	Behavioral/Emotional Condition	Percentage
Temper Tantrums	13%	Wandering	11%
ADD/ADHD	13%	Physically Aggressive	9%
Anxiety	13%	Mental Disorder	8%
Depression	11%	Hyperactivity	6%

## Family Caregiver Data (2015-2017)

### Year 1

Twenty-six family caregivers completed the Family Caregiver Survey. For this pilot evaluation, family caregivers all qualified to receive the Lifespan Respite Subsidy. 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. 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).

### Year 2

Seventy-three family caregivers completed the 2016 Family Caregiver Survey. Of those family caregivers, the majority reported receiving respite care through the Lifespan Respite Subsidy (33%), followed by Medicaid (20%) and the Aged and Disabled Medicaid Waiver (17%). Most survey respondents (76%) reported being the family caregiver for their son/daughter.

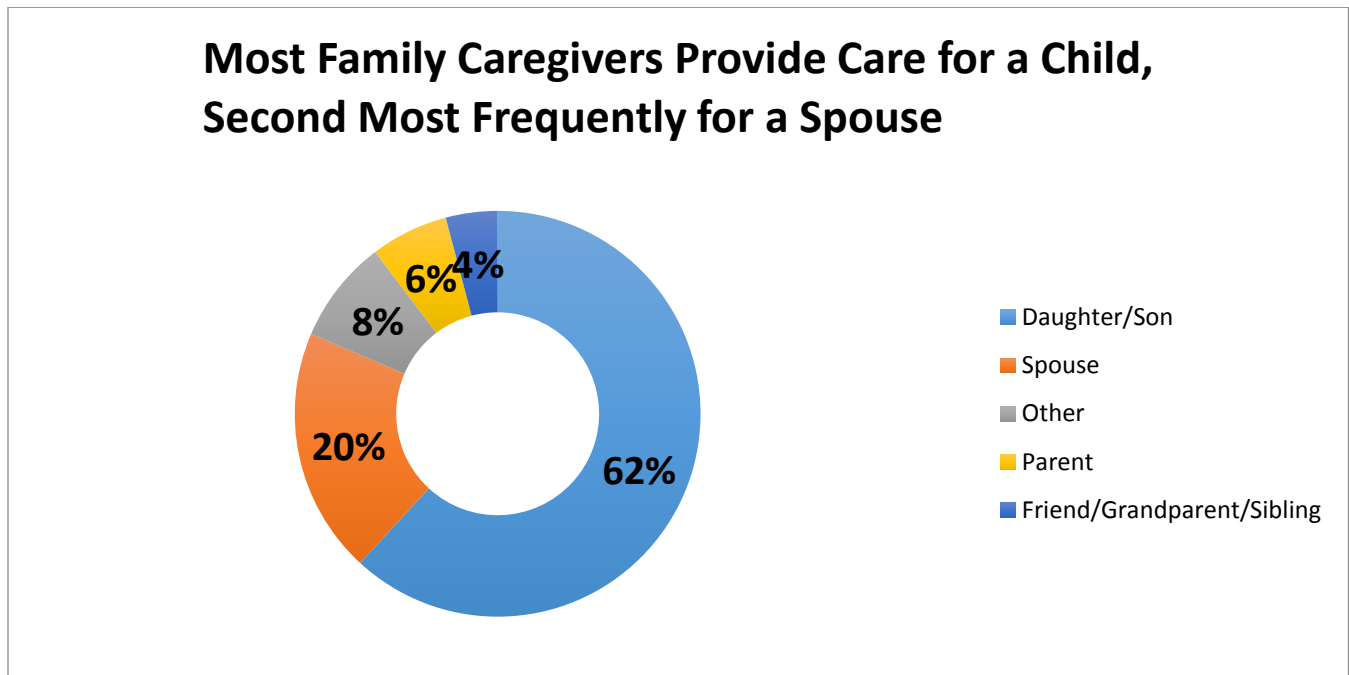
Family Caregiver Satisfaction ratings were high for the care provided to the care recipient (76%) but quite low for the ease of finding a respite care provider with fewer than one third (31%) marking “agree” or “strongly agree”. When asked if respite hours were sufficient, 63% marked that hours were “somewhat” to “not at all” sufficient meaning that most families are finding the hours inadequate to meet their needs.

### Year 3

Seventy-eight eligible family caregivers completed the Family Caregiver Survey. Of these respondents, 72% reported receiving respite care services through the Lifespan Respite Subsidy, followed by Other (8%), SSI/Disabled Children’s Program (7%) and then Alzheimer’s Scholarship (5%). Fewer than 5% reported receiving assistance through Medicaid, Private Pay, Local Area Agency on Aging and Aged and Disabled Waiver.

One interesting finding was that the percentage of family caregivers finding the number of respite hours to be insufficient dropped to 46% down from 63% of family caregivers in Year 2 who indicated that the hours were not adequate. It could be that based on some of the changes made to respite and the availability of the crisis/exceptional needs funds led to increased satisfaction by caregivers.

Family caregivers are most often caring for a daughter/son followed by caring for a spouse. When answering “Other”, the most frequent relationship was caring for grandchildren. Grandparents caring for grandchildren is becoming more common as evidenced by some responses on the survey as well as previous responses in respite workgroups and focus group responses.

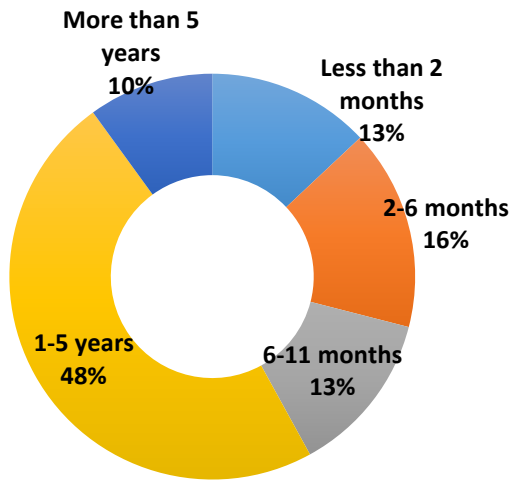


The two most frequently served age groups of care recipients for caregivers completing the survey were those under 19 years of age (49%) and those over the age of 65 (29%) followed by those between the ages of 19-25 (14%). The age ranges of family caregivers varied a great deal more with 25% of family caregivers being over the age of 65, 18% between the ages of 35-40 years, followed by 14% between the ages of 50-55, 13% between the ages of 40-45 and 13% between the ages of 55-60 years old.

### Exceptional Needs Respite Funding

One resource for family caregivers available only through the Lifespan Respite Subsidy is the availability of crisis/exceptional needs respite funding. This funding is for families who may have an extraordinary circumstance and need additional resources and money for respite services. Families can apply for up to \$1000 of exceptional needs funding beyond the \$125.00 per month for planned respite. Applications for funding were approved by the Nebraska Lifespan Respite Statewide Coordinator. Of the survey respondents only 5% stated that they had received this funding in the past 12 months with the dollar amounts ranging from \$100 to \$1000. **Satisfaction levels with this funding resource were positive with 67% saying they were “very” or “extremely” satisfied.**

## Most Caregivers Reported Receiving Respite Care for at Least One Year



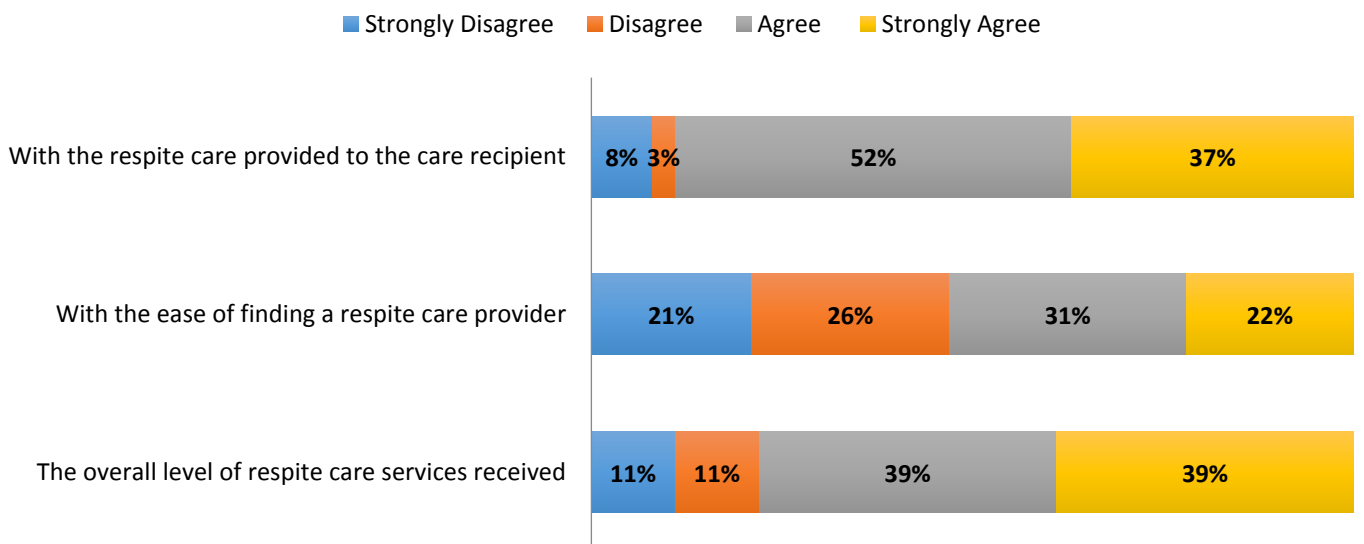
N=77

Most of the survey respondents reported receiving respite between 1-5 years with another 10% receiving respite care for more than five years. The large majority (**66%**) of caregivers received at least 10 paid hours of respite per month with nearly half of those receiving more than 15 paid hours per month. When asked about unpaid respite time received through volunteers,

family members or other, answers varied from zero to over 70 unpaid hours of respite care provided. Even within the Lifespan Respite Subsidy program there appears to be a large amount of variance in the hours of both paid and unpaid respite care services.

## Family Caregiver Satisfaction Data (2015-2017)

### Family Caregivers were Highly Satisfied with the Respite Care Provided

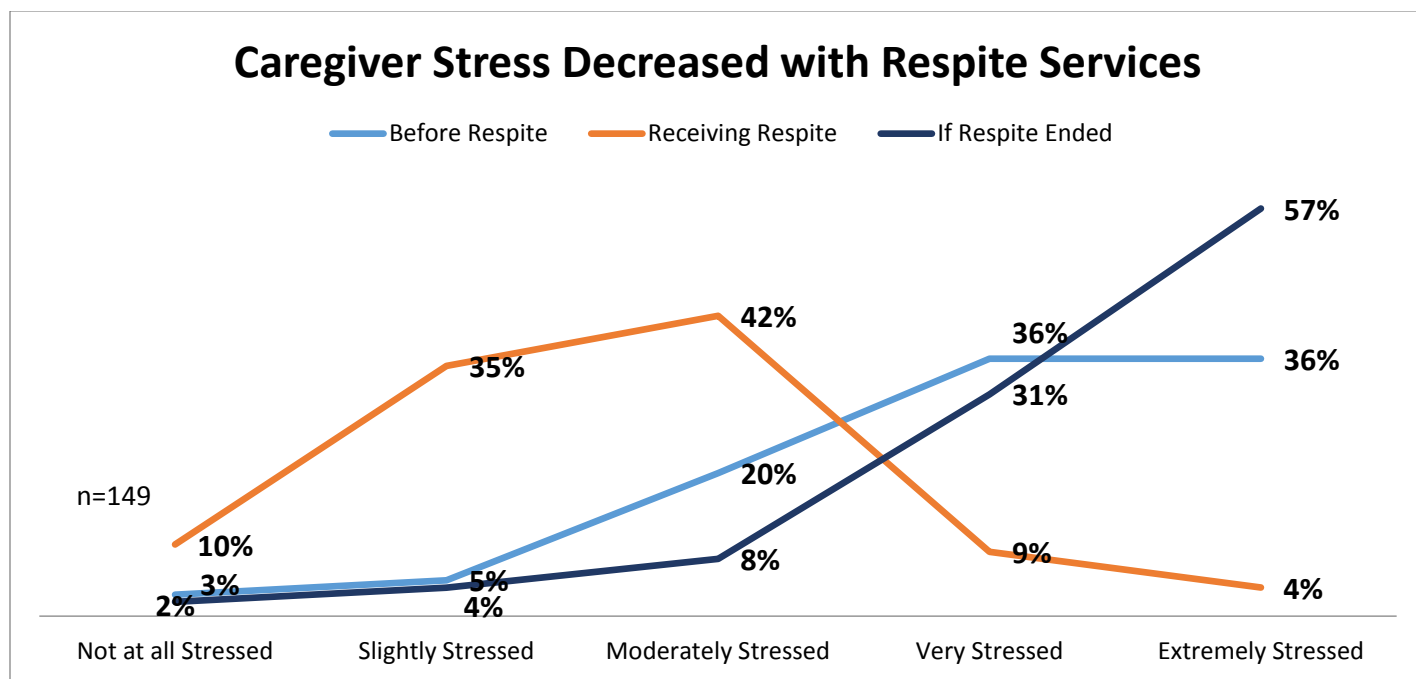


### Summary of Satisfaction by Family Caregivers

Across all three years of the study, the survey respondents (N=176) found the respite care received by the care recipient to be satisfactory. The aggregate data depict the overall pattern of what the survey data of each individual year indicated. Family caregivers found they agreed that the overall level of respite care services was satisfactory (78% in the agree to strongly agree category) but had difficulty in finding respite care providers with 47% rating that item negatively (either rating it as strongly disagree or disagree). The findings are consistent across years and are consistent with year one focus group data, survey comments and anecdotal information shared by regional coordinators in interviews during year two.

## Family Caregiver Outcomes (2015-2017)

When provided respite care services, family caregivers reported improved outcomes including reduction of stress levels, increased quality of relationships and decreased health symptoms. These outcomes were consistent no matter the data point.



As the graph indicates, family caregivers who reported being “extremely stressed” decreased dramatically upon receiving respite care (down to 4% reporting; a decrease of 32%). The majority of family caregivers are at/below the moderately stressed level when receiving respite (87%) compared to just 28% at/below the moderately stressed level prior to receiving respite care services.

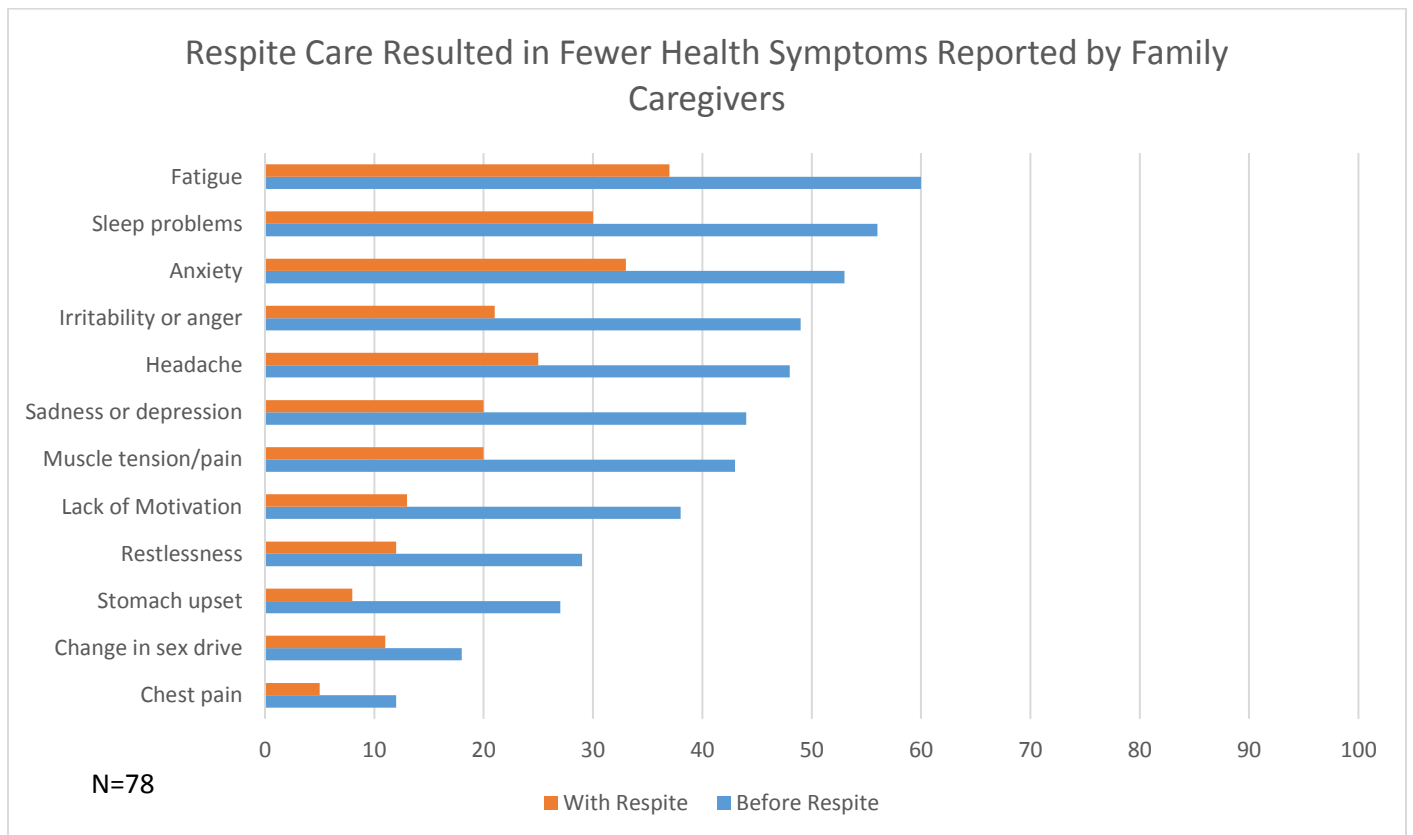
In addition to asking about stress, two questions were on caregiving and health symptoms. In 2016, caregivers reported that respite services reduced the impact of the demands of caregiving on the caregiver’s health. Those reporting that caregiving “greatly” or “extremely” affected their health decreased from 40% to 12%. The same question was repeated for the 2017 evaluation and the response pattern was the same with the percentage of respondents decreasing from 31% to 5% who answered that caregiving “greatly” or “extremely” affected their health. However, across all three years of the

evaluation, more respondents answered that caregiving would “greatly” or “extremely” affect their health if respite were to end (69% (2015), 52% (2016) and 57% (2017) indicating that many respondents were unaware of the benefits of respite prior to receiving the services.

Not only did respite services have an impact on overall health, but also there appeared to be a relationship with specific health symptoms. Upon receiving respite services, many health symptoms reduced dramatically.

## Reduction in Health Symptoms

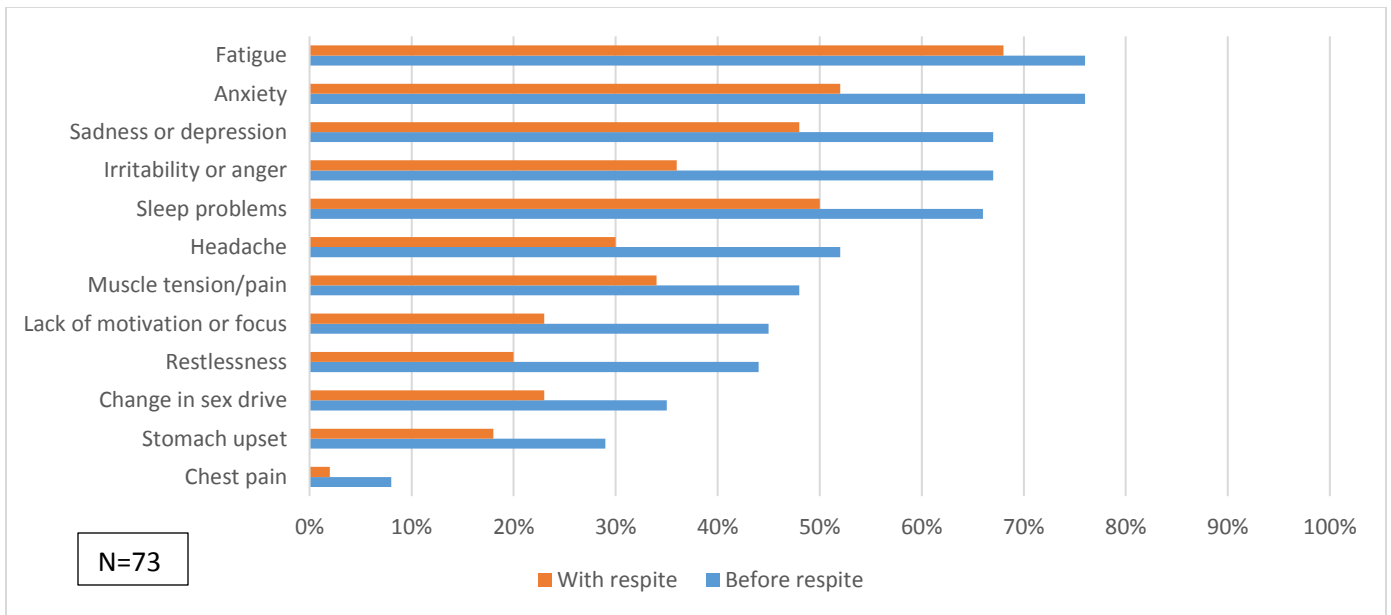
### Year 3 (2017)



Family caregivers experienced far fewer health symptoms while receiving respite care. Some of the most noticeable decreases in symptoms occurred for Fatigue (29% decrease), Headache (30% decrease), Sadness or depression (31% decrease), Sleep problems (33% decrease), and Irritability or anger (35% decrease). Stress levels and health symptoms often co-occur and with respite care services both stress levels and health symptoms are reduced for family caregivers.

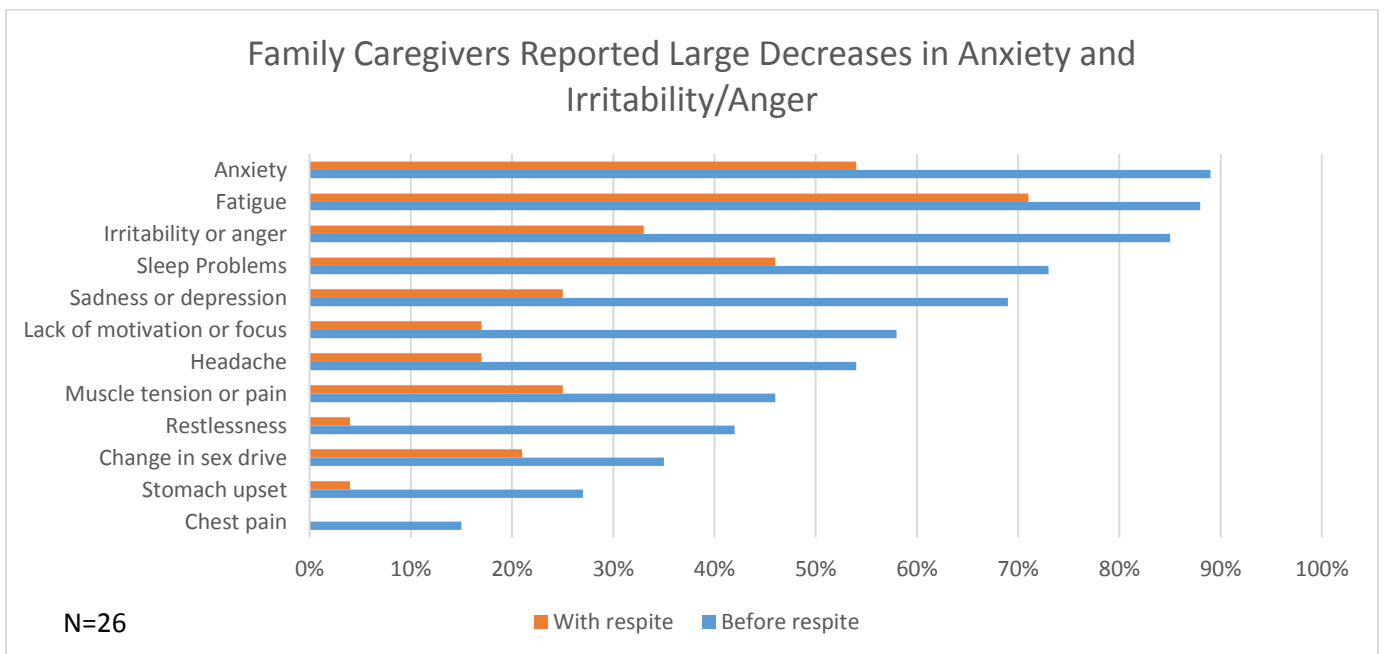
### Year 2 (2016)

#### Family Caregivers Experienced Reduced Health Symptoms While Receiving Respite



All reported health symptoms by family caregivers (N=73) decreased from before respite to currently receiving respite. Family caregivers reported the highest levels of decrease for the following: Irritability or anger (33% decrease), Restlessness (24%), Sadness or depression (24%), Headache (23%), Anxiety (22%) and Lack of motivation or focus (22%).

### Year 1 (2015)



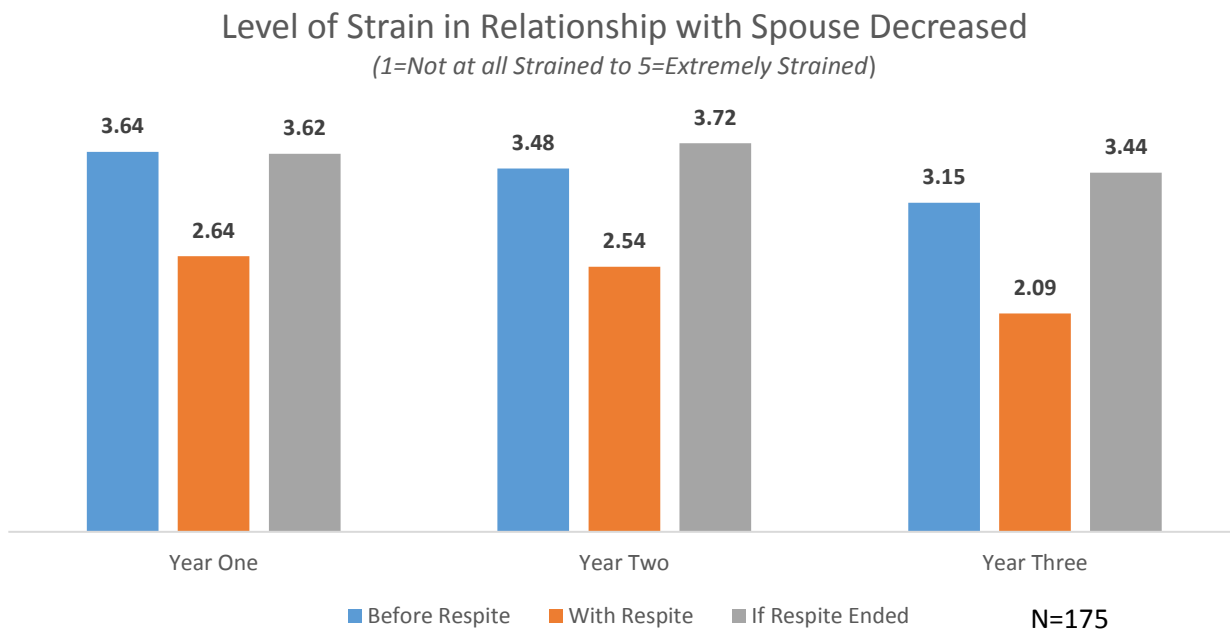
Survey participants (N=26) reported a decrease in health symptoms across all categories after receiving respite care. The most commonly reported health symptoms prior to receiving respite were anxiety (88%

reporting), fatigue (88% reporting) and irritability/anger (85% reporting). 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 but not as much (88% down to 71% reporting the symptom). Some symptoms decreased completely or almost completely for participants such as chest pain (15% reporting down to 0%) and restlessness (42% reporting down to 4%).

The reduction of reported health symptoms was consistent across all three years of the evaluation. One participant remarked, **“It’s probably kept me alive. I’ve had so many illnesses that have been stress related or stress aggravated”**. While another participant shared that respite care services helped get her through her last pregnancy safely because of the support provided.

### Relationship Impact (2015-2017)

In addition to the health and stress outcomes, receiving respite services resulted in increasingly positive relationships with both the caregiver’s spouse and the care recipient. As with other survey questions, survey respondents indicated returning to higher levels of relationship strain if respite were to end.

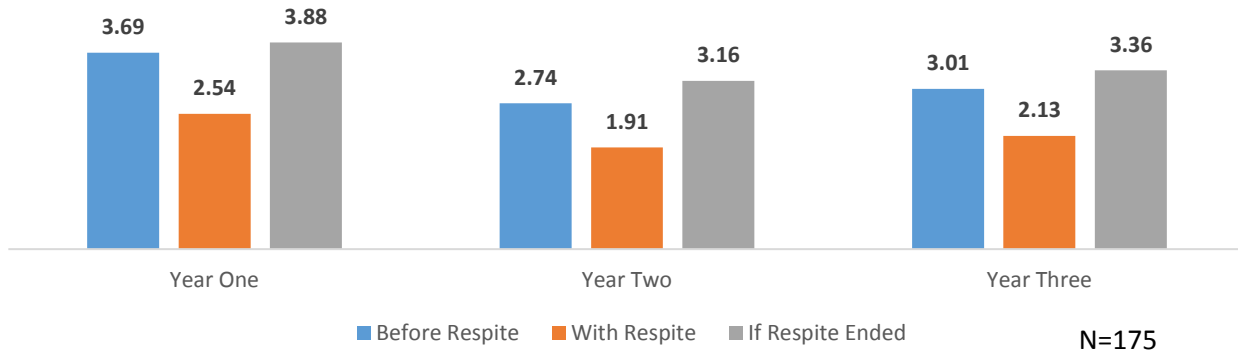


Relationship strain with a spouse decreased from a being the moderately to very strained range to being in the slightly to moderately strained range. Also, when receiving respite a minimal number of family caregivers continued to rate their relationship in the extremely strained range. Multiple focus group participants in 2015 noted that **respite care provided an opportunity to reconnect and have time away with their spouse.**



## Relationship Strain with Care Recipient Decreased When Respite was Provided

(1=Not at all Strained to 5=Extremely Strained)



Relationships between family caregivers and spouse/partner improved as well as relationship with the care recipient when provided respite care. Considering multiple family caregivers identified as taking care of a child, respite care allows for the parent to take care of other responsibilities, have free time or connect socially with others. **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”.**

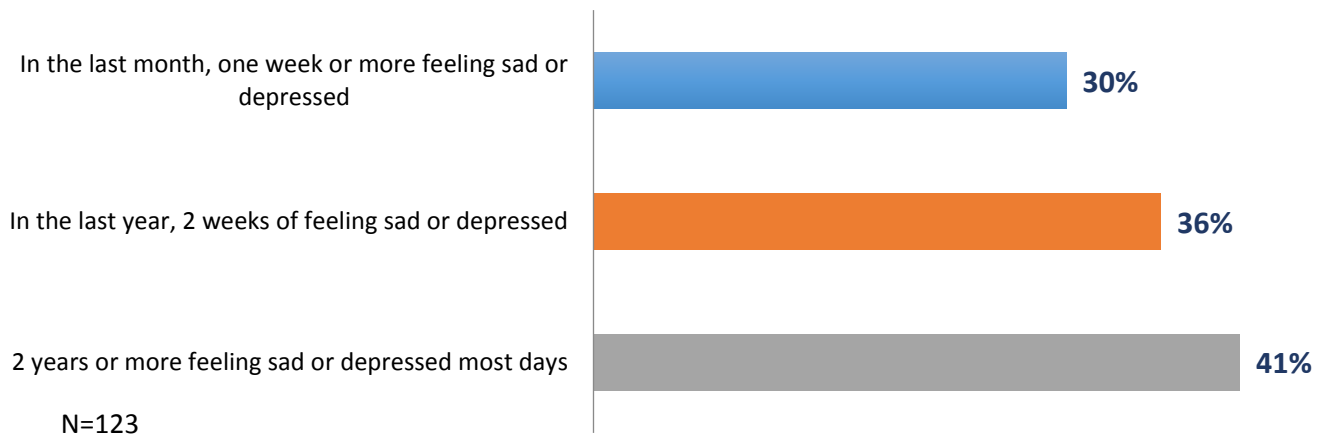
In addition to less strain in the relationship between the family caregiver and care recipient is family caregivers receiving respite consider an out of home placement less often. In 2016, before receiving respite 24% of survey respondents were considering an out of home placement compared to only 8% when receiving respite services. In 2017, 31% were considering an out of home placement prior to receiving respite compared to 23% currently considering an out of home placement even with respite. It is possible that respite services provide enough of a break to allow some families the ability to keep their loved one at home. However, the expense and stress of being a family caregiver may be too much for some families, **“The amount of time and money it takes to keep a loved one at home is unbelievable.”** Even with respite care services being provided, 17% of survey respondents believed that their family member would likely be placed out of home within six months.

There was also an impact of respite care associated with sufficiency of opportunities and time to engage in social/recreational activities. In 2016, one in five respondents believed that the end of respite care was very or extremely likely to impact their social and recreational activities. The same pattern held for 2017 respondents who noted that **without respite care services their opportunities to participate in these activities would be substantially limited.**

Based on the results of the 2016 evaluation and discussions with the state and regional coordinators, it was determined to further explore mental health and employment more in depth. Therefore, a series of

five questions were developed and administered by the regional coordinators and the evaluation team members. Only family caregivers receiving the Lifespan Respite Subsidy were included in this brief telephone interview. If at any time during the interview, the family caregiver identified that they needed support to handle mental health needs, a list of resources and references was provided to them.

## Percentage of Family Caregivers Self-Reporting Depressive Symptoms



For the respondents answering the questions, forty-one percent reported feeling sad or depressed most days over a period of two years, 36% reported having felt sad or depressed over a period of two weeks within the last year and 30% reported feeling sad or depressed for one or more weeks within the past month. The results of these questions highlight the importance of tending to the mental health needs of family caregivers. It should not be surprising given the amount of stress and strain accompanying the responsibilities of caregiving that many respondents have increased levels of depression symptoms. A positive note is the results of the health symptoms, which indicated large decreases in caregivers experiencing both depression and anxiety symptoms upon receiving respite services.

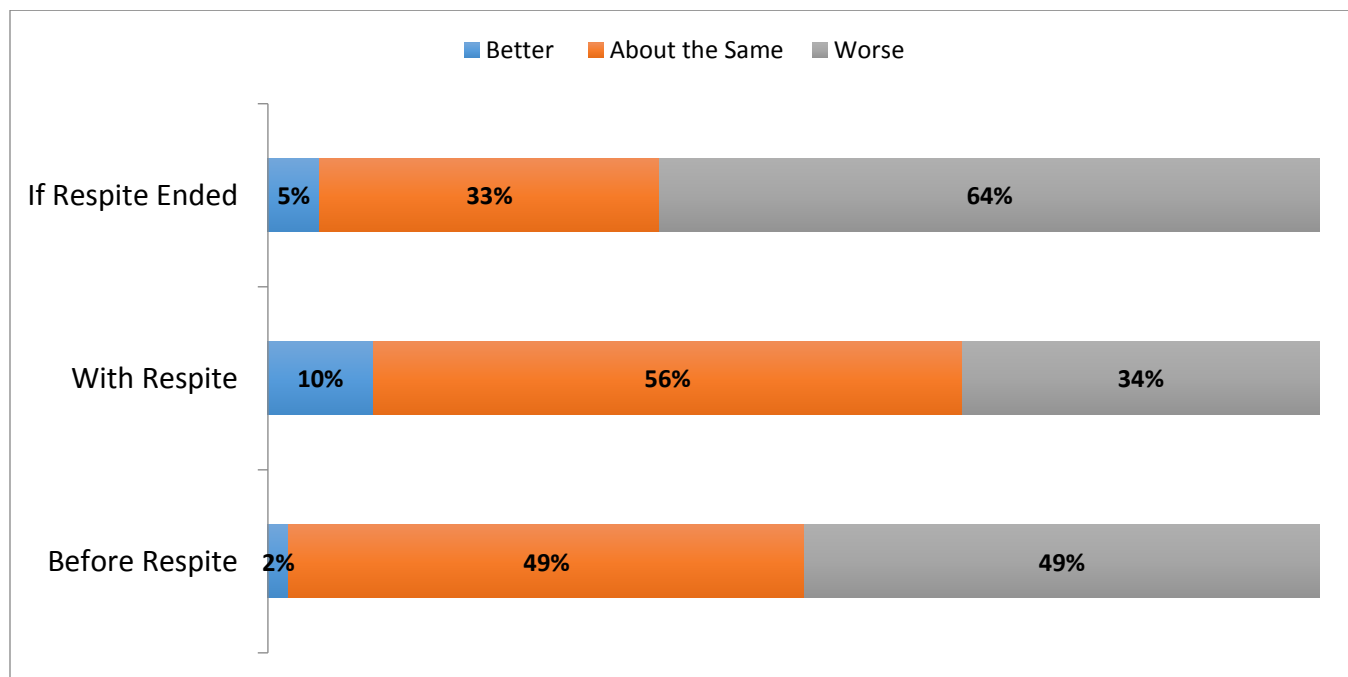
When answering questions about employment, respondents frequently pointed out that they were unable to work due to caregiving responsibilities. Therefore, the numbers reported may be an underestimate of the impact caregiving has on the workforce and employability. When asked if caregiving responsibilities had resulted in missing or being late to work 30% answered yes. For those answering yes, **73% reported that they had missed 1-5 days of work in the past year, 11% missing 5-10 days, 8% missing 10-15 days and 8% missing more than 15 days of work due to caregiving responsibilities.**

### Financial Impact of Caregiving

To assess how family caregiving impacts a family's financial situation a series of questions were asked about income, monthly household expenses, out of pocket costs related to the care recipient and overall

financial status. Of the 2017 survey respondents (N=75), 49% reported a total annual family income of less than \$30,000 and 15% reported an annual income of less than \$10,000. On the other end of the scale, 11% reported an income of \$50,000-60,000 while 22% reported an annual family income of over \$60,000. Additionally, 36% reported not having enough money each month to make ends meet, 48% reported having just enough and only 16% reported having some money left over at the end of each month after paying expenses.

**How well do you think you and your family are doing financially compared to other people your age?**



Families perceive their finances to be in better shape when they receive respite care services and anticipate that their financial situation worsen if respite were to end. Additionally, families reported having far more expenses with an income that is about the same or less than what it was prior to taking on caregiving responsibilities. Families are having to take on additional expenses while at the same time needing to either reduce work time or not work at all. From focus groups and multiple survey comments, many educated family caregivers commented about not being able to work outside the home due to caregiving responsibilities or if they could work they were required to take a job that fit the schedule of the care recipient and was not necessarily in line with the family caregiver’s education or professional background. As one respondent wrote, **“I only work while he is in school, so I am home all summer with him and on school breaks. I could work a full time job but cannot afford the respite care center.”**

**Respite Provider Survey Results (2016)**

The Respite Provider Survey was distributed for the first time during FY2016 to all types of respite providers (volunteer, paid and agency employees). The purpose for including respite providers was to gather information on who was providing respite services, to whom they were providing services for, trainings they had received/needed and to identify potential obstacles in becoming/being respite providers.

### Demographics of Survey Respondents

Of the 80 survey respondents, 29% were employed by an agency while the remaining 71% were independent respite providers. Thirty-six percent had no previous relationship to the care recipient while 24% were a friend or neighbor. The majority of providers provided care to adults. The providers most frequently served individuals with physical disabilities (48.1%) and developmental disabilities (40.5%), among others. Care providers also received various training on possible care recipient needs, such as CPR/first aid (67.1%), daily living skills (51.9%), physical disabilities (49.4%), and developmental disabilities (44.3%). The education level of respite providers was quite varied as 97% of the respondents had a high school diploma or higher and 44% reported a bachelor’s degree or more.

Other information on the survey respondents:

- \*87% reported serving 1-5 families within the last 6 months
- \*70% provided services during weekdays and 54% during the weekends
- \*41% provided overnight respite services
- \*25% provide 41 or more hours of respite per month
- \*57% had been providing respite services for 3 or more years

### Payment Sources reported by Respite Providers

Payment Source	Percentage
<b>Private Pay</b>	42%
<b>Lifespan Respite Subsidy</b>	19%
<b>Developmental Disabilities Waiver</b>	19%
<b>Volunteer</b>	16%
<b>Other</b>	16%
<b>Aged &amp; Disabled Medicaid Waiver (A&amp;D)</b>	14%
<b>Medicaid</b>	13%
<b>Private Insurance</b>	8%
<b>SSI/Disabled Children’s Program</b>	6%
<b>Local Area Agency on Aging</b>	6%

An open-ended question was asked to respite providers as to what they considered to be the greatest challenges in providing adequate respite care in Nebraska. The top three most frequently mentioned were the following:

**Low wages are an obstacle in becoming and staying a respite provider.** Respondents felt that they should be paid more as the work is often challenging but they know the hardship an increase in payment would be to families. Some responded that the state should pay more to families so that providers could stay.

**There is a gap in services for rural vs. urban regions.** Distance to provide services to families was a key concern as was educating families in rural communities about how to access respite services. Some providers stated that the urban areas have greater resources and access than the rural areas of the state.

**Training and strategies are needed for serving care recipients with mental health and behavioral concerns.** Mental health and behavioral concerns were mentioned across multiple survey items. Respondents felt more training was needed for autism spectrum disorder, dementia and challenging behaviors. Some did not feel they had the skills to provide services for someone with challenging behaviors and wondered about their own protection should something happen.

## Systems Level

### Systems Coordination

To delve into systems level coordination, collaboration and challenges, individual interviews were conducted in 2016 with the six local network respite coordinators. Local community organizations are contracted by DHHS to further implement the Nebraska Lifespan Respite Services Program, to develop and expand access to the existing infrastructure of available respite resources. The interviewees were asked about the following areas: 1) Job responsibilities; 2) Role with family caregivers; 3) Feedback received from family caregivers; 4) Gaps or obstacles in working with family caregivers; 5) Role with respite providers; 6) Gaps or obstacles working with respite providers; 7) Collaboration with the respite network; and 8) Unmet needs and areas to improve.

The following themes emerged from the regional coordinator interviews.

**Theme 1:** Family caregivers often have a difficult time accepting respite care.

**Theme 2:** The demands and obstacles are different depending on the region. There continues to be a need for differentiation for rural vs. urban areas.

**Theme 3:** Respite providers stop being providers due to not being called, not enough compensation and the distance to provide respite services.

**Theme 4:** Collaboration has improved between the coordinators statewide but needs to continue improving.

## **Cost and Financial Status (2016 analysis)**

Average total caregiving expenses (not including respite care costs) were \$673 (standard deviation = \$1,224) per month. Among them, 24.4% of individuals spent nothing on total caregiving, while the same percentage spent \$1,000 or more per month.

Average monthly respite care costs were \$220 (standard deviation = \$349). Figure 5 shows that 58.6% of survey participants spent \$100 or less, and 78.0% of them spent \$300 or less on respite care services per month. The correlation between monthly respite cost and annual family income was not statistically significant. The three most frequent types of respite care coverage included Lifespan Respite Subsidy (28.8%), Medicaid (17.8%), and Aged and Disabled Medicaid Waiver (15.1%). Given that average respite care costs were relatively small compared to total caregiving expenses, and that most respite care was covered by a subsidy or Medicaid, respite care costs may not be a large financial burden for most households.

However, there may be substantial indirect costs associated with work productivity and compromised standard of living for the caregiver. The survey data show that one in three caregivers experienced lower total household income after starting to care for their relatives, and overall monthly expenses increased for 42.2% of caregivers. This suggests that many caregivers face significant financial pressures associated with the onset of caregiving responsibilities. Furthermore, fully two-thirds of respondents reported that their financial status would be worse compared to other people their age if respite were to end.

### **Payment report**

Payment data were collected from 4,121 unique individuals with 50,564 respite care utilization episodes between January 2015 and May 2016. Each individual could receive different types and amounts of respite care reimbursements at the same time. Per individual, average respite care utilization was 50.6 units, while median respite care utilization was 13.0 units (results not shown). Thus, there was wide variation in the amount of utilization delivered across individuals.

Among the 4,121 respite care recipients, average age was 13.3 years, and 46.8% were female. The majority of recipients were non-Hispanic white (64.7%), and African American and Hispanic recipients constituted 12.8% and 9.5% of the sample, respectively (results not shown). For the 50,564 respite care episodes, 33.6% and 28.7% of respite care were related to adoption subsidies and foster parent respite care, respectively. Service duration in days spanned from a single day (17.7%) to one month (30 or 31 days) (64.4%) per utilization. Average payments that the Lifespan Respite Subsidy Program paid were \$109 per utilization episode, and the median payment was \$63. The program payments varied substantially from less than \$40 to \$200 or more per episode. Per utilization, the program paid less than \$50 for approximately half of the utilization episodes. The average payment per individual was \$2,675 and median payment was \$1,620. For each utilization episode, the three most frequent types of payment

coverage were made by subsidized adoption or Medicaid (54.2%), Waiver for Aged and Disabled (21.0%), and adult complementary or day waiver (10.3%).

### **Recommendations**

The analysis of non-financial benefits implies that, in the short-term, family caregivers with ongoing respite care experience substantially reduced stress, health problems, tension with other family members and other problems. However, ending respite care would result in a substantial negative impact on these measures, and thus the design and implementation of long-term, sustainable respite care services are important to maintain quality of life for family caregivers.

## **Evaluation Summary and Recommendations**

Based on the results and input from multiple stakeholders including family caregivers, respite care providers, local coordinators and people working in various agencies and community groups serving people with disabilities, it is clear that the Nebraska Lifespan Respite Network serves a definite need in the state. The support and breaks provided to family caregivers by respite care providers positively impact their stress levels, relationship with others, health symptoms and overall mental health. Respite allows family caregivers the opportunity to participate in social/recreational activities, reconnect with other family members including spouses and have some time to take care of themselves before re-engaging with caregiving responsibilities.

Areas that have been addressed and are under continuous improvement include: 1) Working to develop an increase in qualified respite providers; 2) Creating and implementing a high quality training program designed to build capacity of respite care providers; 3) Tracking and partnering with volunteers, agencies and faith-based organizations that are providing respite care; 4) Increasing the data input and data utilization from the data dashboard and 5) Increased dissemination of information and targeted marketing materials to families and agencies to raise the numbers of families who access respite care.

It is recommended that these initiatives and improvements continue in the system. Ongoing evaluation efforts may continue to identify gaps and improve other services provided to families. One area of need is how to address the mental health needs of family caregivers in addition to the mental/behavioral health needs of the care recipients. In order to do so, training and support to respite care providers may need to be developed and/or targeted for this specific population. It is possible a partnership with the Nebraska System of Care (NeSOC) may yield increased positive outcomes and supports for families and their loved ones.

# UNMC/MMI Respite Projects Progress Report

## -YEAR THREE-

The following report consists of two similar yet very distinct projects being carried out by faculty and staff at the University of Nebraska Medical Center's Munroe-Meyer Institute with support from the Nebraska Department of Health and Human Services Respite program through grant funding provided by the federal Administration for Community Living. The projects consist of the UNMC Respite Employer-Engagement Pilot Project and the UNMC Respite College Curriculum Service Learning Project. These projects and outcomes are detailed below.

### UNMC/MMI Respite Employer Engagement Project

Families are the backbone of our long-term services and supports system. They often provide chronic care support for their family members who are aging, have disabilities and/or chronic healthcare needs. Their unpaid financial contributions are more than Medicaid, which is the single largest payer of long-term care services. The economic value of family caregiving is estimated as \$470 billion per year (NASUAD, 2016), which is equivalent to the world's largest company, and bigger than Medicaid and out-of-pocket spending on health care. (AARP, 2015) Yet, families often face many barriers in their caregiving role. For example, 6 out of 10 family caregivers report having had to drop out of the workforce, reduce their work hours or have received a bad evaluation due to their caregiving responsibilities. (AARP, 2015) This becomes especially problematic as our population ages, when there will be less family caregivers to provide support. By 2030, only 4 potential family caregivers will be available for every person 80 and older, down from a high of more than 7 to 1 in 2010. By 2050, when all the baby boomers have reached old age, the ratio will fall to less than 3 to 1, and more individuals with long-term services and supports (LTSS) needs may need to rely on paid services for all or a part of their care. (AARP, 2013) Thus, there is a need to raise awareness of the needs of family caregivers in the workforce and the resources available to support them.

#### UNMC Employer Engagement Project Background

The goal of the UNMC/Respite Employer Engagement Project is to raise awareness of the needs of family caregivers, provide resources and information for employees at the University of Nebraska Medical Center (UNMC) and Nebraska Medicine and create materials that can be used to replicate this pilot project in other sites across the state.

The University of Nebraska Medical Center (UNMC) is one of the four University campuses supported by the state. The Munroe-Meyer Institute (MMI) is one of the academic units on the UNMC Campus. The MMI Director reports directly to the Chancellor of UNMC. The UNMC Omaha campus currently supports



over 3,861 students, and 4,900 employees. (Career OneStop, 2017 & UNMC Today, 2015) In addition, UNMC's hospital partner is Nebraska Medicine (NE Med) and has about 5,300 employees. (Career OneStop, 2017) Nebraska Medicine and UNMC each employ their own Human Resources managers, wellness, and employee assistance programs. As one of the largest employers in the state, UNMC/MMI was identified as an ideal place to implement activities outlined in the Administration for Community Living respite integration grant that was awarded to DHHS (2014-2017) to fund this project. It is our intention that this project can be scaled up across the state through partnerships with the other University campuses and statewide Nebraska Lifespan Respite Network Coordinators.

### **Year One:**

In the first year of implementation, project faculty and staff met with the upper leadership of UNMC to identify ways we could incorporate respite materials throughout the UNMC Campus and to identify if the leadership would be interested in collaborating on this project. After several discussions a plan was generated and agreements were put in place to create a pilot project to disseminate respite resources to UNMC/NE Medicine employees and take steps to make the 'business case' for supporting family caregivers who are also employees. Activities of the first year included identifying the key staff to implement the project, obtaining baseline knowledge of respite within upper leadership, and starting to implement the required activities.

### **Year Two:**

Throughout year two, we continued to develop relationships and contacts in UNMC and Nebraska Medicine's Human Resource (HR) Departments. MMI staff, serving as the UNMC Employee Engagement Coordinator, developed further working relationships with UNMC and Nebraska Medicine's HR staff, Employee Assistance Program (EAP) Counselors, and Public Relation Managers to consistently disseminate respite information to campus employees. Due to the size and diversity of programming on our campus, we are continuing to find additional avenues to share respite resources to additional employees.

### **Year Three:**

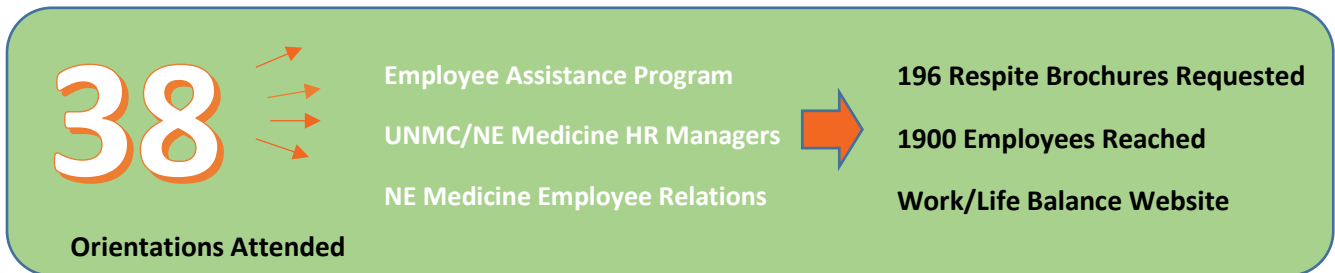
In the final year of the pilot project, MMI staff continued to develop relationships with UNMC and Nebraska Medicine, sustain and expand activities both internal to and external to UNMC/Nebraska Medicine. A survey was disseminated to UNMC and Nebraska Medicine staff as to their knowledge of and use of Respite resources and presentations about the UNMC Employer Engagement Pilot Project was provided at several state and national conferences. Specific examples of activities, which both sustain and expand this project, are detailed below.

## Continued Strategies of the UNMC Employer Engagement Project

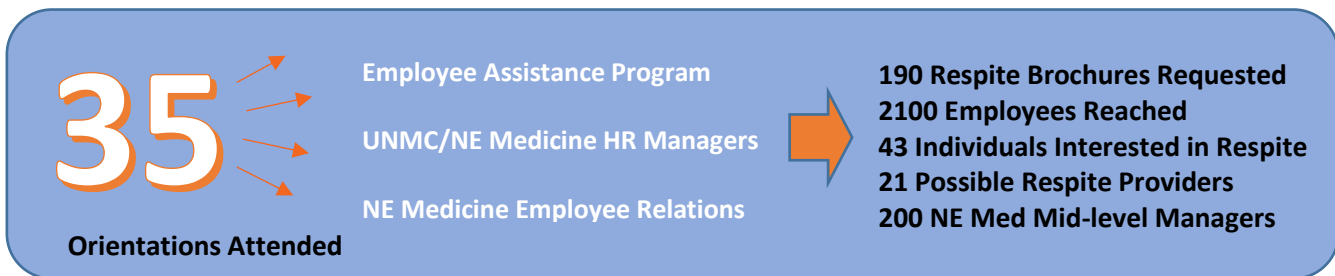
Activities that build off the momentum of previous year’s activities have been continued. This includes consistent attendance at both the monthly University of Nebraska Medical Center’s new employee orientations and the bi-monthly orientations at Nebraska Medicine. This has sustained our relationships with Human Resource Management, Employee Assistance Programs (EAP), Wellness and Public Relations/Marketing staff at both UNMC and Nebraska Medicine. These activities have facilitated building additional contacts to further the outreach of this project. For example, in April 2017 the Respite Employer Engagement Coordinator provided Respite Resource information that was disseminated to over 200 Nebraska Medicine management staff. As a result of this activity, the Marketing Director for Nebraska Medicine was asked to present respite resource information at another event targeting department managers. Every presentation to UNMC/NE Med managers generated additional interest in respite resources.

### Impacts of New Hire Orientation Outreach

#### Year 2 Impacts:



#### Year 3 Impacts:



The charts above illustrate the impacts of outreach efforts on the UNMC campus. Year one implementation started later and orientation attendance started in year two. Outreach efforts resulted in 4000 employees reached and over 350 managers within UNMC and Nebraska Medicine.

## **Employee Assistance Program**

In the last year, UNMC/Nebraska Medicine contracted their Employee Assistance Program (EAP) out to Arbor Family Counseling. This resulted in new relationships being developed and an explanation of the UNMC Respite Employer Engagement Project provided. Since this introduction, respite resources and brochures have been shared with Arbor Family Counseling staff. Monthly contact has been maintained to share respite events, updates and provide additional respite brochures as needed.

## **Lunch Presentation**

In November of 2016, Caregiver Awareness month, a “Brown Bag Presentation: Caring for the Caregiver” was offered for UNMC and NE Med employees and students but no lunch was provided. The event was marketed and titled differently from previous years to determine if changes resulted in increased attendance. The percentage of attendees compared to the time and marketing needed to organize the event proved that this format, at this time, is not the most productive way to promote respite resources at UNMC. We will continue to explore the use of this option as Respite Employer engagement activities are expanded across the state.

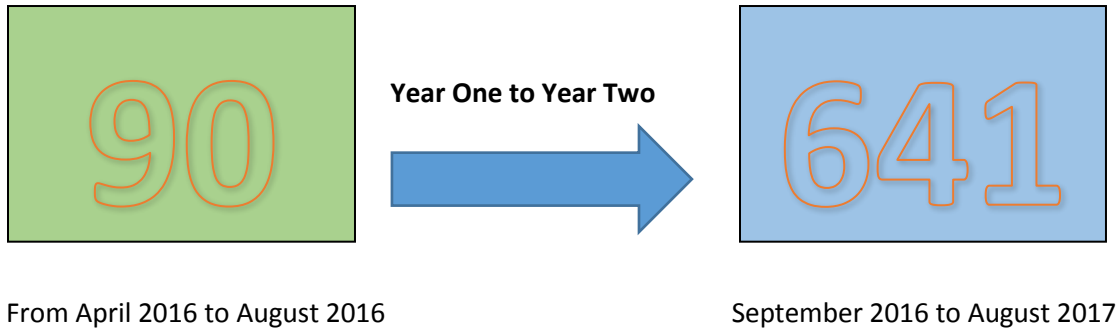
## **Stakeholder Calls**

Bi-monthly calls were conducted with stakeholders as needed. Meeting participants were provided an agenda and the prior meeting notes. Stakeholders often included staff from MMI including the Family Support Coordinator and Respite Employer Engagement Coordinator, MMI’s Program Evaluation faculty and staff, the Nebraska Department of Health and Human Services Respite Coordinator, staff from the ARCH National Respite Resource Center, staff from Respite Education Support Tools (REST), faculty from the UNMC College of Public Health, Answers4Families, AARP and the Nebraska Department of Health and Human Services Aging and Disability Resource Center supervisor.

## **UNMC/Nebraska Medicine’s Respite Resources Webpage**

A webpage for UNMC and Nebraska Medicine employees was created in April of 2016 and updated during the year to reflect new branding for Respite and new web links. The resource page provides information about state Respite resources, the Nebraska Resource and Referral Services (NRRS) and highlights the Nebraska Lifespan Respite Network and Coordinators. The page is listed under UNMC’s “Work-Life Balance” hyperlinked from UNMC Munroe-Meyer Institute’s Respite page and to Nebraska Medicine’s page. The webpage has been shared in articles that have been featured in UNMC and Nebraska Medicine’s internal newsletter and there was a corresponding increase in view during the months that Respite was featured.

## Number of Views from UNMC's Respite Resources Webpage



### Health and Wellness Fairs

The UNMC Respite Employer Engagement Coordinator attended several campus wellness fairs. These include a fair for the College of Public Health and also for the UNMC Olson Center for Women's Health.

### Newsletters and Outreach

The UNMC Today and Nebraska Medicine NOW Newsletters continued to run respite articles and promote respite events when needed. This year, two articles were featured; one to raise awareness of the needs of family caregivers and promote a lunch presentation in November and another in June that again highlighted the project with a link to the Respite Employer Engagement survey.

An attempt was made to disseminate a Press Release with UNMC's Public Relations team. Initially, it looked as though a news station wanted to do a story, unfortunately other stories took precedent.

## Expansion of the UNMC Employer Engagement Project

Expansion of the UNMC Employer Engagement Project included collaborations with Clarkson College and the University of Nebraska at Omaha (UNO). Expanded activities included launching a survey to evaluate the impact of offering Respite resources on campus and disseminating information about the Respite Employer Engagement pilot project. These activities are detailed below.

## Clarkson College and UNO

Respite resources are now offered at Clarkson College and the University of Nebraska at Omaha (UNO). Clarkson College is our partner with offering the Respite College Curriculum to enrolled students. All website information is available to Clarkson staff and students. Respite Employer Engagement Resources will be available at UNO in the fall of 2017. A similar website that is available to UNMC and Nebraska Medicine employees and students will be available at UNO. During the next contract year, assistance will be provided in rolling out respite resources at New Employee Orientations at UNO.

## Wellcom

Wellcom is a membership organization serving employers in Nebraska and Iowa who want to offer wellness initiatives to employees. During the 2016-17 year, UNMC/MMI partnered with Wellcom to offer respite articles which were shared in their Monthly Newsletters.

## Respite Survey

UNMC/Nebraska Medicine employees were surveyed in the spring of 2017 to evaluate the impact of having respite resources available on campus. Articles were disseminated in both the 'UNMC Today' and Nebraska Medicine's 'NOW' newsletters. A total of 200 responses were obtained from the survey dissemination. Of the respondents, 85% (160) indicated that it is helpful to offer Respite resources on campus. When asked if they have a family member with a disability or special healthcare need, 43% indicated they do not provide care. However, of the survey participants that do provide care; 24% indicated they provide on-going care for someone, 17% indicating caregiving has impacted their job attendance and 13% indicating it has impacted their job performance. While the numbers of participants were not as high as we hoped, the responses represent a sample of UNMC/Nebraska Medicine employee's thoughts regarding the respite resources being provided. Specific survey responses are available in the appendix. The following information reflects survey responses.

**85%** of respondents indicated: "It is helpful to have information about respite resources on campus."

**24%** of respondents indicated: “They provide on-going care for someone.”

**17%** of respondents indicated: “That providing care has impacted their job attendance.”

**13%** of respondents indicated: “That providing care has impacted their job performance.”

### **Outreach Activities**

- Association of University Centers for Disabilities (AUCD)

In December 2016, the Executive Director of the ARCH National Respite Resource Center, the UNMC/MMI Respite Employer Engagement Coordinator and the UNMC/MMI Family Support Coordinator presented a concurrent session at the Association of University Centers for Disabilities (AUCD) Conference in Washington D.C. Information regarding national respite information, respite evaluation in Nebraska and the UNMC/Nebraska Medicine Respite Employer Engagement Pilot were presented. A proposal for the AUCD 2017 conference was also submitted.

- Wellcom Conference

The UNMC Respite Employer Engagement Coordinator presented at conferences for Wellcom’s quarterly symposium on “The Working Caregiver’s Impact to Your Business” in June 2017. Approximately one hundred people were in attendance that represented employers across the state and western Iowa who have (or have interest in) employee wellness.

- Access to Respite Care @ Help (ARCH) National Respite Conference

The UNMC/MMI Respite Coordinator and Family Support Coordinator presented Respite projects with the Nebraska DHHS Lifespan Respite Network Coordinator at the ARCH National Respite Conference in Denver, Colorado in September 2016. Additionally, these same presenters were selected to present at the ARCH National Respite conference in October 2017 in Alabama.

- U.S. Department of Agriculture Conference

The United States Department of Agriculture (USDA) had an employee meeting in Omaha in July 2017. Organizers for this conference contacted UNMC/MMI to provide Respite information, disability information and other resources to better support their employees. The UNMC Respite Employer Engagement Coordinator provided an overview of the UNMC pilot project and a summary of Respite resources available to support family caregivers. It is anticipated that there was around 50 individuals in attendance.

## Next Steps

Many outreach activities over the past three years resulted in increased knowledge of the needs of Nebraska's working caregivers and the importance of respite. As this pilot transitions into full project implementation and expands across the state, the Respite Employer Engagement Coordinator at UNMC/MMI will provide training and technical assistance for Nebraska Lifespan Respite Network Coordinators.

The following summarizes 'next steps' and lessons learned from the pilot project:

- Respite Employer Engagement Training

With the start of the 2017 contract with the Nebraska Department of Health and Human Services Respite Network, the UNMC/MMI Respite Employer Engagement Coordinator will present a branded Respite Employer Engagement Initiative training for the Nebraska Lifespan Respite Coordinators.

### **Lessons Learned**

Before employers are approached to provide respite resources, there is a need to look at employers individually and assess the most effective way to approach the individual employer/business. Considerations regarding the employer size, the number and ages of employees and the programming and infrastructure should all be considered.

- Know and Tailor the Message to the Audience

There are many programs at both UNMC and NE Med that support employees and each program required a different approach to gain interest and investment into this project. However, each (program) has a unique focus and it was necessary to tailor the message to fit the audience.

Campus wellness programs have historically looked at physical activity and nutrition and not necessarily at mental wellbeing and stress reduction. However, when data was presented about the impacts of caregiving and associated stress and absenteeism, there was an understanding and interest in respite. Employee Assistance Programs (EAP) are in place to assist employees with personal and/or work-related problems that may impact job performance, health, mental and emotional well-being. EAP staff have had interest in the project because respite is a resource that can be used to support employees who are

experiencing stress due to their caregiving responsibilities. Human Resources are concerned with employee satisfaction, monitoring employee compliance and employee retention. When HR personnel were approached about our project, the message was targeted to share data about the number of employees that drop out of the workforce due to caregiving and also decreased work productivity. Next, data shared about the impact of how providing respite can help family caregivers recharge and return to work relaxed and more engaged. This helped to generate interest and buy-in for the project.

- Use a Targeted Approach

As Nebraska Respite Network Coordinators or others who are interested in targeting employers to increase awareness for the need for Respite, a key strategy is to target organizations that offer Employee Assistance Programs (EAP) and/or Wellness Initiatives currently. These two programs already are working towards supporting employees. Further, they are looking for strategies and resources to reach employees, so this is an easy way to build off of the activities they likely have underway.

- Use Data to Attract Interest

There is data that demonstrates that Respite decreases caregiver stress and burnout. Further, there is data that shows that because our population is aging there will be increasing demands on family caregivers which will in turn impact the workforce. Utilizing this data can help open doors to demonstrate how it will impact them (and their bottom line).

- Develop and Sustain Relationships

When a contact is made within an organization/business, it is important to maintain a relationship with this key contact. Relationships help to open doors, facilitate additional contacts and often offer additional support to the project. For example, during the pilot project the UNMC Employer Engagement Coordinator found that by having a relationship with the marketing director helped open the door to do a presentation with 200 mid-level managers at Nebraska Medicine.

## UNMC Respite College Curriculum Pilot

Goals of the Respite College Curriculum pilot included evaluating the impact of the Respite Education and Support Tools (R.E.S.T.) training program and also offering a field-based or service learning experience to a minimum of four college students. The following provides specific information about these requirements.



## R.E.S.T. Evaluation

As a result of the evaluation of the Respite Education Support Tools (REST) training program implemented in Nebraska from May 1, 2015 to August 1, 2016 it was decided that we would not continue with this training platform. The number of trainings, number of participants who participated, cost of each training and number of participants that became respite providers were tracked and evaluated for impact. Our analysis showed that of the 130 individuals who were REST trained, only 42 went on to become respite providers, yielding a 32% retention. Additionally, the average cost of the 23 trainings was \$677. Based on this information, it was determined that R.E.S.T. was not increasing the number of respite providers in the state and created expenses which were difficult to sustain. Therefore, it was determined that we would shift directions and create a Nebraska-specific respite training platform. (It is important to note that the evaluators feel strongly that the finding from Nebraska should not be inferred to REST's impact in other states.)

## Nebraska Specific Respite Training/Orientation

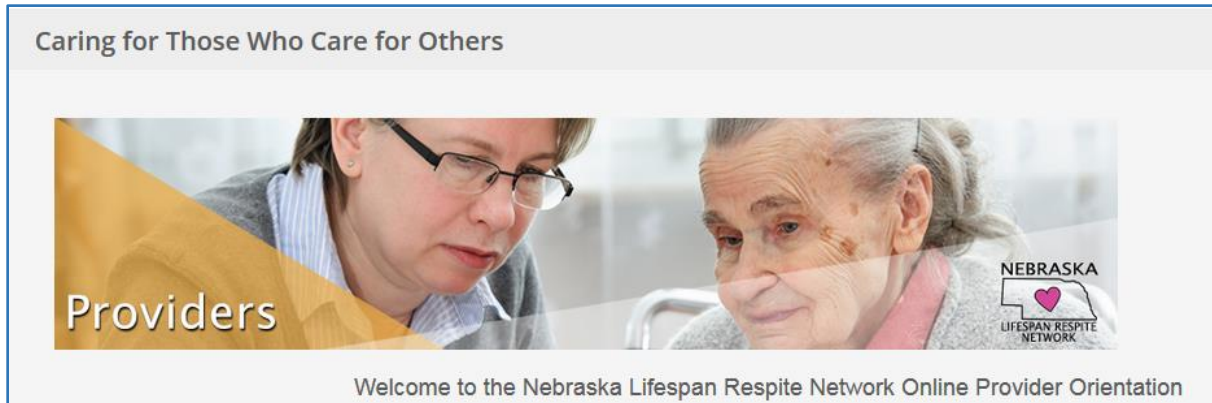
The decision to transition the training from R.E.S.T. to a Nebraska-specific training required us to 'start from scratch'. The structure of the training, content and all materials had to be developed. After much discussion, collaboration and debate between UNMC/MMI program evaluation staff, DHHS, Clarkson College faculty, the UNMC/MMI Respite Coordinator, UNMC/MMI Respite Employer Engagement Coordinator and UNMC/MMI Family Support Coordinator it was decided that a *Certificate of Achievement in Direct Workforce with specialization in home-base Respite Care* will be issued to students that complete the following requirements:

- Pass an online Respite Orientation (80%)
- Complete 10-12 hours of structured respite in a community agency (UNMC/MMI's Recreational Therapy Program)
- Complete 8 hours of home-based respite care

This structure was selected because the team felt strongly that the students needed mentorship and hands-on learning. The training would start with the online orientation, move to a structured program with staff oversight and finally transition to a family home. However, members of the team expressed concerns about student safety and the need to have mentorship in the family home. As a result, it was decided that students would be partnered with another student and receive mentorship from the family. It was also decided that the family needed training to insure that there was fidelity in the training and mentorship provided. To address these concerns, it was decided that we would identify two families to become the 'Family Caregiver Respite Coach' to mentor the student and teach them about their family member's care needs but also be more inclusive and broaden their focus to other family caregiver

concerns. The Family Caregiver Respite Coach would be paid a \$500 stipend for their time and expertise. The specific training curriculum will be discussed later.

## Online Respite Orientation



Initially, a Respite online training orientation was developed by one of our Respite Network partners and placed on the Answers4Families website at the University of Nebraska Center for Children, Families and the Law. This orientation was modified and edited by several UNMC staff, the Director of Professional Development at Clarkson College, Center on Children Families and the Law (CCFL) and DHHS. UNMC/MMI staff also incorporated several pictures and videos to add more variety and personalization.

### Modules include:

- I. **What is Respite?**
  - Definitions of Respite
  
- II. **Basic Respite Caregiving Knowledge**
  - General Information about Disabilities and Special Needs
  - Basic Respite Caregiving
  - Activity Ideas
  
- III. **Safety Issues:**
  - First Aid and Emergency Procedures
  - Abuse and Neglect Reporting
  - Challenging Behaviors

**IV. What Do I Need to Know to Become a Respite Provider?**

- Respite Programs and Funding Sources
- Respite is Directed by the Family Caregiver
- Information About Nebraska Respite Programs

**V. How Do I Get Connected to Families as a Respite Provider?**

- Suggestions for Finding Families Needing Respite
- Training with the Family Caregiver
- Communication with Your Local Respite Coordinator
- Resources

**VI. How Do I Get Paid as a Respite Provider?**

- Nebraska Lifespan Respite Provider Network
- Nebraska Lifespan Respite Subsidy Program Billing Documents

Students must complete an assessment and pass (80%) in order to successfully complete the Orientation Training.

**Structured Respite in Community Agency**

Next, students take the knowledge they learned through the NLRN respite orientation and apply it with oversight and support. Working with their local Respite Network Coordinator, students complete between 10-12 hours of respite in a structured program. Having students attend a structured respite program allows them to receive mentorship and have exposure to individuals who have special care needs with support from paid staff. With time, the students



**Participant and volunteer in UNMC/MMI's Recreational Therapy Program**

transfer to more hands-on care and likely gain more comfort in this role. After each session, the student is required to have agency staff sign off on their learning log and add comments.

The pilot project built off of UNMC/MMI's Recreational Therapy program. It was decided for other respite service areas that any camp or facility that provided services, which fit the definition of respite, could be used in this capacity. The priority for this activity is that the facility provide quality services and



**Students must understand the wants, needs and desires of the care recipient. They must provide person and family-centered care.**

has a 'person-centered' approach to care. This means that the needs, wants, interests and desires of the participant should be at the forefront of all activities and that staff exemplify these values. The selection of the structured respite setting needs to be carefully considered, as this is critical to the overall success of the students' training.

### **Home-Based Respite Care**

To help transition students from a structured, agency setting to a home-based setting, students needed on-going mentoring and support. To help respite providers understand the concerns of families and feel comfort in providing care in the family home, there was a need for students to receive mentoring in a family home by a family caregiver. The decision to incorporate a paid family caregiver into the training was given careful thought. Unanimously, the team decided that we could develop a curriculum to train a "Family Caregiver Respite Coach" by designing a structured program that provides the students mentorship, allows the family caregiver to share their experiences as a caregiver and also receive support from the Lifespan Respite Coordinator.

During the home-based respite care, each student is partnered with another student to provide respite care in the family home. Oversight and training is provided by a paid "Family Caregiver Respite Coach." This 'Coach' is trained by the Respite Network Coordinator and required to review specific materials and go through predetermined, structured activities with the students. For example, students are required to go through a set of interview questions to understand the care needs for the family member who needs support, understand the concerns of the family caregiver and also understand how the individual's disability and/or long-term care need has impacted the family overall. Next, the Family Caregiver Coach will provide a tour of the family home and show any modifications the family has made and also provide demonstrations for any sort of specialized equipment that the respite provider may need to use. Additionally, each student and the family caregiver will exchange a sheet they have filled out which details specific information about the care recipient and the care provider. The family Caregiver Respite Coach must sign off on the student's log and write comments about the experience. A minimum of eight hours of respite is required of the student in the home setting.

## Pilot Implementation

Clarkson College, a private, accredited health care services college, is physically close to the UNMC campus with professional ties to UNMC, helped pilot the college curriculum. Clarkson College trains many pre-nursing, nursing and allied health students. Many meetings to discuss this collaboration occurred with the upper leadership at Clarkson and also within MMI where it was decided that targeting Certified Nursing Assistant (C.N.A.) students would be the best place to start. Next, agreements needed to be established between Clarkson College and UNMC. This step took much more time than expected as there was misunderstanding about whether agreements were current. We needed to consult UNMC Legal to determine whom the agreement was needed with. After much discussion, it was decided that C.N.A. students were not 'official' Clarkson students and were obtaining professional certification/development, the agreement was needed with the student alone.

### Get Paid for Direct Workforce Experience

*You are invited to learn about a New Certificate of Achievement in Direct Workforce with specialization in 'Community-Based' Respite Care.*

Picture reflects part of the recruitment flyer disseminated to Clarkson College C.N.A. students.

## Student Recruitment

The Director of Clarkson Professional Development was instrumental in helping identify four students for this pilot project. She helped disseminate flyers, market the program and provided class time to present to the students. As an added bonus, she provided food-dinner for the evening class and snacks and beverages for the lunch class. The UNMC/MMI Family Support Coordinator and the Nebraska Lifespan Respite Coordinator met with two classes composed of approximately 15-20 students in each class. A PowerPoint of the project was provided and applications disseminated.

Five students submitted their applications. Four were initially selected. However, during the initial meeting, one of the four students indicated that they would be moving to Lincoln. As a result of this, the fifth applicant was also selected.

## Materials

Training manuals for the students, the Respite Family Caregiver Coaches and the Nebraska Lifespan Respite Network Coordinators were developed. Each manual has individualized materials. However, the Respite Network Coordinator manual is inclusive and contains all materials from each manual. Each manual is described below.

### I. Student Manual:

The student manual is designed to provide all the materials students need to successfully complete the project and receive a "Certificate of Achievement in Direct Workforce with Specialization in Home-Based Respite".

The manual includes:

#### Student Respite Provider Competencies:

- Provide Person/Family-Centered Care;
- Be attentive to the wants, needs and desires of the care recipient;
- Ability to convey the importance of

- Project background and anticipated outcomes
- Key contacts
- Facts about the “Role of Family Caregivers and the Need for Respite”
- Impact infographics
- Student Training Expected Outcomes and Requirements
- Training log
- Online Respite Orientation Training log-in Instructions
- Family Caregiver Respite Coach interview questions
- A Respite Provider Bio (they must fill out)
- Caregiver Instruction template forms
- Copies of UNMC Agreement

**II. Respite Family Caregiver Coach Manual:**

The Respite Family Caregiver Coach manual is designed to provide consistent training materials to each Respite Family Caregiver Coach. This manual includes:

- Project background and anticipated outcomes
- Key contacts
- Facts about the “Role of Family Caregivers and the Need for Respite” and Impact infographic information
- Family Caregiver Respite Coach Competencies
- Student Training Expected Outcomes and Requirements
- Student Project Work plan
- Online Respite Orientation Training log-in instructions
- Student interview questions for Family Caregiver Respite Coach
- A Care Recipient Storyboard (they must fill out)
- Copies of UNMC Agreement

**Family Caregiver Respite Coach Competencies:**

- Ability to follow the training curriculum with fidelity;
- Ability to convey the importance of respite for the family caregiver;
- Ability to explain the needs of and involve the care recipient as appropriate;
- Demonstrate care recipient tasks as needed; and
- Communicate how having a family member with special healthcare needs impacts the entire family.

**III. Nebraska Lifespan Respite Network Coordinator Manual:**

The Nebraska Lifespan Respite Network Coordinator manual includes all documents included in both the Family Caregiver Respite Coach manual and the Student manual. It also includes more specific information about how to recruit the students, Family Caregiver Respite Coach and structured Respite site.

Examples of materials include:

- Steps for Nebraska Lifespan Network Coordinators
- Graphic detailing each partner’s responsibility
- Student Recruitment Flyer
- Student Application
- UNMC/MMI Letter of Acceptance
- Email Template to initiate UNMC Background Checks
- Learning Vignettes

### Family Caregiver Learning Vignettes

Two family caregiver stories have been created to help students critically reflect on the needs of families who are serving as a family caregiver and the often conflicting demands of their time. The Nebraska Lifespan Respite Coordinator will review this material with each student to help him or her understand how respite can help provide balance for family caregivers. The stories are fictitious but represent typical family experiences. ‘Annie and David’ are married and have three children, one which has autism. They are struggling to care for all their children but especially provide for their child with autism. ‘Helen’ is also a family caregiver who is struggling to support her aging parents, care for her brother with intellectual disabilities and her own family. Both of these learning vignettes detail the various stressors and concerns of family caregivers and also demonstrate the impact of providing Respite.

### Family Caregivers:



#### Helen

Helen is a family caregiver and part of what is considered the ‘sandwich generation’. She is caring for her children and her aging parents. In addition, Helen is caring for her brother who will likely need lifelong supports. Helen is being pulled in many directions and this is likely impacting her health.



#### Annie and David

Annie and David are caring for three young children. Having a child with a disability adds additional stress. They rarely have time alone and never have time together. They are worried about Mark’s development and feel guilty that they aren’t doing enough. They constantly fight and have a lot of debt due to Mark’s needs. They feel very isolated and both have secretly wondered if their marriage can sustain the constant stress.



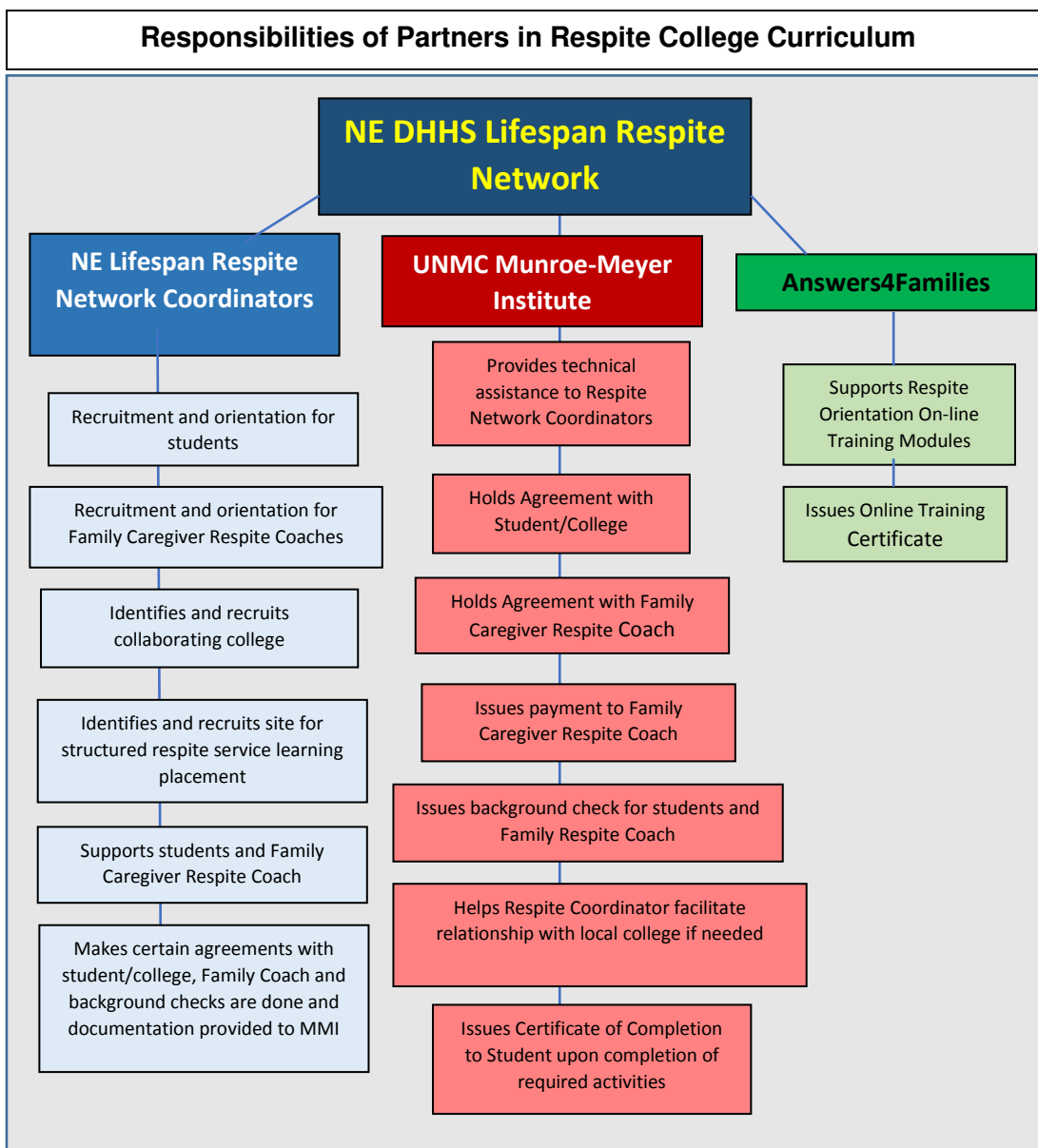
### Other Materials Created:

- Student Recruitment PowerPoint

- UNMC/MMI “Certificate of Achievement in Direct Workforce with Specialization in Home-Based Respite.”

### Expansion of the Respite College Curriculum

As the pilot is expanded to full implementation, the Nebraska Lifespan Respite Coordinators should be able to build off of all the materials developed from the pilot project. The graph below illustrates key responsibilities from each of the Nebraska Respite Network partners. In the 2017-2018 DHHS contract, four students will be identified to implement the Respite Service Learning curriculum in each of the five other Respite regions. UNMC/MMI (the Eastern Respite region) will train a total of eight students; four in each semester. It is anticipated that a total of twenty-eight students will receive a “Certificate of Achievement in Direct Workforce with Specialization in Home-Based Respite.”



### Evaluation



A large component of this project is to evaluate its impact. As the pilot project is still underway, no specific impacts can be shared at this time. UNMC/MMI program evaluation staff will contact the students, Family Caregiver Respite Coach and the collaborating college to help evaluate the impact of this pilot project. Based on this feedback modifications will be made.

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**\*Supported in part by a federal DHHS Administration for Community Living, CDAP-Lifespan Respite Integration Program grant awarded to the NE Department of Health & Human Services (09LI008-02-00).**

