Nebraska Lifespan Respite Network

Three Year Evaluation: Results and Lessons Learned

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Introduction and Purpose
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
Evaluation Questions
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
Methods

Year 3

Family Caregiver Survey mailed to all participants receiving Lifespan Respite Subsidy

Additional items were developed and integrated into a brief interview

Survey on respite was sent out campus wide (Employer Engagement piece)
Instruments

Family Caregiver Survey

Respite Provider Survey

REST Follow-Up Survey

Employer Engagement Survey

Phone Interview
Outcomes
Aggregated when possible

Some data were collected only for one year of the process
Need & Access
Who Does Nebraska Serve?

Source: Lifespan Respite Subsidy Regions
Age of the primary Family Caregiver

Source: 2016 Family Caregiver Survey
Most Family Caregivers Provide Care for a Child (62%) Second Most Frequently for a Spouse (20%)
Respite Hours

66% reported receiving at least 10 hours of paid respite care per month

In addition, unpaid respite hours ranged from zero to 70 additional hours per month
From Year 2 to 3

• Satisfaction Increased with the number of respite hours provided (63% down to 48% were not satisfied)

• Possible explanations:
  • Exceptional Needs Funds
  • More training for respite providers, more volunteer hours
Length of Time Receiving Respite Services Varies

- More than 5 years: 27.59% (16)
- Less than 2 months: 22.41% (13)
- 2-6 months: 1.72% (1)
- 6-11 months: 6.90% (4)
- 1-5 years: 41.38% (24)

Source: 2016 Family Caregiver Survey
Caregiver and Providers FY 2016

Data from eLifespan Network

- Caregiver
- Provider

Axis Title
Family Caregivers were Highly Satisfied with the Respite Care Provided

- With the respite care provided to the care recipient:
  - Strongly Disagree: 8%
  - Disagree: 3%
  - Agree: 52%
  - Strongly Agree: 37%

- With the ease of finding a respite care provider:
  - Strongly Disagree: 21%
  - Disagree: 26%
  - Agree: 31%
  - Strongly Agree: 22%

- The overall level of respite care services received:
  - Strongly Disagree: 11%
  - Disagree: 11%
  - Agree: 39%
  - Strongly Agree: 39%

N=176
Exceptional Needs/Crisis Funding

Up to $1000 per year

5% of survey respondents had received this funding

67% were “satisfied” to “highly satisfied”
Family Caregiver Outcomes
Mental Health

Percentage of Family Caregivers Self-Reporting Depressive Symptoms

- In the last month, one week or more feeling sad or depressed: 30%
- In the last year, 2 weeks of feeling sad or depressed: 36%
- 2 years or more feeling sad or depressed most days: 41%

N=123
Respite Services Have a Positive Impact on Relationships
Relationship Strain with Care Recipient Decreased When Respite was Provided

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

Year One Year Two Year Three
Before Respite With Respite If Respite Ended
N=175
Level of Strain in Relationship with Spouse Decreased

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

<table>
<thead>
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<th></th>
<th>Year One</th>
<th>Year Two</th>
<th>Year Three</th>
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<tbody>
<tr>
<td>Before Respite</td>
<td>3.64</td>
<td>3.48</td>
<td>3.15</td>
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<tr>
<td>With Respite</td>
<td>2.64</td>
<td>2.54</td>
<td>2.09</td>
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<tr>
<td>With Respite</td>
<td></td>
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<td>3.44</td>
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N=175
Health
Health Symptoms
N=26

Health Symptoms Decreased After Receiving Respite Care Services

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?

Source: 2015 Lifespan Respite Subsidy Family Caregiver Survey
Health Symptoms Decreased for Family Caregivers

Source: 2016 Family Caregiver Survey
Respite Care Resulted in Fewer Health Symptoms for Family Caregivers

- Headache: Before receiving respite - 48%, Now that you are receiving respite - 25%
- Muscle tension or pain: Before receiving respite - 43%, Now that you are receiving respite - 20%
- Chest pain: Before receiving respite - 12%, Now that you are receiving respite - 5%
- Fatigue: Before receiving respite - 60%, Now that you are receiving respite - 37%
- Change in sex drive: Before receiving respite - 18%, Now that you are receiving respite - 11%
- Stomach upset: Before receiving respite - 27%, Now that you are receiving respite - 8%
- Sleep problems: Before receiving respite - 56%, Now that you are receiving respite - 30%
- Anxiety: Before receiving respite - 53%, Now that you are receiving respite - 33%
- Restlessness: Before receiving respite - 29%, Now that you are receiving respite - 12%
- Lack of motivation: Before receiving respite - 38%, Now that you are receiving respite - 13%
- Irritability or anger: Before receiving respite - 49%, Now that you are receiving respite - 21%
- Sadness or depression: Before receiving respite - 44%, Now that you are receiving respite - 20%
Caregiver Stress Decreased with Respite Services

- **Extremely Stressed**
  - Before Respite: 36%
  - Receiving Respite: 4%
  - If Respite Ended: 57%

- **Very Stressed**
  - Before Respite: 36%
  - Receiving Respite: 9%
  - If Respite Ended: 31%

- **Moderately Stressed**
  - Before Respite: 20%
  - Receiving Respite: 42%
  - If Respite Ended: 8%

- **Slightly Stressed**
  - Before Respite: 5%
  - Receiving Respite: 35%
  - If Respite Ended: 4%

- **Not at all Stressed**
  - Before Respite: 3%
  - Receiving Respite: 10%
  - If Respite Ended: 2%

N=142
“It’s probably kept me alive. I’ve had so many illnesses that have been stress related or stress aggravated”
Social & Recreational Activities

1 in 5

Reported that without Respite Services Opportunities to have Social/Recreational Activities would be “Substantially Limited”

“It can be the difference between being a parent who just can’t keep going to being a parent who can hang in there”.
Finances
Total annual family income

Source: 2016 Family Caregiver Survey
Work Missed Due to Caregiving

Majority of Employed Caregivers Missed 5 or Fewer Days

- 1-5 days: 73%
- 5-10 days: 11%
- 11-15 days: 8%
- 16+ days: 8%
“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.”
In general, how do your family finances work out at the end of the month?

- Some money left over: 27.69% (18)
- Not enough to make ends meet: 21.54% (14)
- Just enough to make ends meet: 50.77% (33)

Source: 2016 Family Caregiver Survey
How well do you think you and your family were doing financially compared to other people your age?

- **Before Respite:**
  - Better: 2%
  - About the Same: 49%
  - Worse: 49%

- **With Respite:**
  - Better: 10%
  - About the Same: 56%
  - Worse: 34%

- **If Respite Ended:**
  - Better: 5%
  - About the Same: 33%
  - Worse: 64%
Standard of Living and Expenses

Source: 2016 Family Caregiver Survey
Out of Home Placement

2016: 24% before respite; 8% with respite

2017: 31% before respite; 23% with respite

“The amount of time and money it takes to keep a loved one at home is unbelievable.”

17% believe out of home placement is inevitable
Respite Care Providers

2016 Survey Results
Education Level

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

While 72% provided services during weekdays;

More difficult to find Overnight Respite (40%)

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
Provider Challenges

Low Wages

Gap in Services for Rural and Urban

Training and Strategies for Mental/Behavioral Health Concerns

One provider stated, “I believe with the education, experience, and qualifications I bring, my greatest challenge is being properly compensated by the state waiver. I believe meaningful services provided by a professional are greatly beneficial for individuals ESPECIALLY when offered within the community...however, the rate range set forth by the state is capped significantly below what I charge private pay or what a specialized provider would make for lesser services.”
Systems

Family Caregiver Readiness

Rural vs. Urban Areas

Respite Provider Obstacles

Collaboration
Evaluation Lessons

Be clear on the objectives

Realistic on timelines and budget

Be prepared to shift focus; change direction or method
Evaluation led to.....

Additional items related to mental health and employment

Development of a curriculum

Partnerships
Thank You

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