Respite-Focused: Student Service Learning College Curriculum Employer Engagement

Presented: October 13, 2017

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Nebraska Activities:

2 Projects:
- Respite College Curriculum
- Outreach to Employers
Nebraska Activities:

In Partnership with:

- Nebraska Dept. of Health and Human Services Respite Network
- Nebraska’s six Lifespan Respite Network Coordinators
- Nebraska’s University Center for Excellence in Developmental Disabilities (UCEDD)
- University of Nebraska Lincoln’s Answers4Families
Background:

Families are the backbone of our Long-Term Services and Supports Systems. They need a break to continue in their caregiving role.
Background:

29% of the US population provides care for someone who is ill, aging or who has a disability.

(National Alliance for Caregivers, 2012)
Nebraska Evaluation: Respite Decreases Caregiver and Care Recipient Stress:

Level of Strain in Relationship with Spouse Decreased
(1=Not at all Strained to 5=Extremely Strained)

<table>
<thead>
<tr>
<th></th>
<th>Before Respite</th>
<th>With Respite</th>
<th>If Respite Ended</th>
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<tbody>
<tr>
<td>Year One</td>
<td>3.64</td>
<td>2.64</td>
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</tr>
<tr>
<td>Year Two</td>
<td>3.48</td>
<td>2.54</td>
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<tr>
<td>Year Three</td>
<td>3.15</td>
<td>2.09</td>
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Relationship Strain with Care Recipient Decreased When Respite was Provided
(1=Not at all Strained to 5=Extremely Strained)

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<th>With Respite</th>
<th>If Respite Ended</th>
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<tbody>
<tr>
<td>Year One</td>
<td>3.69</td>
<td>2.54</td>
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<td>Year Two</td>
<td>3.88</td>
<td>1.91</td>
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<td>Year Three</td>
<td>3.16</td>
<td>3.01</td>
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Source: Dr. Jolene Johnson, UNMC/MMI Respite Evaluation 2016-2017
Nebraska Evaluation: Respite Improves Caregiver Health

Year One:

Health Symptoms Decreased for Caregivers Receiving Respite Care

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<thead>
<tr>
<th>Symptom</th>
<th>Before Respite</th>
<th>Now Receiving Respite</th>
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<td>(N=26)</td>
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Source: Dr. Jolene Johnson, UNMC/MMI Respite Evaluation 2016-2017

Year Three:

Respite Care Resulted in Fewer Health Symptoms for Family Caregivers

(N=78)


Source: Dr. Jolene Johnson, UNMC/MMI Respite Evaluation 2016-2017

Data from eLifespan Network
FY 2016

Source: Dr. Jolene Johnson, UNMC/MMI Respite Evaluation 2016-2017
### Problem:

As our population ages there will be increased demand for Direct Care Workers.

<table>
<thead>
<tr>
<th>Year</th>
<th>Person in Need of LTSS</th>
<th>Number of Caregivers Available</th>
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<tbody>
<tr>
<td>2010</td>
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<td>2030</td>
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<td>2050</td>
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Source: AARP, 2013 ‘The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers’
Problem: Nebraska’s Respite Evaluation

Families may be eligible for respite programs but often cannot find trained providers who they are comfortable to leave their loved one with.

Statewide:

- General need for skilled respite providers
- Specialized training for respite providers to provide care for individuals with high medical and behavioral health needs.
Goal:

Increase the number of and quality of Respite Providers across the state by offering a Service-Learning Curriculum in partnership with a local college and Nebraska’s Lifespan Respite Network.
History:

- Need to create a curriculum that aligned with Nebraska’s Respite Programs
- Created our own “Homegrown” Respite Training
College Curriculum Components:

I. Online Respite Provider Orientation

II. Center Based Respite Service Learning/Mentoring

III. Home Based Respite
Role of Nebraska’s Respite Coordinators:

I. Mentor and Recruit Students

II. Identify Site for Structured Respite Care

III. Identify and Train Family Caregiver Respite Coaches
Training: Infographics

The Growing Value of Caregiving

Uncompensated Family & Friend Caregiving: $470 Billion
Total Medicaid Spending: $449 Billion

Economic Value: $470 Billion

Level of Strain in the Relationship Decreases when Respite is Provided for the Family Caregiver

Year | Person in Need of LTSS | Number of Caregivers Available
--- | --- | ---
2010 | ![Image of Person in Need](image1.png) | ![Image of Caregivers](image2.png)
2030 | ![Image of Person in Need](image1.png) | ![Image of Caregivers](image2.png)
2050 | ![Image of Person in Need](image1.png) | ![Image of Caregivers](image2.png)
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.
Project Requirements Overview:

I. Online Respite Orientation

- 1 ½ hours
- Testing requirement
What is Respite?
• Definitions of Respite

Basic Respite Caregiving Knowledge
• General Information about Disabilities and Special Needs
• Basic Respite Caregiving
• Activity Ideas

Safety Issues:
• First Aid and Emergency Procedures
• Abuse and Neglect Reporting
• Challenging Behaviors

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

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

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.
Project Requirements Overview:

II. Center Based Respite Service Learning/Mentoring

- 10-12 Hours Structured Respite
- Pilot was done at MMI in our Recreational Therapy Program
- Mentor must sign Student’s Learning Log
- Examples: Camps, Day Programs, Specific Programs
Structure-Based Respite Setting:

Criteria to guide site selection:

- philosophy of person-directed care
- respect for both the care recipient and caregiver
- quality programming
- willingness to partner and support this project
- having a volunteer program that could be built upon/or a willingness to develop
# Center and Home-Based Log

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<tr>
<th>Agency/Organization Service Learning Log</th>
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<tbody>
<tr>
<td>Date of Attendance</td>
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**Helping People Live Better Lives.**

Project Requirements Overview:

III. Home Based Respite

- Students will be paired with another student
- Completes 8-10 hours in family home
- Mentored by “Family Caregiver Respite Coach”
- “Family Caregiver Respite Coach” is trained
- “Family Caregiver Respite Coach” receives a stipend
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
- Communicate how having a family member with special healthcare needs impacts the entire family unit
Home Based Respite:

Student Interview Questions for Family Caregiver Respite Coach

**Background:** Families are the backbone of our Long-Term Care System. The care that families provide keeps individuals who are aging, have disabilities and/or chronic conditions or special healthcare needs in their homes and communities. However, we often find that family caregivers do not take time to care for themselves when they are caring for their loved ones.

These questions have been developed to help Respite Providers who may be going into family homes to better understand family concerns and be equipped to support the care recipient. These questions should be considered whenever a Respite Provider is meeting with a new family.

**Directions:** Please ask every question.

1. How long have you been acting as a caregiver?
2. Tell me about the (child, adult’s) disability/special healthcare need.
3. When did the disability/special healthcare need begin? (Lifelong, Injury, aging?)
4. Discuss how the individual’s special healthcare needs has affected the family as a whole.
5. How have you adapted your home to fit the needs of the individual?
Replicable Model:

Manuals have been developed for:
- Nebraska Lifespan Respite Coordinators
- Students
- Family Caregiver Respite Coaches

Marketing materials developed

UNMC/MMI supports infrastructure:
- Agreement with College/Student
- Employ and pay “Family Respite Coaches”
Roles and Responsibilities:

**NE DHHS Lifespan Respite Network**

**NE Lifespan Respite Network Coordinators**
- Recruitment and orientation for students
- Recruitment and orientation for Family Caregiver Respite Coaches
- Identifies and recruits collaborating college
- Identifies and recruits site for structured respite service learning placement
- Supports students and Family Caregiver Respite Coach
- Makes certain agreements with student/college, Family Coach and background checks are done and documentation provided to MMI

**UNMC Munroe-Meyer Institute**
- Provides technical assistance to Respite Network Coordinators
- Holds Agreement with Student/College
- Holds Agreement with Family Caregiver Respite Coach
- Issues background check for students and Family Respite Coach
- Helps Respite Coordinator facilitate relationship with local college if needed
- Issues Certificate of Completion to Student upon completion of required activities

**Answers4Families**
- Supports Respite Orientation On-line Training Modules
- Issues Online Training Certificate
Statewide Respite Employer Engagement Initiative
Family Caregiving in the U.S. and Nebraska

- More than 43 million adults in the U.S. are family caregivers of an adult or a child with a disability or chronic condition.
- 80% of those needing long-term services and supports in the U.S. are living at home.

Sources:
2) Congressional Budget Office (2013). Rising Demand for Long-Term Services and Supports for Elderly People.
Employers Role

Employers need to recognize their role in supporting working caregivers.

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)
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<tr>
<th>Objective</th>
<th>3 Year Project</th>
<th>Model for Replication</th>
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| • Evaluate the impact of employers offering and promoting Respite to their employees | • Partner with UNMC & NE Med’s Human Resources and Public Relations Depts.  
• Provide Respite Resources for Employee Assistance Programs & Wellness Programs | • Nebraska Lifespan Respite Network statewide outreach |
RESPITE EMPLOYER ENGAGEMENT INITIATIVE STEPS

Impact of Attendance at UNMC/NE Medicine New Hire Orientations

73 Orientations Attended
- Employee Assistance Program
- UNMC/NE Medicine HR Managers
- NE Medicine Employee Relations
- Marketing & Wellness Programs

386 Respite Brochures Requested
- Reached over 4000 Employees
- 60 follow-up contacts
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RESPITE EMPLOYER ENGAGEMENT INITIATIVE STEPS

Respite Care Resources Website

Are you one of the 200,000 caregivers in Nebraska?
Do you have respite?

Family caregivers play a critical role in supporting individuals who need long-term services and supports. Respite provides an opportunity for family caregivers of individuals with disabilities, chronic health conditions or who are aging to take a much-needed break to care for themselves. Research shows that when family caregivers make time for themselves, they are better caregivers and continue in the caregiving role.

The Nebraska Resource and Referral System (NRRS)/Respite
This website is a free service available 24 hours, seven days a week. It provides assistance in finding Nebraska Lifespan Respite Network-screened respite providers that best fit a family’s needs and location.

RESPITE EMPLOYER ENGAGEMENT INITIATIVE STEPS

Number of Views from UNMC’s Respite Resources Webpage

90

Year One to Year Two

641

From April 2016 to August 2016

September 2016 to August 2017
HELPING PEOPLE LIVE BETTER LIVES.

RESPITE EMPLOYER ENGAGEMENT INITIATIVE STEPS

Results of UNMC/NE Medicine Survey

- 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.”

- 85% of respondents indicated: “It is helpful to have information about respite resources on campus.”

N=200
RESpite Employer Engagement Initiative Steps

Statewide Expansion
RESPIE EMPLOYER ENGAGEMENT INITIATIVE STEPS

Offer additional presentations for employee outreach

- Department Heads
- Managers
- Supervisors

Employees in need of Respite
RESPITE EMPLOYER ENGAGEMENT INITIATIVE STEPS

Employee Assistance Programs
• Distribute Respite Resources
• Assist employees in need
• Caregivers need a break
• Stay focused on work

Wellness Programs
• Distribute Respite Resources
• Support Mental Wellness
• Relieve Stress
• Take time to take care of yourself
RESPITE EMPLOYER ENGAGEMENT LESSONS LEARNED

Use a Targeted Approach
Employee Assistance Programs (EAP) and/or Wellness programs

Know and Tailor the Message to Your Audience
EAP interested in supporting employees who are experiencing stress due to their caregiving responsibilities.
HR are concerned with employee satisfaction, monitoring employee compliance and employee retention.

Use Data to Attract Interest
Utilizing data can help to open doors when you can demonstrate how it will impact them

Develop and Sustain Relationships
Maintain relationships, identify key contacts. Relationships help to open doors, facilitate additional contacts and often offer additional support to the project
A KEY MESSAGE TO EMPLOYERS

Nebraska Lifespan Respite Network Partnership – Let us help!

• Respite Resources are already available.
• We are a consistent referral source for your employees.
• We collect data on numbers of employees that are using the referral.
• We will continue to expand resources and supports of Respite Care.
Questions?

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