

# 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  
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UNL

Sarah Swanson & Kimberly Falk  
(MMI/UNMC)

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College of Public Health  
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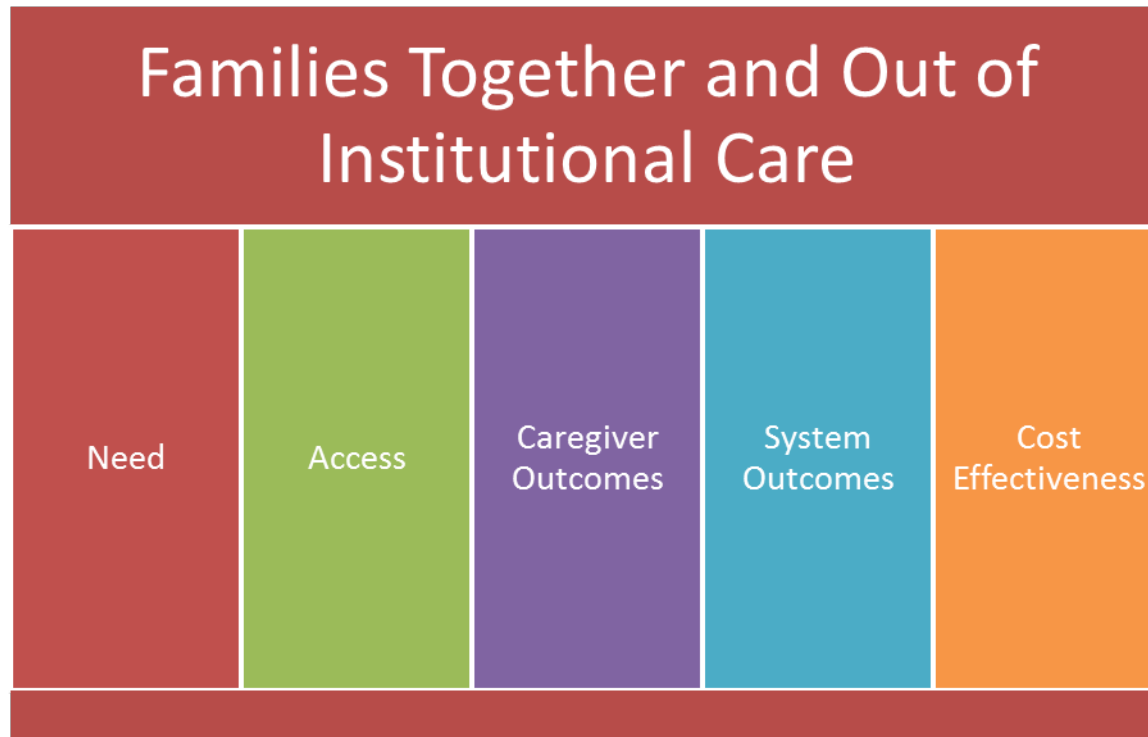


# Project Overview

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



# Evaluation Framework



# 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

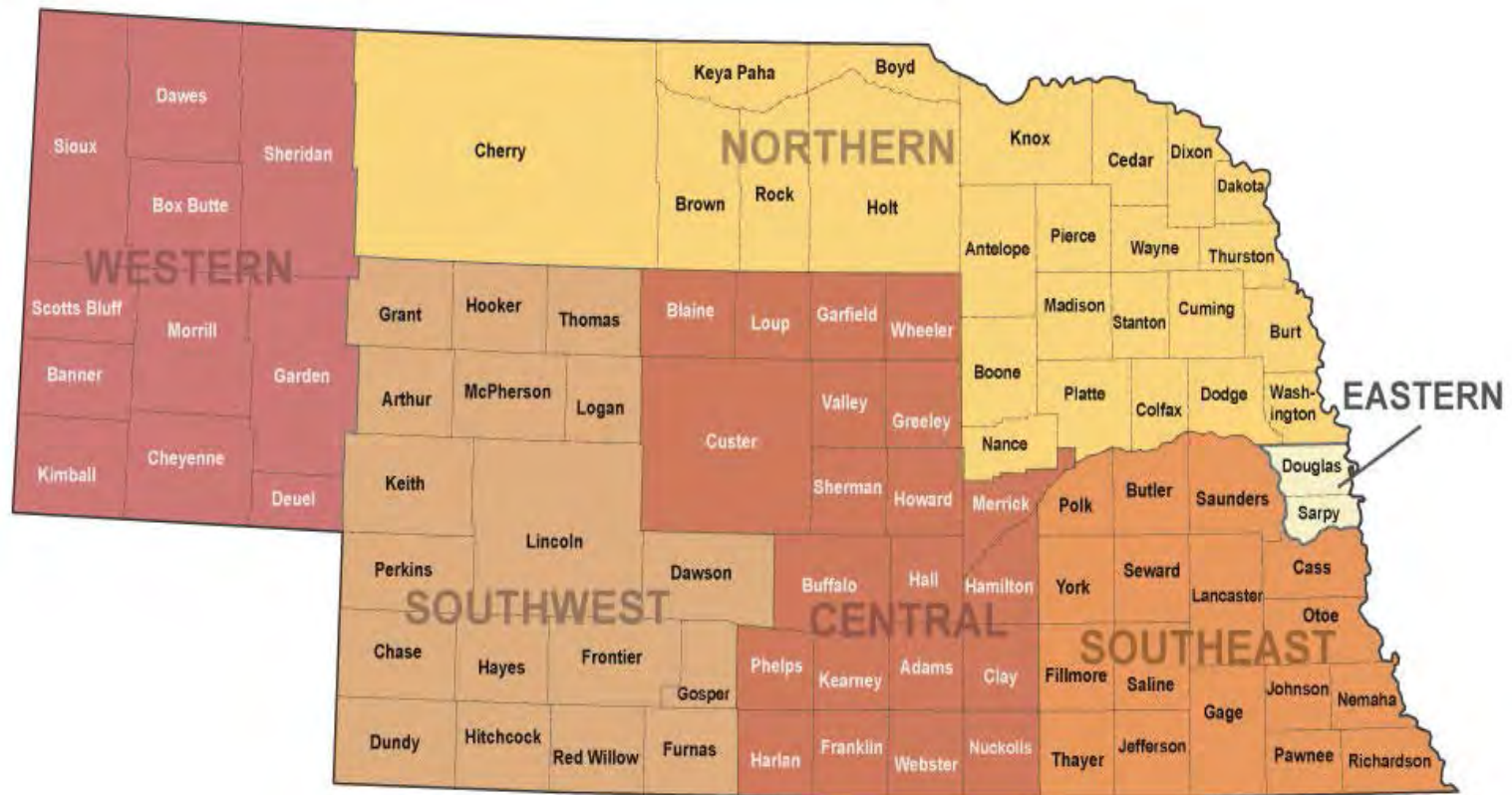
Respite Provider Survey

REST Follow-Up Survey





# Who Does Nebraska Serve?



Source: Lifespan Respite Subsidy Regions



# Nebraska Lifespan Respite Resources



Name of Program	Eligibility	Contact Information	Website
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 <a href="mailto:dhhs.respite@nebraska.gov">dhhs.respite@nebraska.gov</a>	<a href="http://dhhs.ne.gov/Pages/hcs_programs_lifespan-respite.aspx">http://dhhs.ne.gov/Pages/hcs_programs_lifespan-respite.aspx</a>
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	<a href="http://dhhs.ne.gov/Pages/hcs_programs_dcp.aspx">http://dhhs.ne.gov/Pages/hcs_programs_dcp.aspx</a>
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 <a href="mailto:deanna.brakhage@nebraska.gov">deanna.brakhage@nebraska.gov</a> .	<a href="http://dhhs.ne.gov/children_family_services/Pages/adoption.aspx">http://dhhs.ne.gov/children_family_services/Pages/adoption.aspx</a>



Name of Program	Eligibility	Contact Information	Website
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 <a href="mailto:pam.hovis@nebraska.gov">pam.hovis@nebraska.gov</a>  877-667-6266 dhhs.dddcommunitybased@nebraska.gov	<a href="http://dhhs.ne.gov/developmental_disabilities/Pages/developmental_disabilities_index.aspx">http://dhhs.ne.gov/developmental_disabilities/Pages/developmental_disabilities_index.aspx</a>
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	<a href="http://dhhs.ne.gov/Pages/hcs.aspx">http://dhhs.ne.gov/Pages/hcs.aspx</a>
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. <small>YoungerLifespan Respite Resources/SJohnson/Statewide Respite Coordinator</small>	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)	<a href="http://dhhsemployees/sites/mltc/Pages/MLTCHome.aspx">http://dhhsemployees/sites/mltc/Pages/MLTCHome.aspx</a>



Name of Program	Eligibility	Contact Information	Website
Foster Care/Child Protective Services	<p>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.</p> <p>Licensed and kinship foster parents may pay for respite for themselves as caregivers using foster care maintenance funds.</p>	<p>1-800-7PARENT (1-800-772-7368)</p> <p>OR</p> <p><b>ACCESS Nebraska Economic Assistance Customer Service</b>  (800) 383-4278  In Lincoln (402) 323-3900  In Omaha (402) 595-1258  8:00 am - 5:00 pm Monday thru Friday</p> <p>OR</p> <p>1-866-RESPITE (1-866-737-7483)</p>	<p><a href="http://dhhs.ne.gov/Pages/localoffices.aspx">http://dhhs.ne.gov/Pages/localoffices.aspx</a></p> <p><a href="http://www.answers4families.org/family/foster-adoptive">http://www.answers4families.org/family/foster-adoptive</a></p> <p><a href="http://dhhs.ne.gov/children_family_services/Documents/CFSPSMap.pdf">http://dhhs.ne.gov/children_family_services/Documents/CFSPSMap.pdf</a></p> <p><a href="http://nrrs.ne.gov/respitesearch">nrrs.ne.gov/respitesearch</a> (NE Lifespan Respite network provider resources)</p>
Medicaid through Personal Assistance Services and Skilled Nursing Care Services	Active Medicaid and program-specific eligibility. Applicant must request respite resource from Access Nebraska Medicaid & Long-Term Care staff who determines eligibility.	<p>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</p>	<p><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></p>
Adult Protective Services (Title XX)	<p>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.</p> <p>Nebraska Lifespan Respite Resources/SJohnson/Statewide Respite Coordination</p>	<p>Call the 24-hour toll-free hotline at 1-800-652-1999</p> <p>OR</p> <p>local law enforcement</p>	<p><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></p>



Name of Program	Eligibility	Contact Information	Website
Nebraska Western Iowa Veterans Administration Caregiver Support Program: General Caregiver Support Services and Comprehensive Assistance for Family Caregivers	<p>If the veteran is not connected to the VA, visit their local county Veteran Service Officer</p> <p>If the veteran goes to the VA contact their PACT team social worker for services</p> <p>Caregiver may contact the Caregiver Support Coordinator</p> <p>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.</p>	<p>Caregiver Support Coordinator at each VA medical center            1-855-260-3274 to reach VA's Caregiver Support Line</p> <p>Joni S Morin MSW, LCSW            Caregiver Support Coordinator            Nebraska Western Iowa VA Health Care System            402-995-4618</p> <p>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</p> <p>VA Caregiver Support website  <a href="http://www.caregiver.va.gov">www.caregiver.va.gov</a></p>	<p><a href="http://www.caregiver.va.gov">www.caregiver.va.gov</a></p>



Name of Program	Eligibility	Contact Information	Website
U.S. Air Force (USAF) Exceptional Family Member Program (EFMP)	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.	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.	



# 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/respitesearch/>. 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**



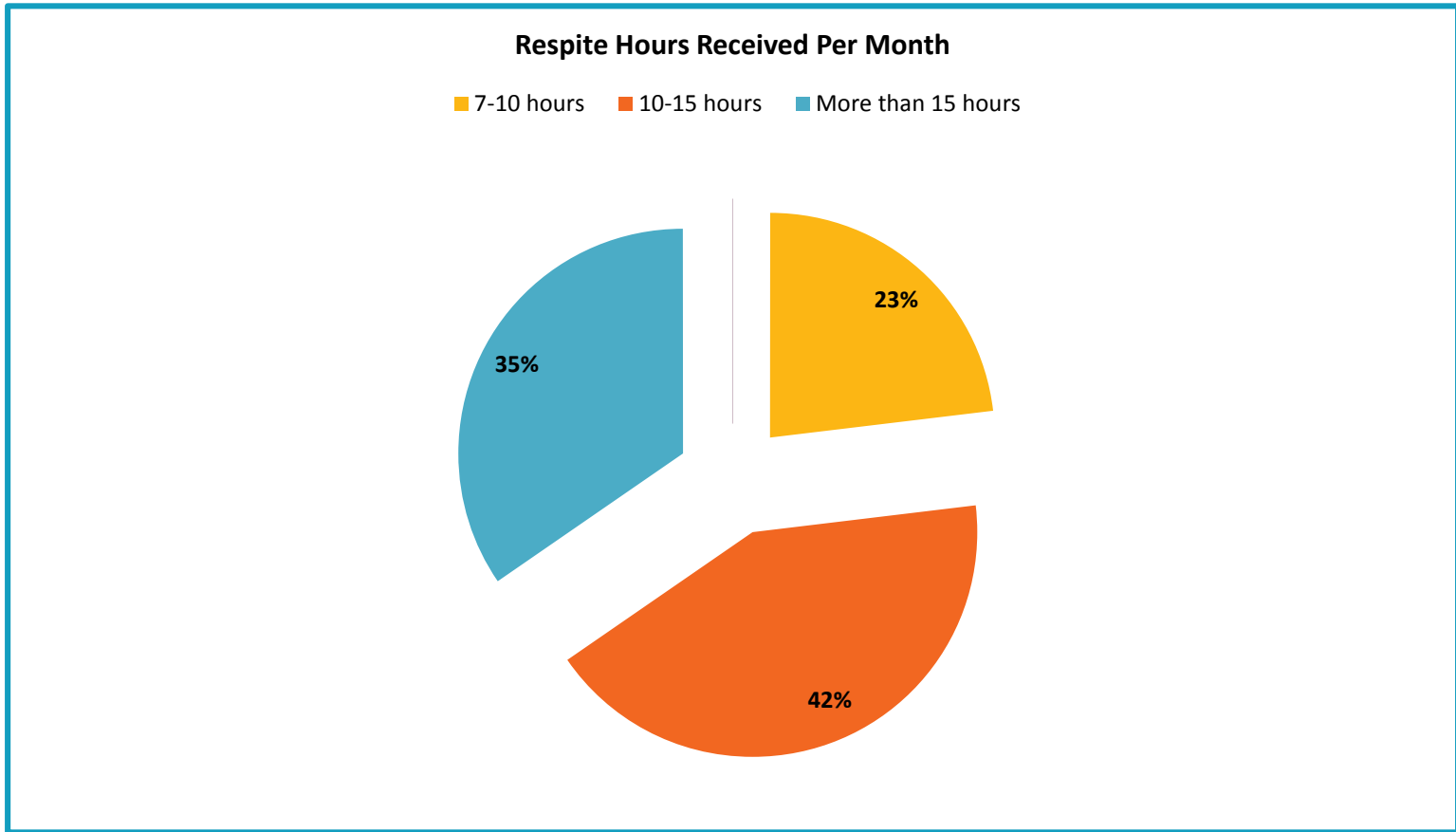
# Year One Evaluation Survey Results (Satisfaction)

N=26

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

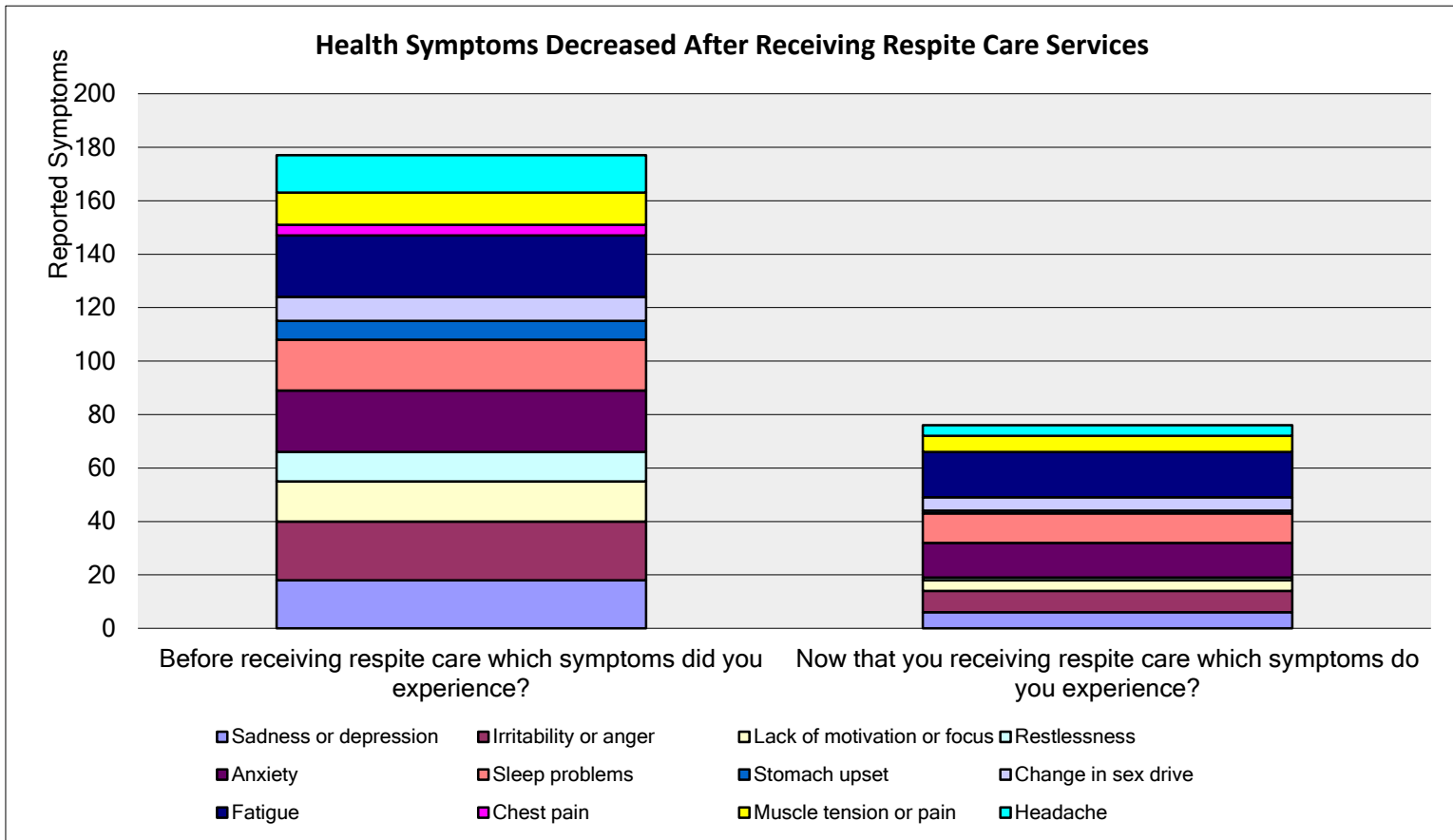
# Respite Hours Received

23% rated hours received as 'sufficient'



# Health Symptoms

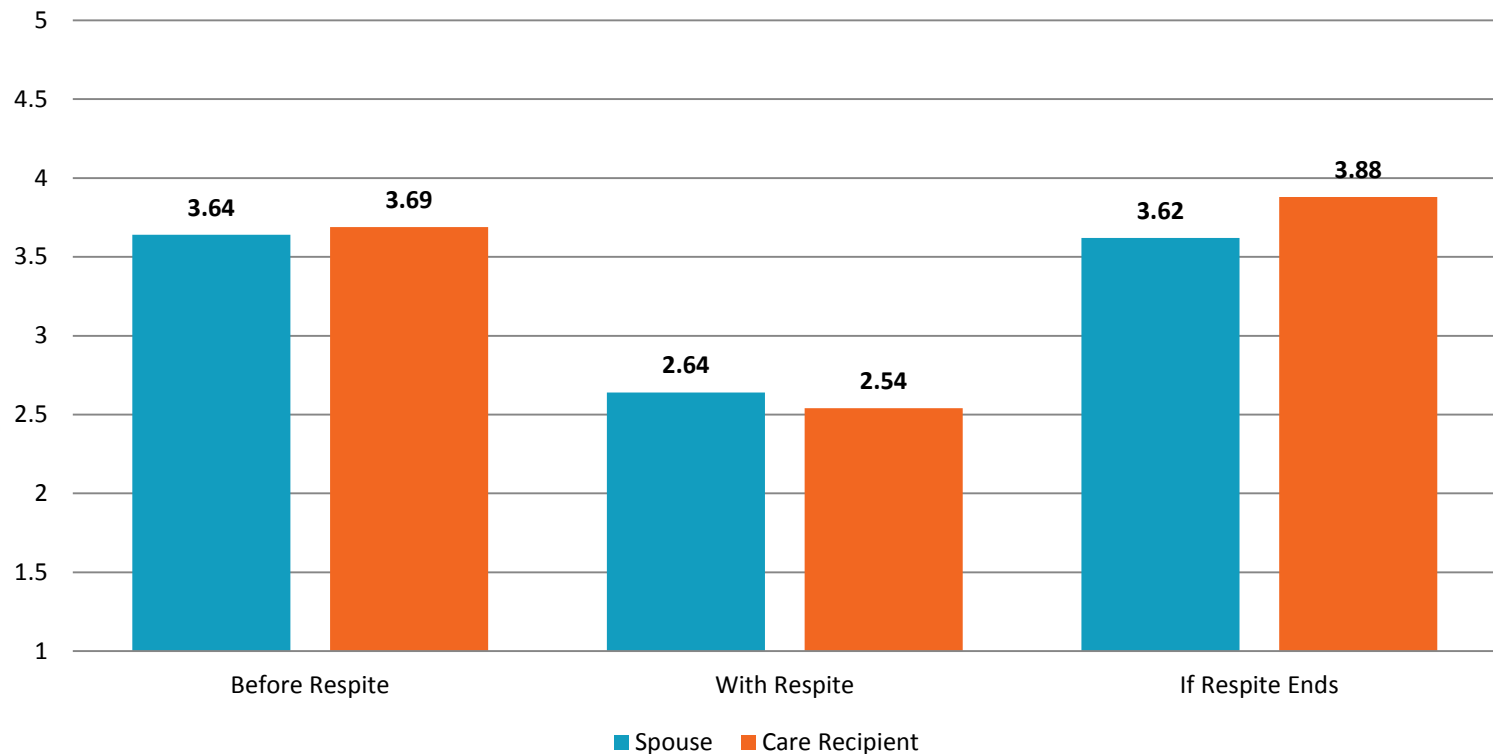
N=26



# Relationships

## Relationship Strain Decreased With Respite Services

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



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

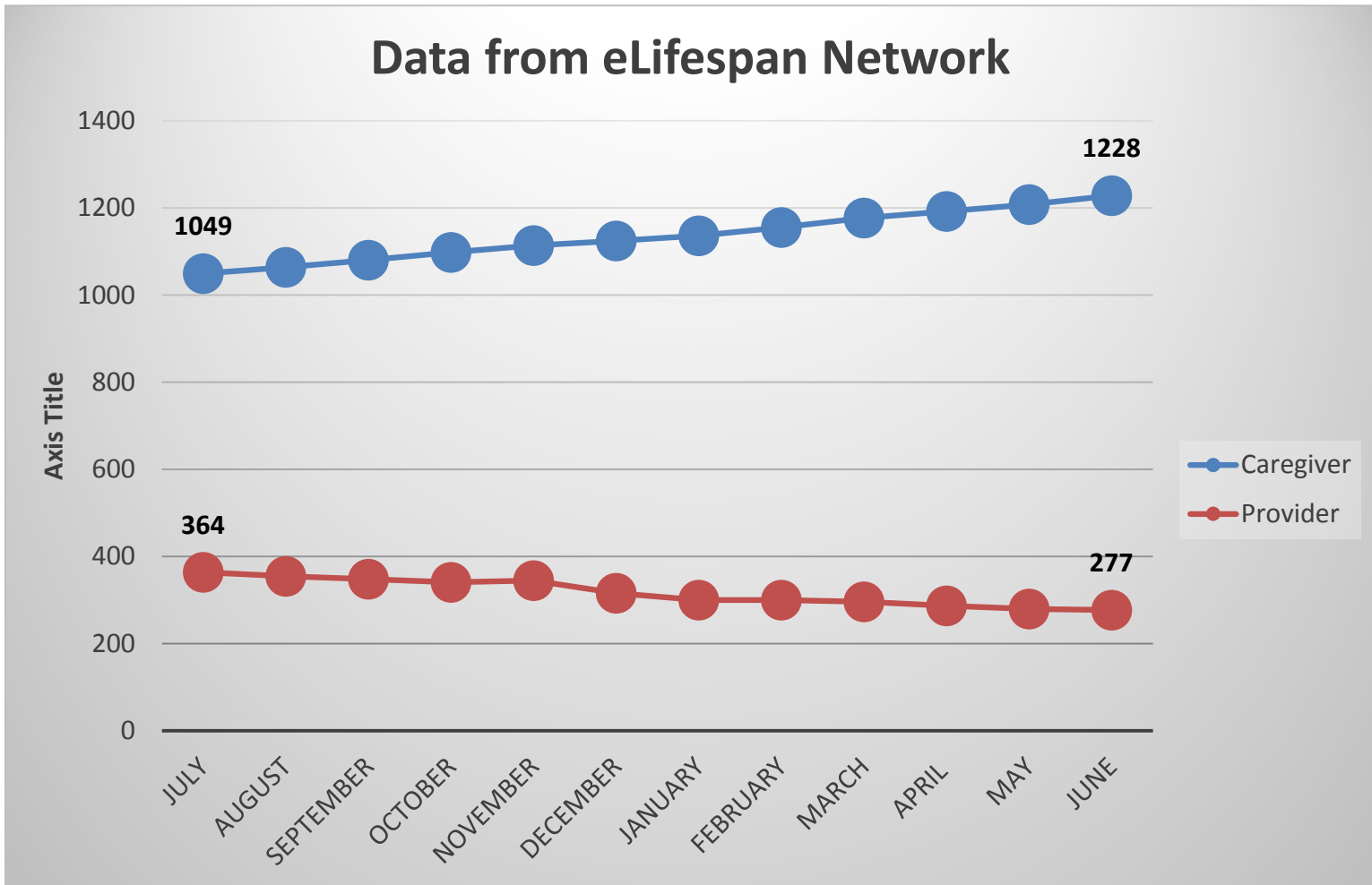
Data Dashboard

REST training follow-up (still collecting)

Employee Engagement Interviews (still collecting)



# Caregiver and Providers FY 2016



# 2016 Survey Respondents

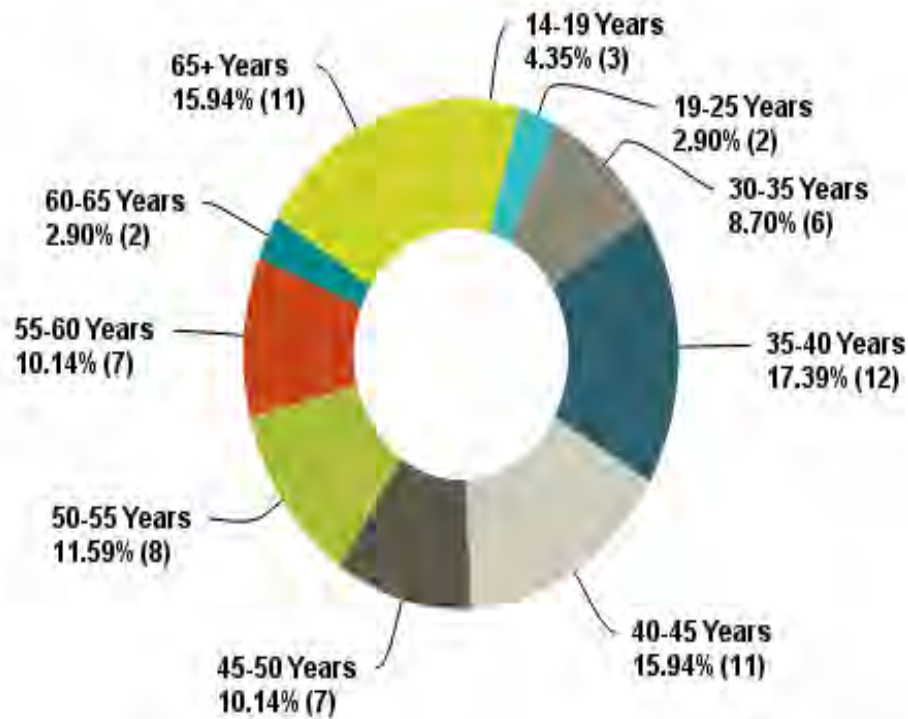
Family Caregivers

Respite Providers

Across multiple funding sources



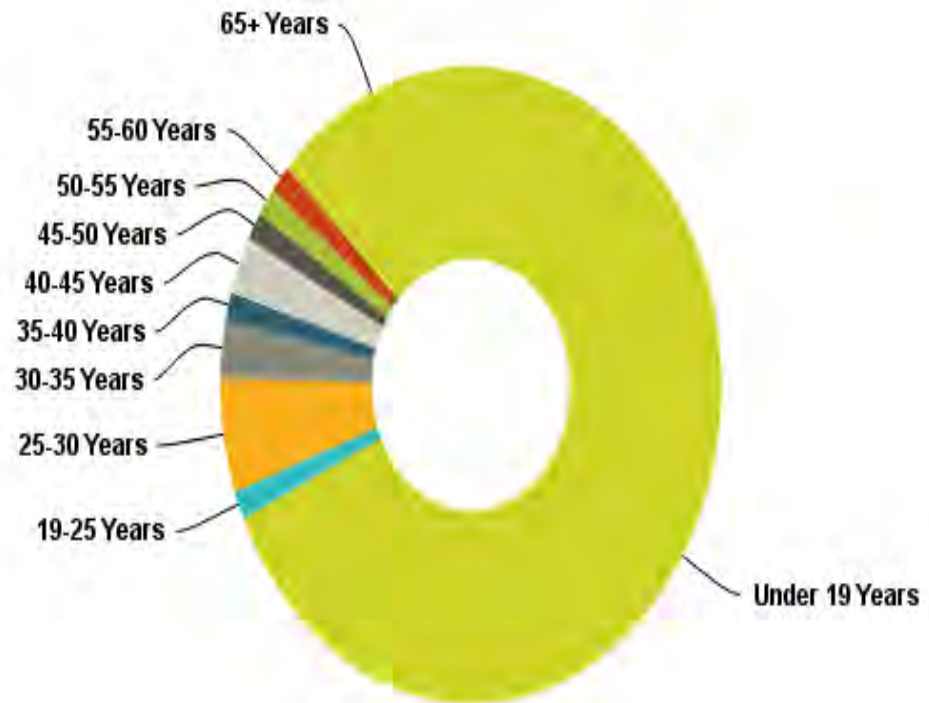
# Age of the primary Family Caregiver



Source: 2016 Family Caregiver Survey



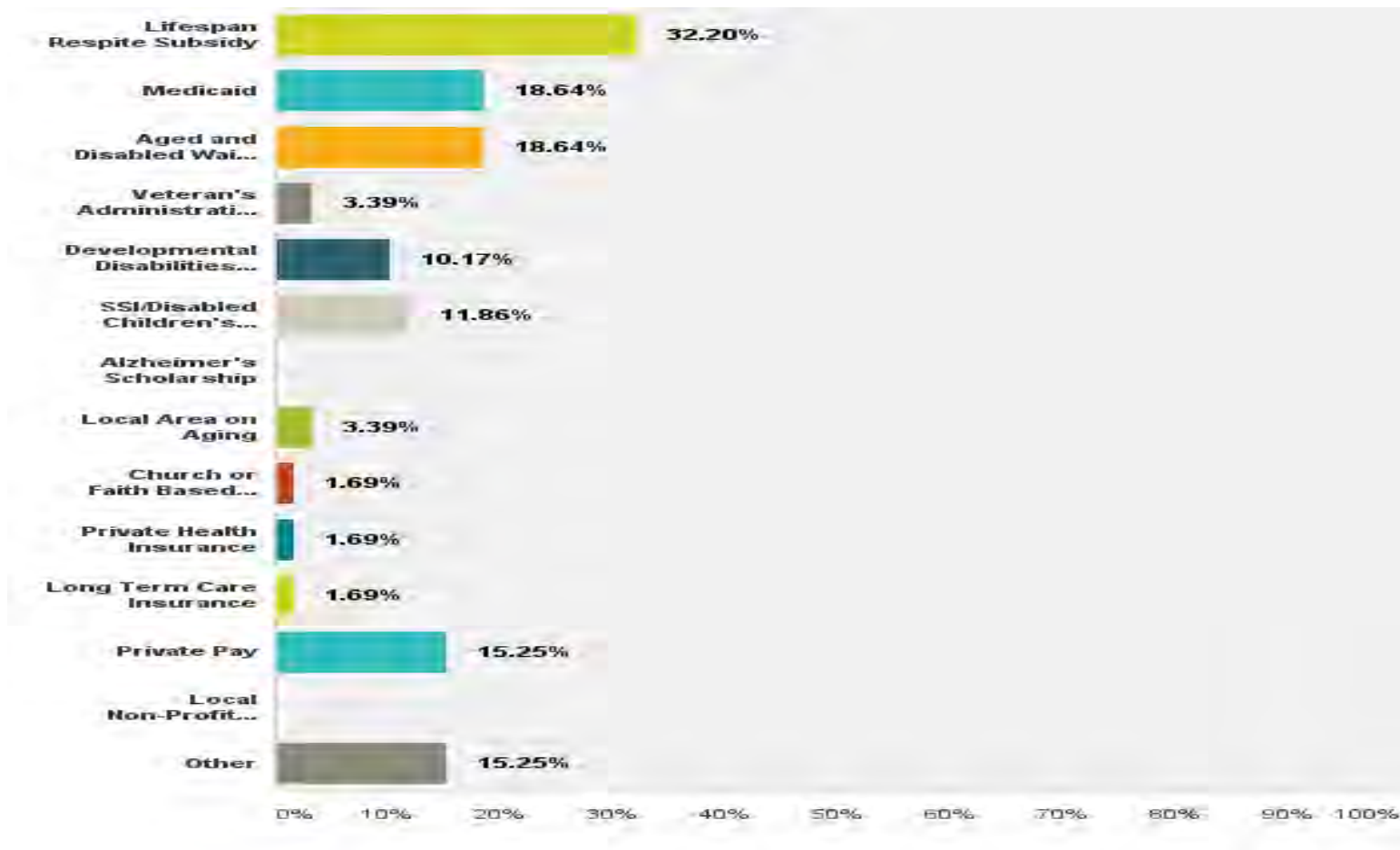
# Age of the primary care recipient



Source: 2016 Family Caregiver Survey



# My family receives respite care services through:

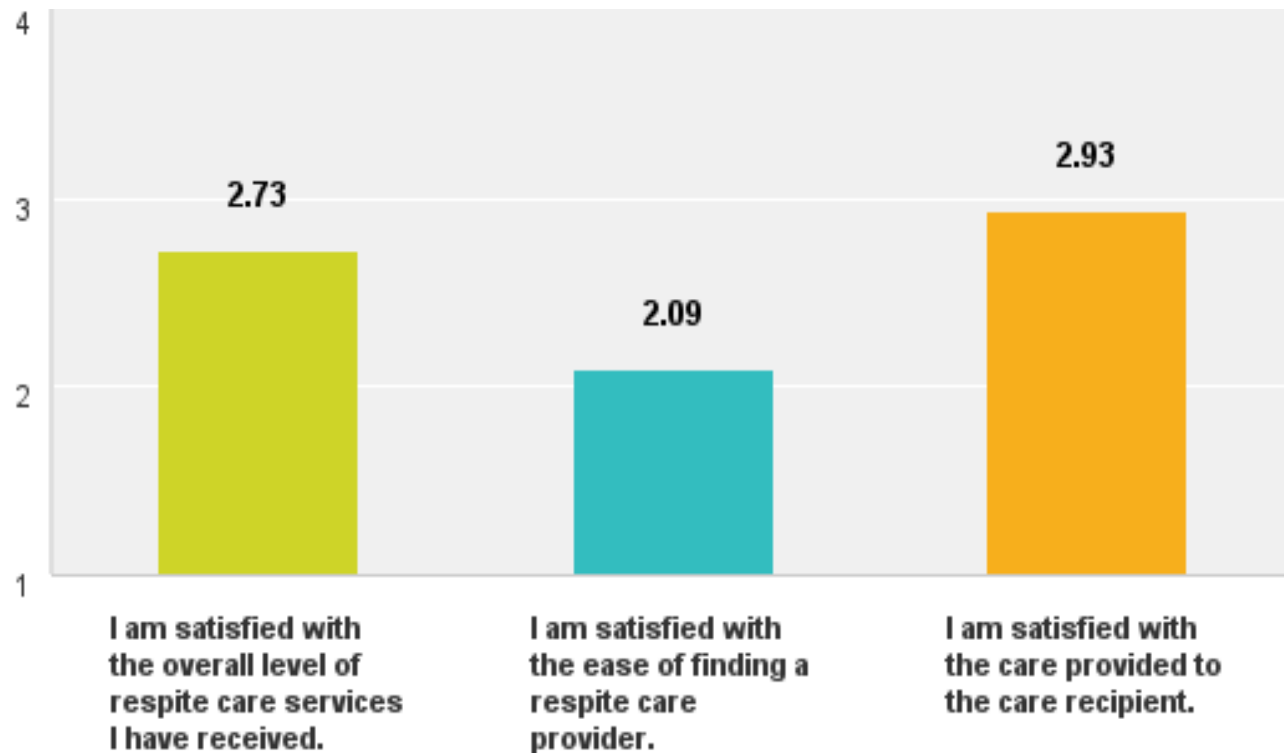


Source: 2016 Family Caregiver Survey



# Satisfaction with Respite

N=71

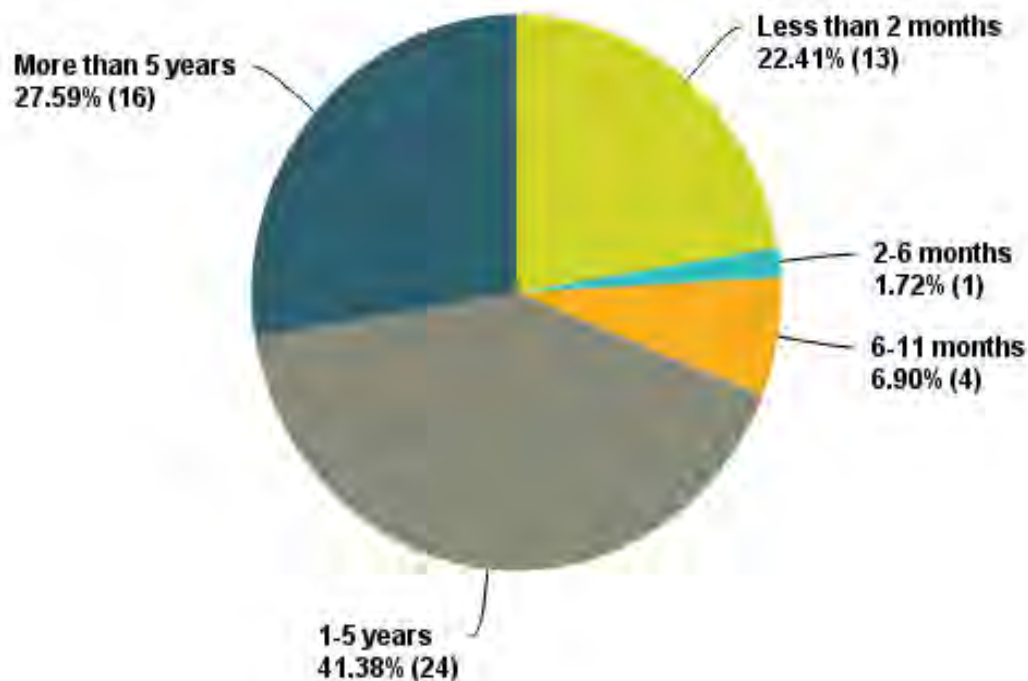


1=Strong Disagree to 4=Strongly Agree



Source: 2016 Family Caregiver Survey

# Length of Respite Service Received

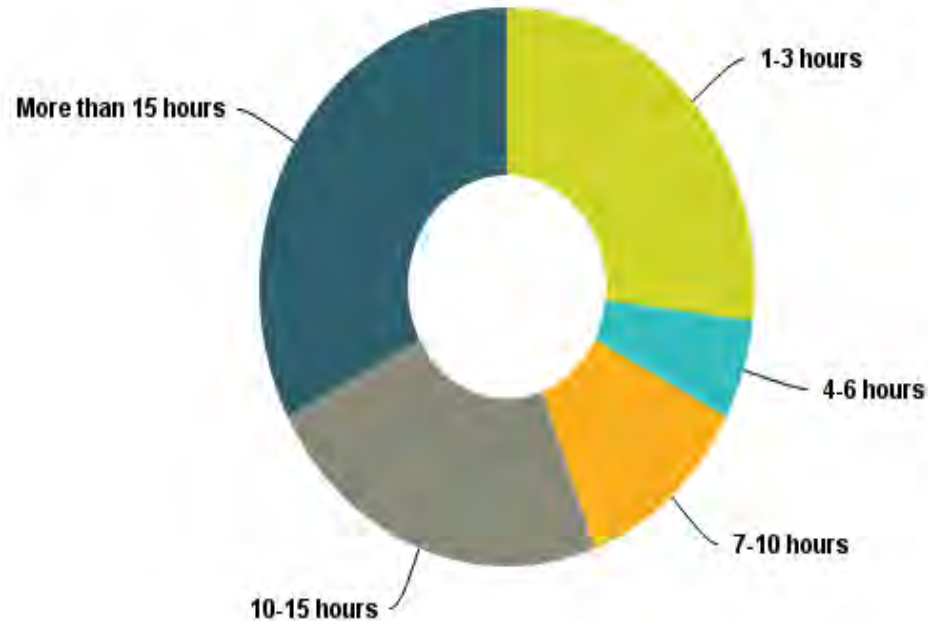


Source: 2016 Family Caregiver Survey





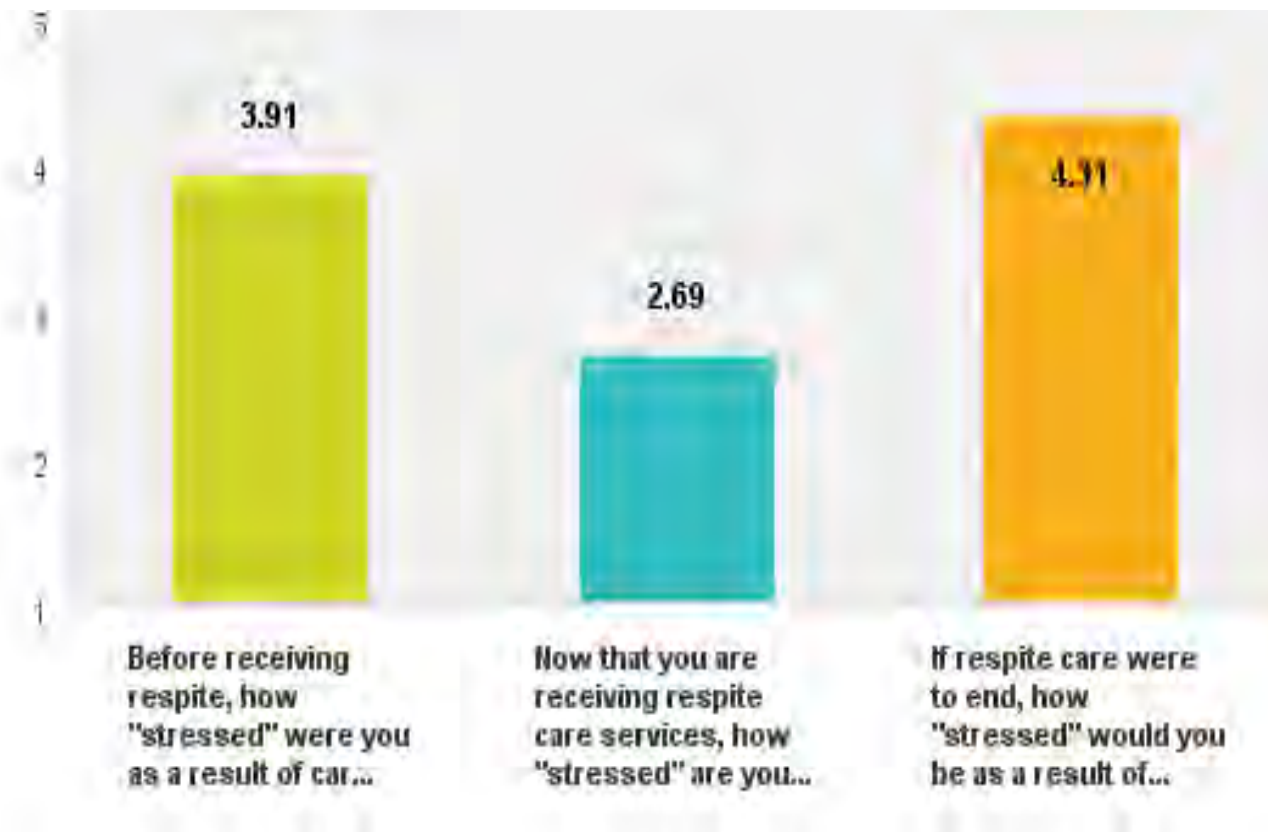
# Hours of paid respite care per month



Source: 2016 Family Caregiver Survey



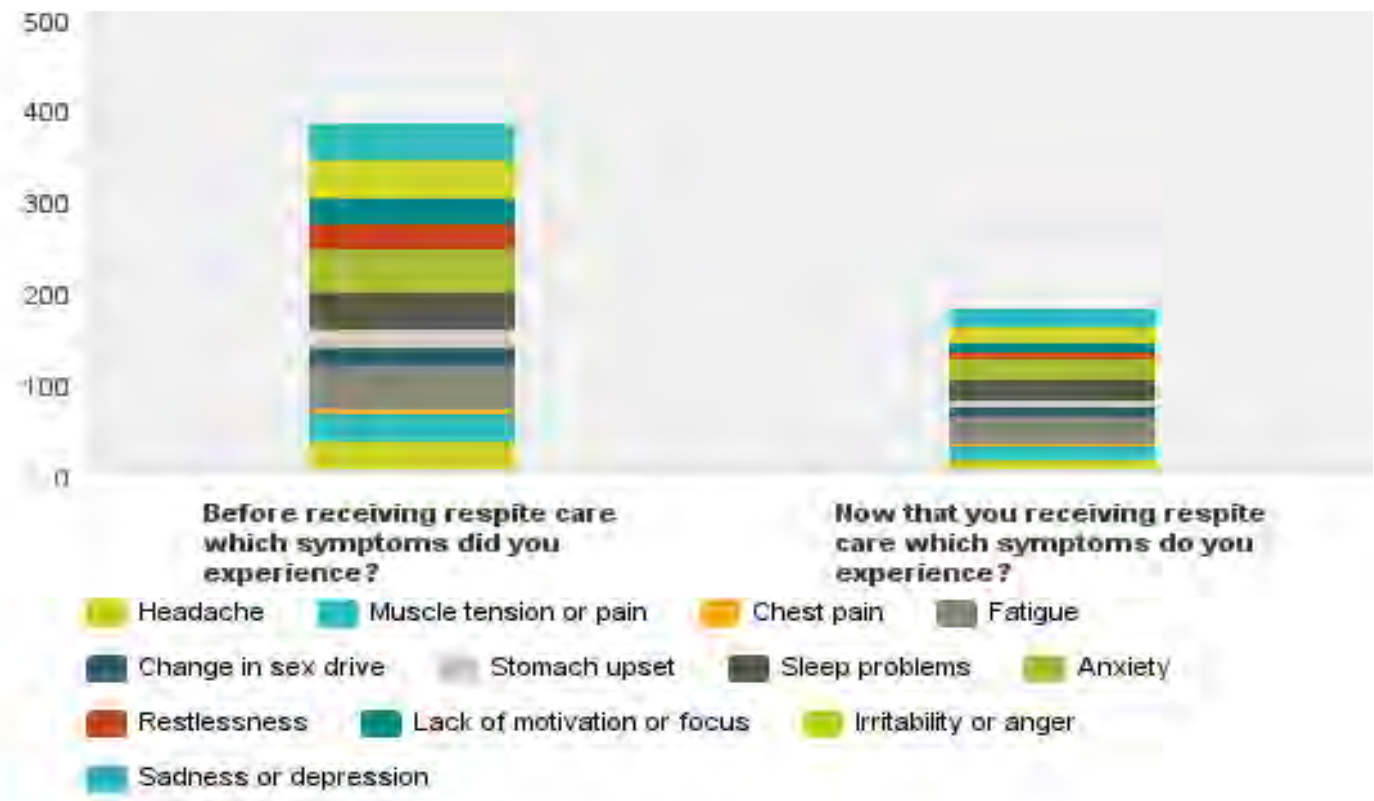
# Stress levels decreased for family caregivers when provided respite



Source: 2016 Family Caregiver Survey



# Health Symptoms Decreased for Family Caregivers

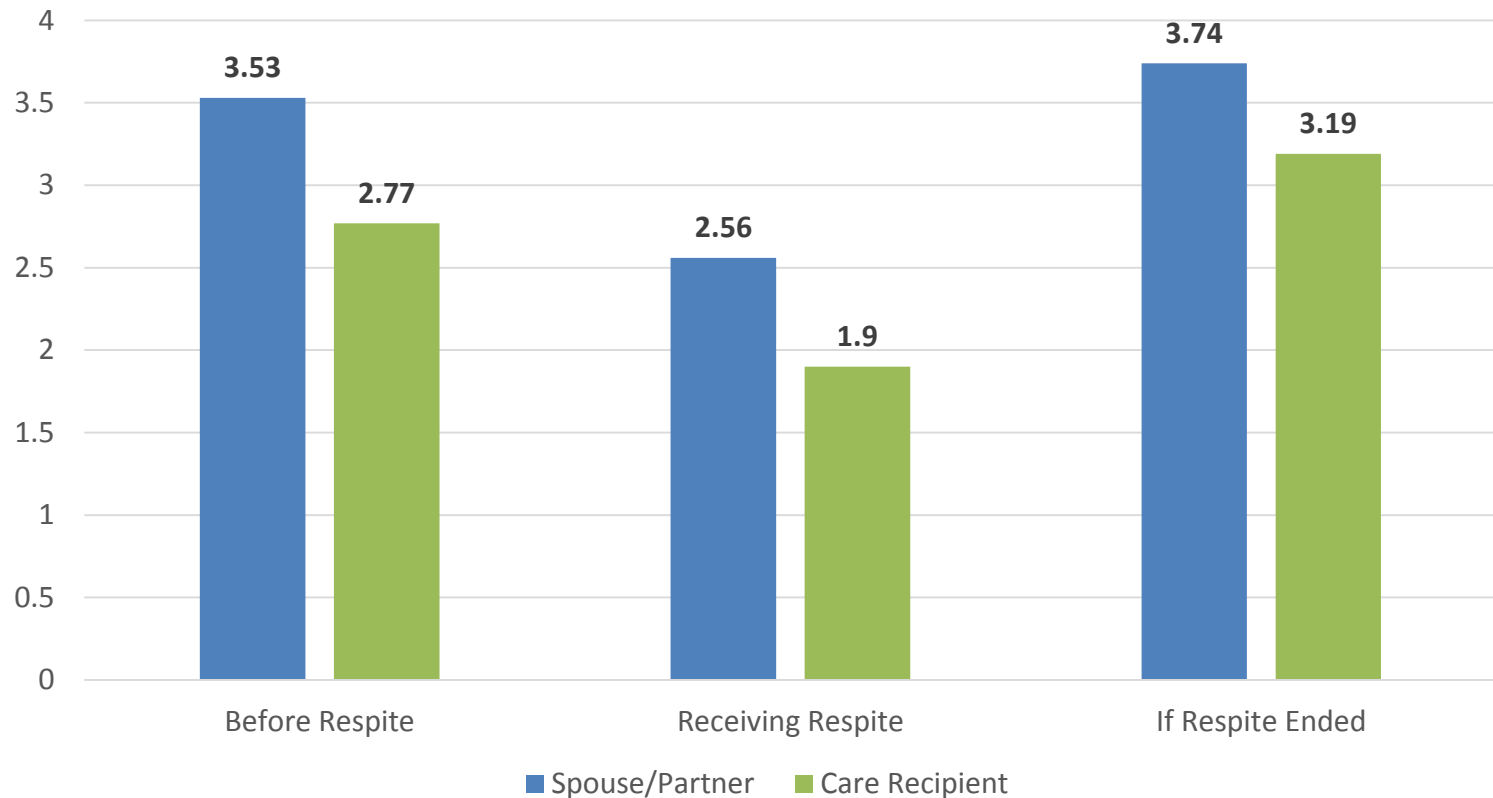


Source: 2016 Family Caregiver Survey

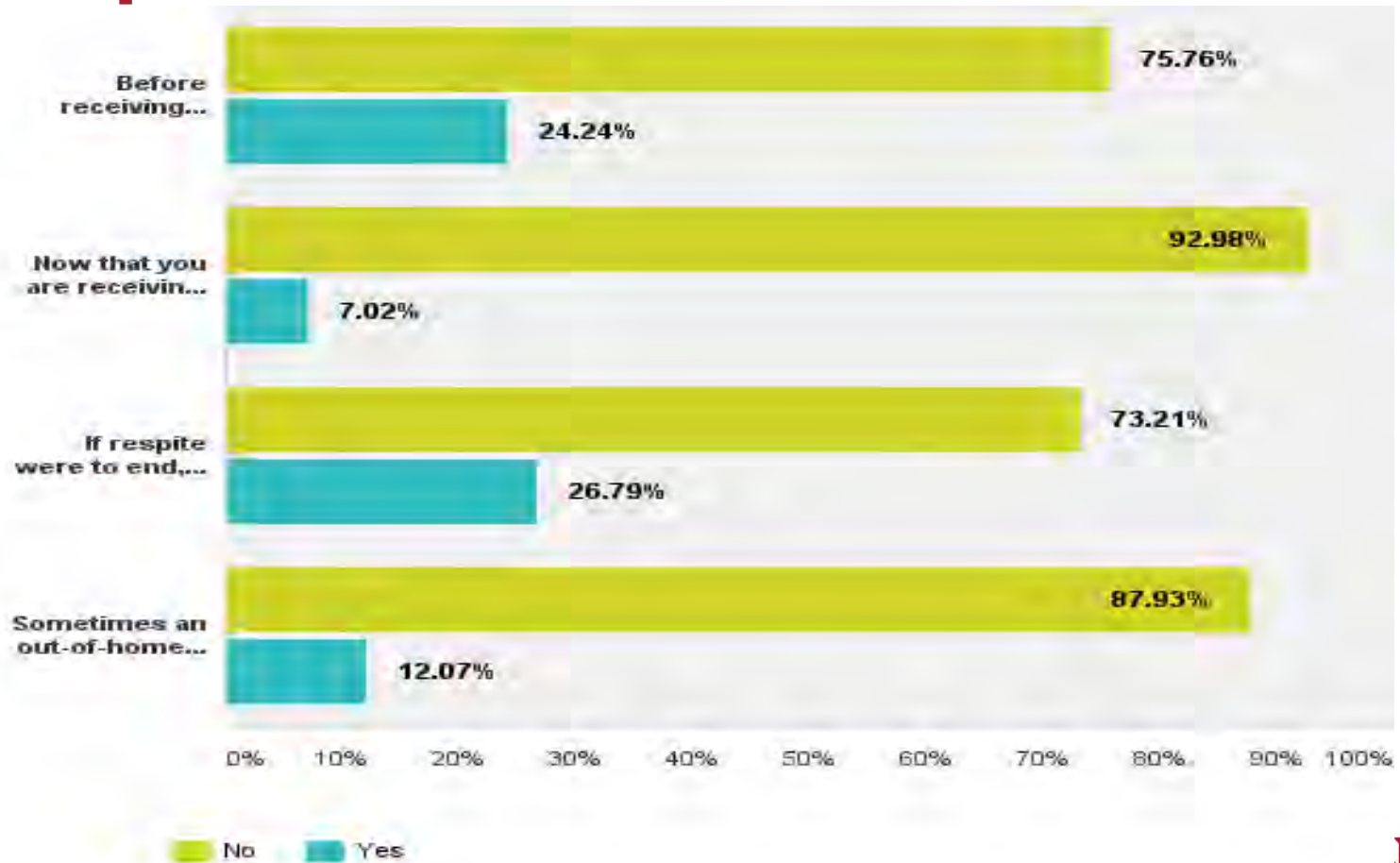


# Relationship Outcomes

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



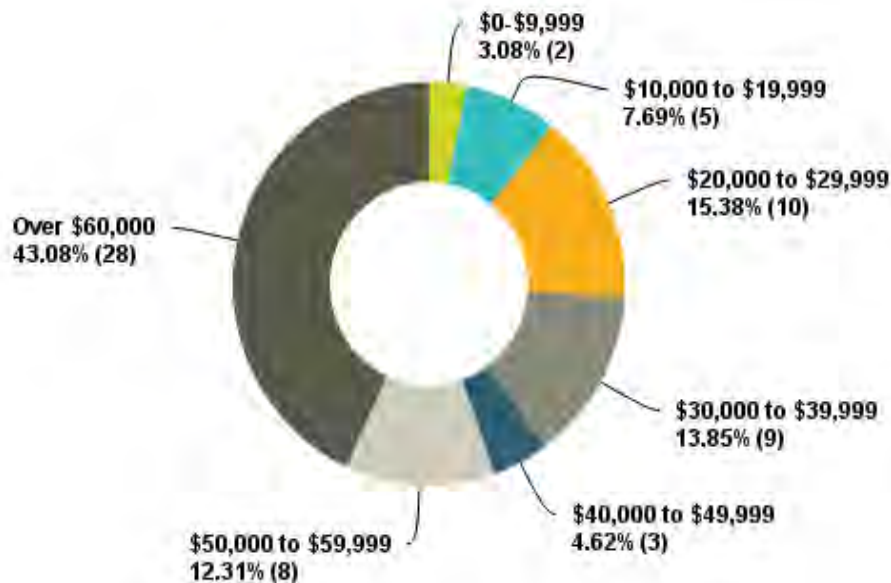
# Possible out-of-home placement consideration decreased with Respite.



Source: 2016 Family Caregiver Survey



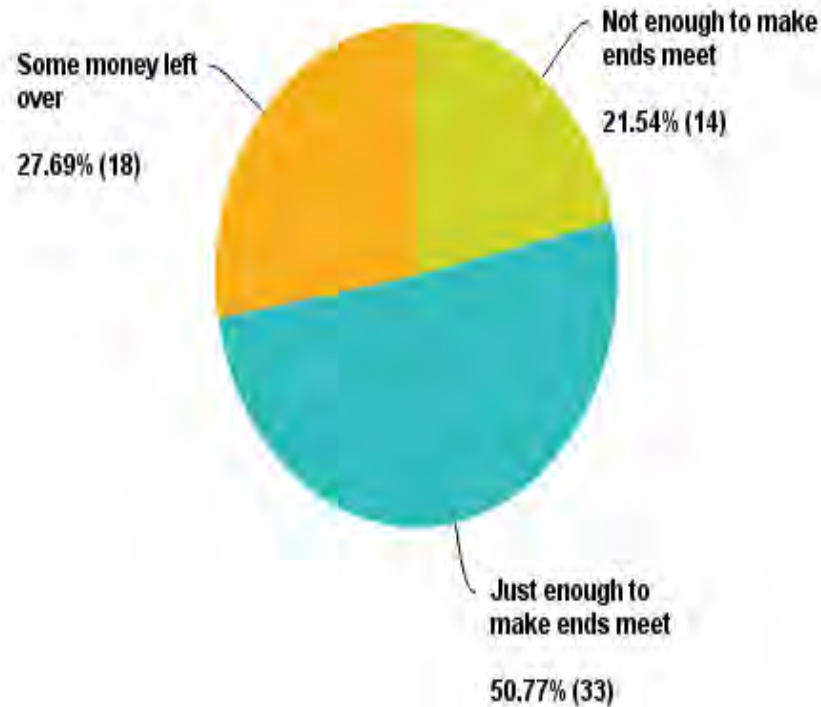
# Total annual family income



Source: 2016 Family Caregiver Survey



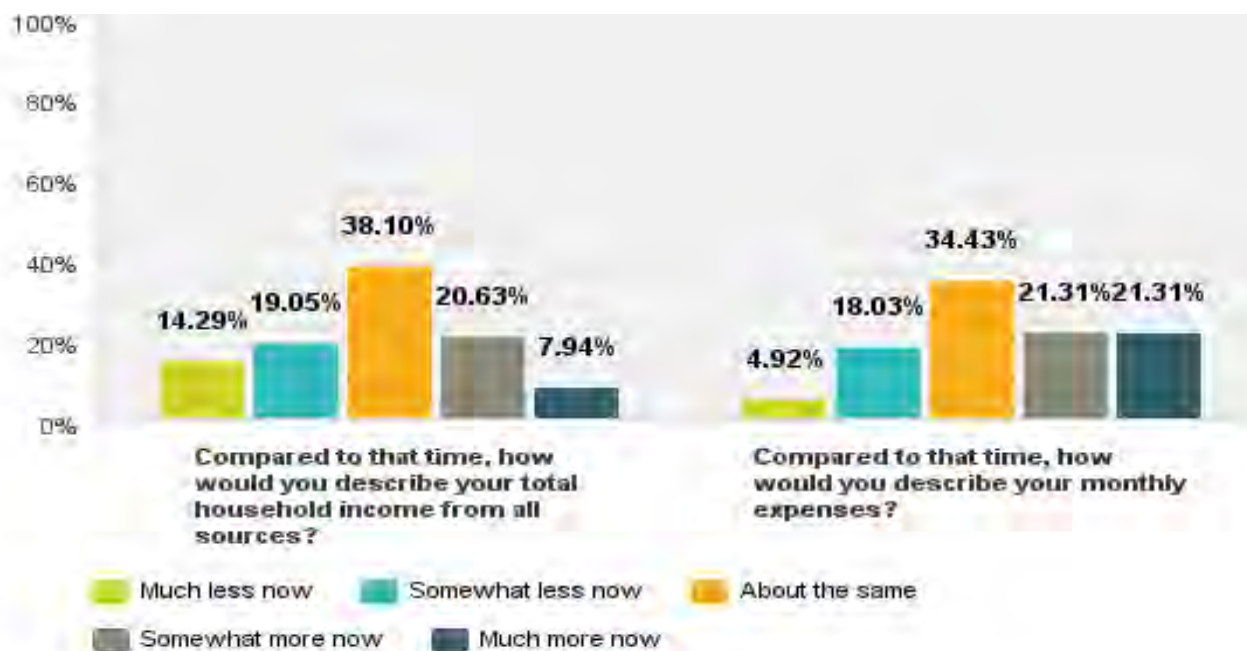
# In general, how do your family finances work out at the end of the month?



Source: 2016 Family Caregiver Survey



# Standard of Living and Expenses



Source: 2016 Family Caregiver Survey



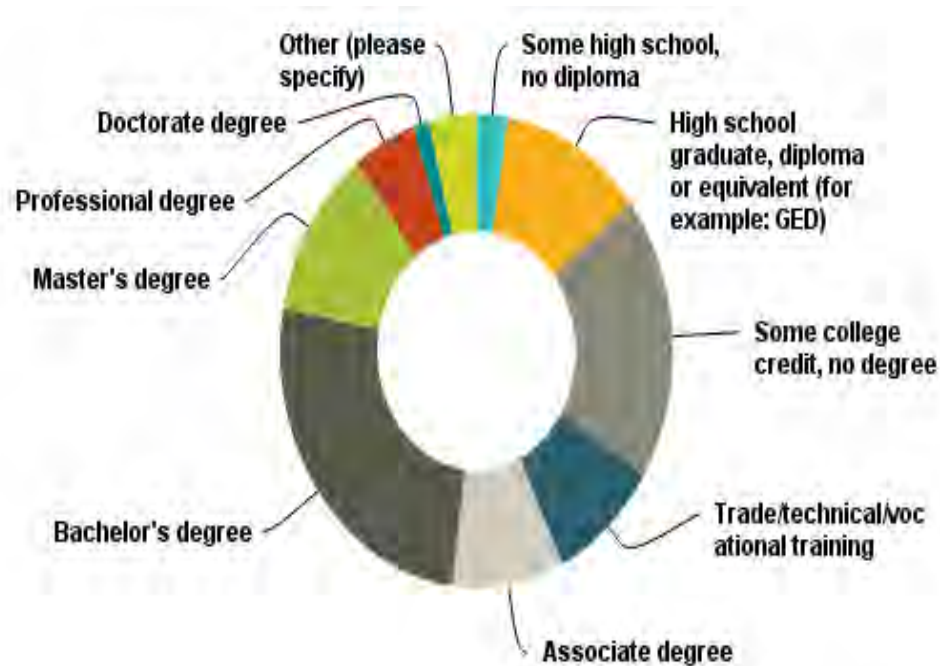


# Respite Care Providers

2016  
Survey Results



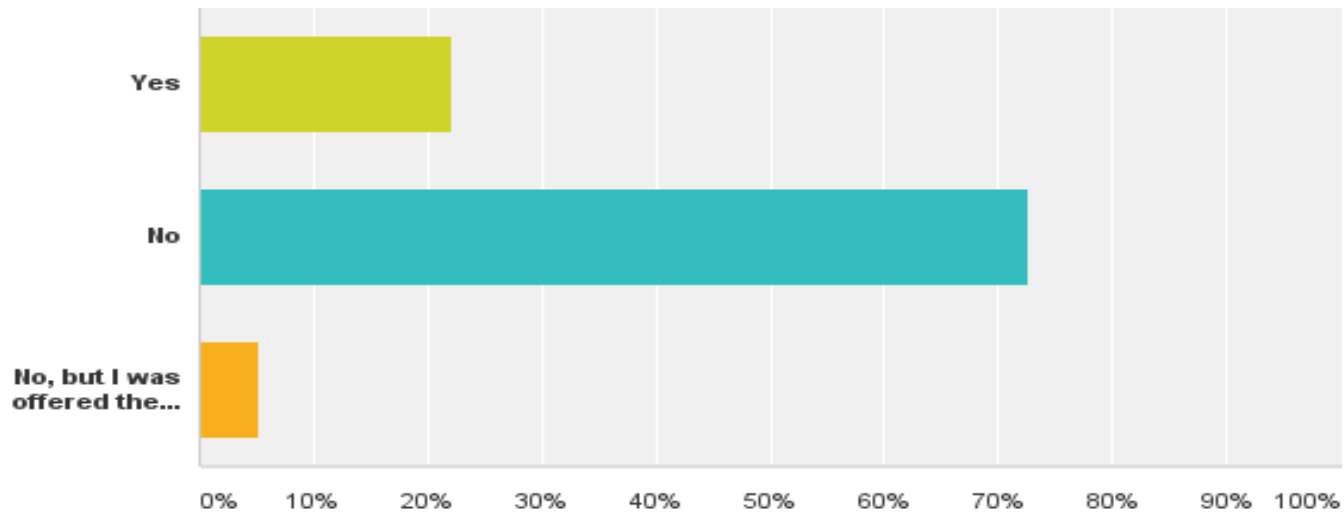
# Education Level



Source: 2016 Respite Provider Survey



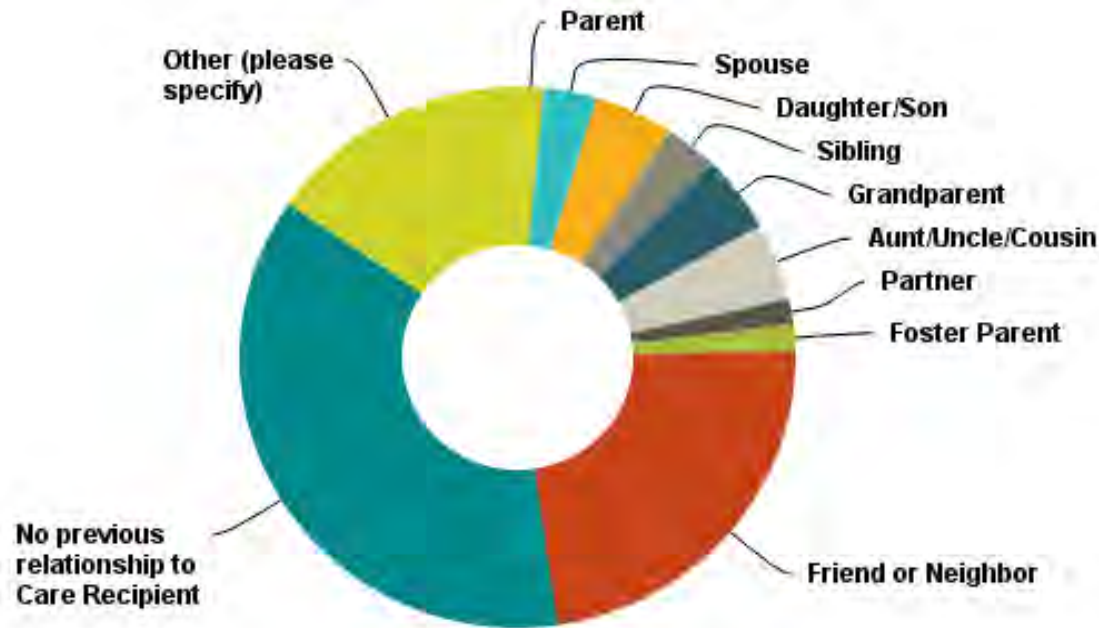
# Have you completed REST (Respite Education and Support Tools) training?



Source: 2016 Respite Provider Survey



# Relationship to the Care Recipient



Source: 2016 Respite Provider Survey



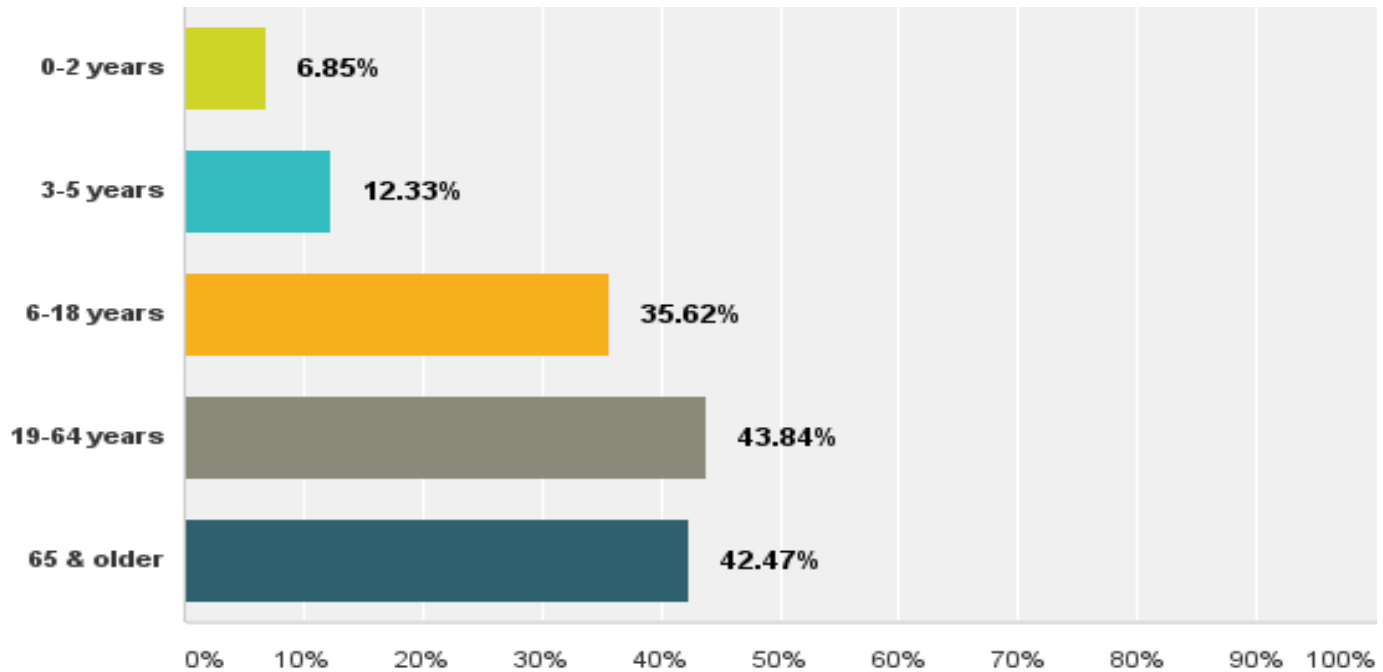
# How long have you been providing respite services?



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%)

Medical Needs (27%)

Developmental Disabilities (40%)

Chronic Illness (27%)

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

Intellectual Disabilities (26%)

Frail Elderly (30%)

Autism Spectrum Disorders (26%)

Behavioral/Emotional Needs (30%)

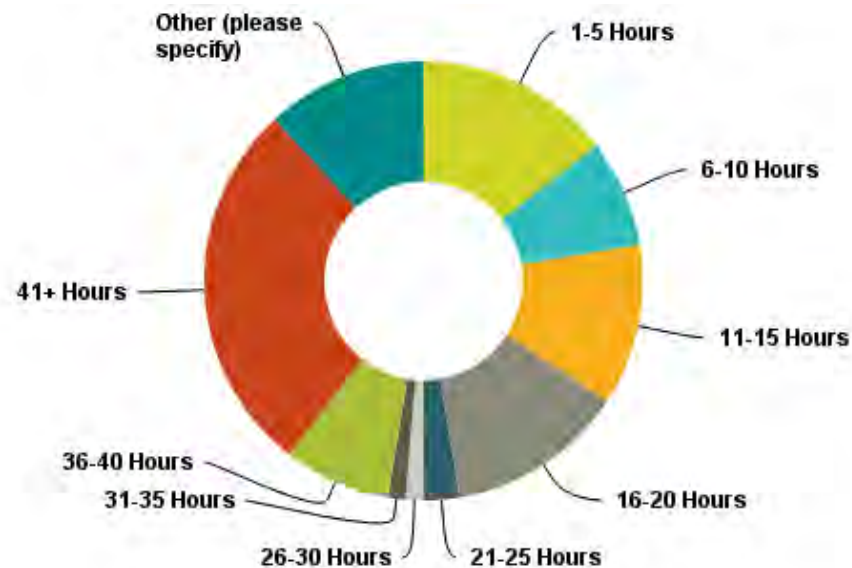
Limited or Non-mobile (22%)

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



# 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:

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