Nebraska Lifespan Respite Network

Evaluation Collaboration

Dr. Jolene Johnson (UNMC) & Sharon Johnson (DHHS)
Introductions

Jolene Johnson, Ed.D.
Education and Child Development
UNMC

Sharon Johnson, DHHS
Children and Family Services

Other Collaborators:

Charlie Lewis
Center on Children, Families and the Law
UNL

Sarah Swanson & Kimberly Falk
(MMI/UNMC)

Asia Sikora-Kessler, Ph.D.
College of Public Health
UNMC
Project Overview

- 3 years
- Evaluation
- Data Dashboard
- Employee Engagement
- Multi-Agency Collaboration
Evaluation Framework

Families Together and Out of Institutional Care

- Need
- Access
- Caregiver Outcomes
- System Outcomes
- Cost Effectiveness
Evaluation Areas

Need

Access

Caregiver Outcomes

Systems Level Outcomes

Cost Effectiveness
Planning

Team Effort

Monthly meetings

Coordination of Efforts

Involvement of the Respite Network
Methods

**Year One**

Survey Monkey
- Tracked emails and sent reminders
Focus Groups with scripted questions
Baseline interviews with HR personnel
Financial Analysis

**Year Two**

Survey Monkey
- Web links posted and sent across the state through multiple agencies
  - For all 3 surveys
Conference Attendance to distribute surveys and promote evaluation
Regional Interviews with scripted questions
Baseline interviews with HR personnel
Instruments

Family Caregiver Survey
Respite Provider Survey
REST Follow-Up Survey
Who Does Nebraska Serve?

Source: Lifespan Respite Subsidy Regions
Nebraska Lifespan Respite Resources

Department of Health & Human Services

Nebraska Respite Network
1-866-RESPITE
1-866-737-7483
<table>
<thead>
<tr>
<th>Name of Program</th>
<th>Eligibility</th>
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| Lifespan Respite Subsidy | Individual of any age with a special need who lives with an unpaid caregiver in a non-institutional setting, and meets financial criteria. Special needs include, but are not limited to, developmental disabilities, physical disabilities, chronic illness, physical, mental or emotional conditions, special health care needs, cognitive impairments that require on-going supervision, or situations in which there is a high risk of abuse or neglect for the individual with special needs. Crisis respite available. | Linda Lehde  
Social Services Worker  
(402) 471-9188  
dhhs.respite@nebraska.gov | http://dhhs.ne.gov/Pages/hcs_programs_lifespan-respite.aspx |
| SSI/DCP (Disabled Children’s) Program | Children age birth to 16 who receive SSI (Social Security Insurance) benefits. | Western Nebraska--Gering (800) 477-6393  
Central Nebraska--Grand Island (800) 892-7922  
Southeast Nebraska--Lincoln (877) 213-4754  
Northern Nebraska--Norfolk (888) 704-0180  
Southwest Nebraska--North Platte (800) 778-1600  
Omaha area-- (402) 595-2120 | http://dhhs.ne.gov/Pages/hcs_programs_dcp.aspx |
| Subsidized Adoption | Adoption subsidy approved by DHHS prior to the finalization of an adoption. Adoptive parent(s) may request an increase in the subsidy rate if your child encounters an unusual expense not generally incurred by a family and which is based on the child’s special needs. Note: Private or out-of-state subsidized adoptions have unique considerations and may qualify for Lifespan Respite Subsidy. | Deanna Brakhage  
Sub-Adopt Program Specialist  
(402) 417-9331 or deanna.brakhage@nebraska.gov | http://dhhs.ne.gov/children_family_services/Pages/adoption.aspx |
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| Developmental Disabilities HCBS Medicaid Waivers    | Individuals with intellectual and related developmental disabilities (DD). Respite included in available services. Income eligibility requirements. | Pam Hovis  
Waiver Manager, Division of Developmental Disabilities  
(402) 471-8717  
pam.hovis@nebraska.gov  
877-667-6266  
dhhs.dddcommunitybased@nebraska.gov | http://dhhs.ne.gov/developmental_disabilities/Pages/developmental_disabilities_index.aspx                |
| Aged & Disabled Medicaid Waiver                      | Individuals of all ages who are eligible for Medicaid and have needs at nursing facility level of care. Want to live at home rather than a nursing facility and can be served safely at home. | Children ages birth to three: Early Childhood Planning Regions  
Children ages 3 to 17: Local DHHS offices  
Adults 18-64: Independent Living Centers  
Adult over 65: Area Agencies on Aging | http://dhhs.ne.gov/Pages/hcs.aspx                                                                                           |
| Title III of Older Americans Act (National Family Caregiver Support Program) | Provides support services to informal family caregivers of individuals 60 years of age and older. The Caregiver can receive support in the form of care management, respite, education and training, information and assistance and various supplemental services. A service can be approved if it allows the caregiver to successfully maintain their caregiving role. Another aspect of the NFCSP is support for grandparents or relative caregivers who are the primary caregiver for a grandchild who is eighteen years of age or younger. | Local Area Agency on Aging office  
OR  
Department of Health & Human Services  
State Unit on Aging  
(402) 471-2307  
1-800-942-7830 (Nebraska only) | http://dhhsemployees/sites/mltc/Pages/MLTCHome.aspx                                                                   |
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<td>Foster Care/Child Protective Services</td>
<td>Children who are unable to live safely at home. The Department provides the child with a substitute family approved or licensed by the Department. DHHS and a family team work with children and families to find solutions for needs, including respite. Licensed and kinship foster parents may pay for respite for themselves as caregivers using foster care maintenance funds.</td>
<td>1-800-7PARENT (1-800-772-7368) OR ACCESS Nebraska Economic Assistance Customer Service (800) 383-4278 In Lincoln (402) 323-3900 In Omaha (402) 595-1258 8:00 am - 5:00 pm Monday thru Friday OR 1-866-RESPITE (1-866-737-7483</td>
<td><a href="http://dhhs.ne.gov/Pages/localoffices.aspx">http://dhhs.ne.gov/Pages/localoffices.aspx</a> <a href="http://www.answers4families.org/family/foster-adoptive">http://www.answers4families.org/family/foster-adoptive</a> <a href="http://dhhs.ne.gov/children_family_services/Documents/CFSPSMap.pdf">http://dhhs.ne.gov/children_family_services/Documents/CFSPSMap.pdf</a> nrrs.ne.gov/respite (NE Lifespan Respite network provider resources)</td>
</tr>
<tr>
<td>Medicaid through Personal Assistance Services and Skilled Nursing Care Services</td>
<td>Active Medicaid and program-specific eligibility. Applicant must request respite resource from Access Nebraska Medicaid &amp; Long-Term Care staff who determines eligibility.</td>
<td>Medical Eligibility Customer Service Contact: Call (855) 632-7633 In Lincoln (402) 473-7000 In Omaha (402) 595-1178 8:00 am - 5:00 pm Monday thru Friday</td>
<td><a href="http://dhhs.ne.gov/Children_Family_Services/AccessNebraska/Pages/accessnebraska_index.aspx">http://dhhs.ne.gov/Children_Family_Services/AccessNebraska/Pages/accessnebraska_index.aspx</a></td>
</tr>
<tr>
<td>Adult Protective Services (Title XX)</td>
<td>Persons who are 18 years of age or older and have a substantial functional or mental impairment OR 18 years of age or older and have a guardian that was appointed by the Nebraska probate code AND there are allegations of abuse, neglect, or exploitation, including self-neglect.</td>
<td>Call the 24-hour toll-free hotline at 1-800-652-1999 OR local law enforcement</td>
<td><a href="http://dhhs.ne.gov/children_family_services/Pages/nea_aps_apsindex.aspx#Eligibility">http://dhhs.ne.gov/children_family_services/Pages/nea_aps_apsindex.aspx#Eligibility</a></td>
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| Nebraska Western Iowa Veterans Administration Caregiver Support Program: General Caregiver Support Services and Comprehensive Assistance for Family Caregivers | If the veteran is not connected to the VA, visit their local county Veteran Service Officer  
If the veteran goes to the VA contact their PACT team social worker for services  
Caregiver may contact the Caregiver Support Coordinator  
Program specifically developed to support Caregivers of Veterans. Assists with accessing a wide range of services available to Veterans that may help ease Caregiver burden. Identifies and creates support resources to help educate Caregivers, alleviate Caregiver stress and improve wellness of Caregivers. | Caregiver Support Coordinator at each VA medical center  
1-855-260-3274 to reach VA’s Caregiver Support Line  
Joni S Morin MSW, LCSW  
Caregiver Support Coordinator  
Nebraska Western Iowa VA Health Care System  
402-995-4618  
VA Caregiver Support Line  
1-855-260-3274  
Monday through Friday, 8:00 am – 11:00 pm ET  
Saturday, 10:30 am – 6:00 pm ET  
VA Caregiver Support website  
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<td>U.S. Air Force (USAF) Exceptional Family Member Program (EFMP)</td>
<td>Families stationed throughout the country who have children requiring unique child care considerations due to the child’s moderate or severe special needs. USAF EFMP Respite Care is specifically designed for children whose medical conditions require assignment near major medical facilities in the continental U.S. Or whose needs are complex and require specialized community of care.</td>
<td>Call Child Care Aware at 1-800-424-2246 or email <a href="mailto:michelle.pridell@offutt.af.mil">michelle.pridell@offutt.af.mil</a>. Or call the EFMP Office at 402-294-4329 for more information.</td>
<td></td>
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Nebraska Lifespan Respite Network

Call a Respite Network Coordinator in your area at 1-866-RESPITE (1-866-737-7483) for help with respite resources.

You may also visit the DHHS supported website “Nebraska Resource and Referral System” at https://nrrs.ne.gov/respite/search/. This free service will assist you 24/7 in finding Network-approved respite providers that best fit your needs and location. You can easily search for respite resources and supportive services throughout Nebraska on this site.
Year One
Pilot Evaluation
Lifespan Respite Subsidy
$125 per month
Employer Engagement
REST Training and Follow-Up
## Year One Evaluation Survey Results (Satisfaction)

**N=26**

<table>
<thead>
<tr>
<th>I am satisfied with...</th>
<th>Strongly Agree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>The overall level of respite care services I have received.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>4%</td>
<td>16%</td>
<td>40%</td>
<td>40%</td>
</tr>
<tr>
<td>With the ease of finding a respite care provider.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>20%</td>
<td>24%</td>
<td>32%</td>
<td>24%</td>
</tr>
<tr>
<td>With the care provided to the care recipient.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>4%</td>
<td>0%</td>
<td>50%</td>
<td>46%</td>
</tr>
<tr>
<td>With the number of hours of respite care received per month.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>19%</td>
<td>12%</td>
<td>46%</td>
<td>23%</td>
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Source: 2015 Lifespan Respite Subsidy Family Caregiver Survey
Respite Hours Received
23% rated hours received as ‘sufficient’

Source: 2015 Lifespan Respite Subsidy Family Caregiver Survey
Health Symptoms
N=26

Before receiving respite care which symptoms did you experience?

Sadness or depression
Irritability or anger
Lack of motivation or focus
Restlessness
Anxiety
Sleep problems
Stomach upset
Change in sex drive
Fatigue
Chest pain
Muscle tension or pain
Headache

Now that you receiving respite care which symptoms do you experience?

Sadness or depression
Irritability or anger
Lack of motivation or focus
Restlessness
Anxiety
Sleep problems
Stomach upset
Change in sex drive
Fatigue
Chest pain
Muscle tension or pain
Headache

Source: 2015 Lifespan Respite Subsidy Family Caregiver Survey
Relationships

Relationship Strain Decreased With Respite Services

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

Before Respite  With Respite  If Respite Ends

3.64  2.64  2.54
3.69  2.54  3.88

Spouse  Care Recipient

Source: 2015 Lifespan Respite Subsidy Family Caregiver Survey
Employee Engagement 2015

Activities
Activities for the Employee Engagement Pilot for 2014-15 included meeting with the directors of Human Resources at UNMC and Nebraska Medicine, attending new employee orientation and distributing information about both respite care services and how to become a respite care provider and collecting baseline data from the human resources, employee assistance and wellness programs.

Baseline Questions (N=5)
What is your current understanding of Respite Care?

What respite information are you currently providing to UNMC/Nebraska Medicine employees?

Approximately how many Respite referrals have you made in the past year and to what organization do you send referrals?
Other Reported Outcomes

1. Decreased Stress Levels while receiving Respite
2. Increased Opportunities to Engage in Social and/or Recreational Activities
3. Evaluation is helping to address cross-system barriers
4. REST cost benefit and looking at sustainability
5. Data Dashboard Development and Use
Data Dashboard
Year 2 Evaluation Sources

Family Caregiver Survey: N=71

Respite Provider Survey: N=78

Regional Coordinator Interviews

Data Dashboard

REST training follow-up (still collecting)

Employee Engagement Interviews (still collecting)
Caregiver and Providers FY 2016

Data from eLifespan Network

- Caregiver:
  - July: 1049
  - August: 1228

- Provider:
  - July: 364
  - June: 277
2016 Survey Respondents

Family Caregivers

Respite Providers

Across multiple funding sources
Age of the primary Family Caregiver

Source: 2016 Family Caregiver Survey
Age of the primary care recipient

Source: 2016 Family Caregiver Survey
My family receives respite care services through:

- LifeSpan Respite Subsidy: 32.20%
- Medicaid: 18.64%
- Aged and Disabled Waiver: 18.64%
- Veteran's Administration: 3.39%
- Developmental Disabilities: 10.17%
- SSI/Disabled Children's: 11.86%
- Alzheimer's Scholarship: 3.39%
- Local Area on Aging: 1.69%
- Church or Faith Based: 1.69%
- Private Health Insurance: 1.69%
- Long Term Care Insurance: 1.69%
- Private Pay: 15.25%
- Local Non-Profit: 15.25%

Source: 2016 Family Caregiver Survey
Satisfaction with Respite

N=71

1=Strong Disagree to 4=Strongly Agree

Source: 2016 Family Caregiver Survey
Length of Respite Service Received

Source: 2016 Family Caregiver Survey
Hours of paid respite care per month

Source: 2016 Family Caregiver Survey
Stress levels decreased for family caregivers when provided respite

Source: 2016 Family Caregiver Survey
Health Symptoms Decreased for Family Caregivers

Source: 2016 Family Caregiver Survey
Relationship Outcomes

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

Before Respite

Spouse/Partner: 3.53
Care Recipient: 2.77

Receiving Respite

Spouse/Partner: 2.56
Care Recipient: 1.9

If Respite Ended

Spouse/Partner: 3.74
Care Recipient: 3.19
Possible out-of-home placement consideration decreased with Respite.

Source: 2016 Family Caregiver Survey
Total annual family income

Source: 2016 Family Caregiver Survey
In general, how do your family finances work out at the end of the month?

Source: 2016 Family Caregiver Survey
Standard of Living and Expenses

Source: 2016 Family Caregiver Survey
Respite Care Providers

2016 Survey Results
Education Level

Source: 2016 Respite Provider Survey
Have you completed REST (Respite Education and Support Tools) training?

Source: 2016 Respite Provider Survey
Relationship to the Care Recipient

Source: 2016 Respite Provider Survey
How long have you been providing respite services?

Source: 2016 Respite Provider Survey
Age groups served in the past 12 months by the provider

Source: 2016 Respite Provider Survey
Top 10 populations of need

Physical Disabilities (48%)

Developmental Disabilities (40%)

Alzheimer’s/Dementia/Memory Loss (30%)

Frail Elderly (30%)

Behavioral/Emotional Needs (30%)

Medical Needs (27%)

Chronic Illness (27%)

Intellectual Disabilities (26%)

Autism Spectrum Disorders (26%)

Limited or Non-mobile (22%)

Source: 2016 Respite Provider Survey
Average number of hours provided per month

27% provided 41 or more hours per month

Source: 2016 Respite Provider Survey
Respite Provided

87% served 1-5 families per month

72% provided services during weekdays; 40% provided respite overnight

66% provided respite in the care recipient’s home followed by 33% providing services in their own home

21% provided respite at community activities and events

Source: 2016 Respite Provider Survey
REST Training and Follow Up

130 participants for 30 trainings (Regionally based)

2 canceled due to no registrants

September 2015-August 2016

Cost: $9759

In-Kind Contributions: $5817

Follow Up:

26/130 participants have become respite providers

Survey: Data are limited with only 8 respondents and of whom only 3 became providers
Data Patterns
Multi-Agency Collaboration
Successes

Increased collaboration

Preliminary Results

Another year to gather more data
Challenges

Survey Return Rate
--Looking at length, adding more options for returns (including paper/pencil and text messaging)

Expense of Evaluation for the State

Differing Definitions
Thank You

Contact Information:

Jolene Johnson, Ed.D.
Assistant Professor
Interdisciplinary Center for Program Evaluation
University of Nebraska Medical Center
Munroe-Meyer Institute
985605 Nebraska Medical Center
Omaha, NE 68198-5605
Email: jolene.johnson@unmc.edu
Phone: 402-559-5723

Sharon J Johnson, Program Coordinator
Lifespan Respite Program and Disabled Persons & Family Support
DHHS - Division of Children & Family Services
PO Box 95026
301 Centennial Mall South
Lincoln, NE 68502-5026
(402) 471-1764
https://nrrs.ne.gov/respitesearch/