

Engaging Employers in Respite and Caregiver Support

ARCH Webinar

July 11, 2019



Presenters



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The Employed Caregiver Survey: A tool for understanding the scope and needs of employees with caregiving responsibilities

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Objectives

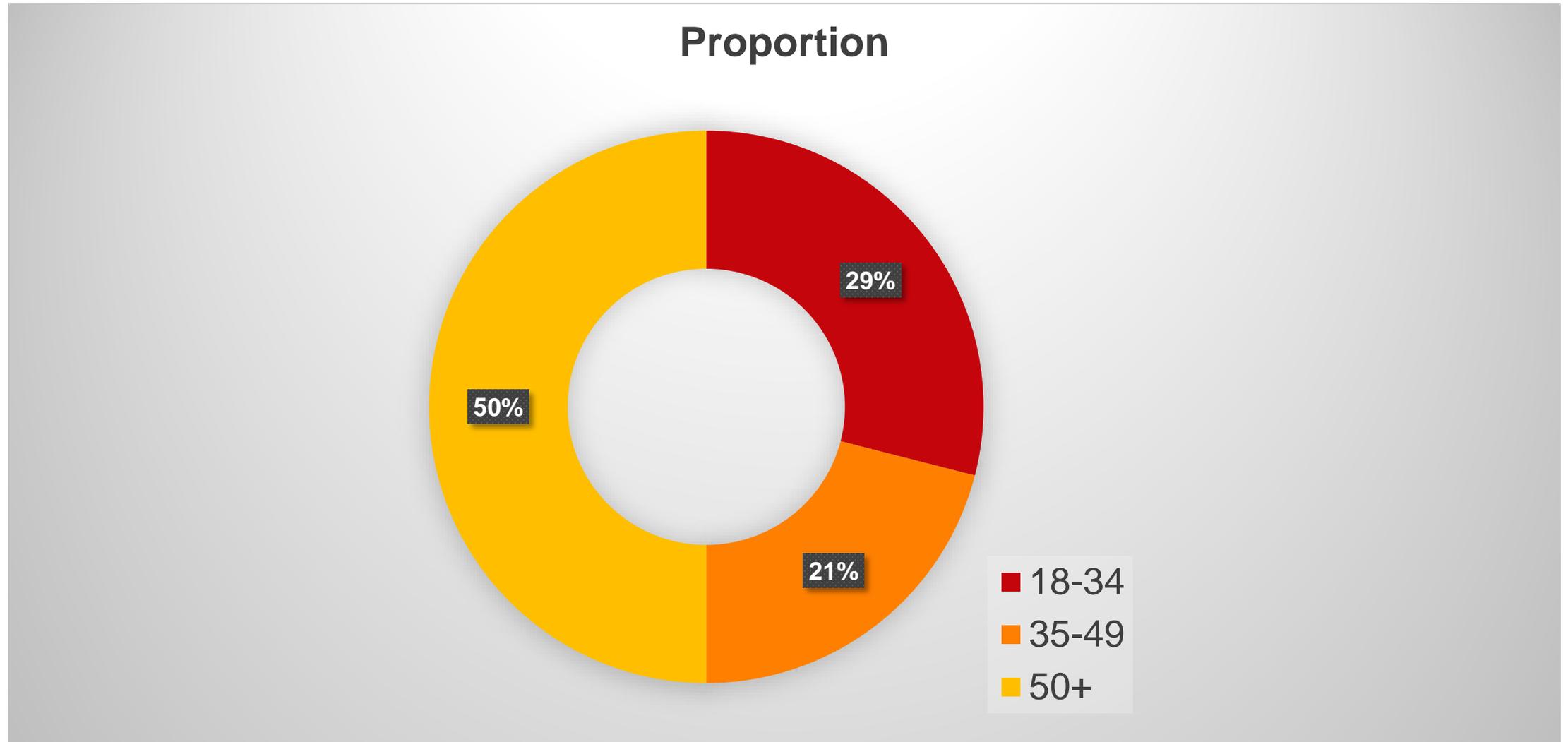
- Describe the prevalence of caregiving among workers
- Recognize the impacts of caregiving on employees and employers
- Discuss the Employed Caregiver Survey as a tool to understand and act on the needs of caregiving employees

Employed Caregivers

- ~ 40 million US adults are caregivers
 - 60% (~24 million adults) also work a paying job
- On average, at or near full-time level employment (34.7 hours/week)
- One in four provide more than 21 hours of care/week

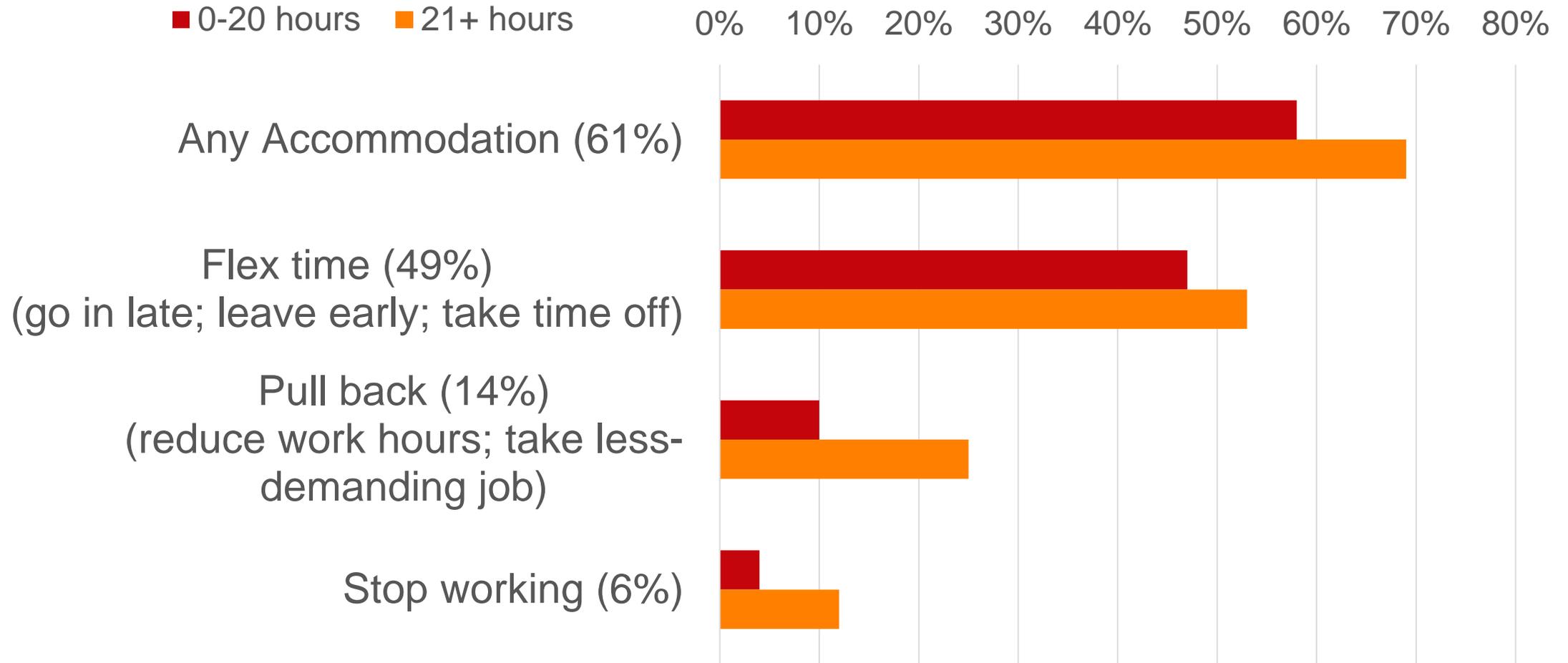
Source: Feinberg, L.F., 2016. *The dual pressures of family caregiving and employment*. Washington (DC): AARP Public Policy Institute.

Employed Caregiving Spans Age-groups



Source: Feinberg, L.F., 2016. *The dual pressures of family caregiving and employment*. Washington (DC): AARP Public Policy Institute.

Most (61%) make some kind of work place accommodation



Adapted from: Feinberg, L.F., 2016. *The dual pressures of family caregiving and employment*. Washington (DC): AARP Public Policy Institute.

Failing to support caregiving employees has consequences for employers

- E.g., increased absenteeism, unplanned absences, increased employee turnover, decreased employee retention, productivity loss and increased disability costs
- Example from Canada, 2012:
 - 9.7 million days of absenteeism
 - 256 million fewer hours of paid work
 - Loss of 557,698 employees from the paid labor force

Sources: Ireson et al. 2018. Availability of caregiver-friendly workplace policies (CFWP s): an international scoping review. *Health & social care in the community*, 26(1), pp.e1-e14.; Fast et al. 2014. *Combining Care Work and Paid Work: Is It Sustainable?*. Research on Aging, Policies and Practice (RAPP), Edmonton

Caregiver-friendly workplace policies

- May include:
 - flexible work arrangements;
 - support and referral services;
 - educational opportunities;
 - more extensive supports (e.g., case management; adult day care facilities)

- Beneficial outcomes for employer and employee, e.g.,:
 - Increase employee retention/decrease turnover
 - Reduce absenteeism
 - Decrease stress and role conflict

Purpose of the employed caregiver survey

- Help employers understand the prevalence and needs of their employees who have caregiving responsibilities
- Opportunity to enhance and/or better disseminate caregiver-friendly policies and supports

The Employed Caregiver Survey

- Administered to an organization's employees via UW-Madison
 - Survey request form
 - Employer receives anonymous survey link to distribute
 - Survey is open for up to 6 weeks
- 20 items (~10 minutes)
- Employer receives aggregate report

Employers get information on:

- Proportion of respondents who have caregiving responsibilities
- Distribution of types and intensity of caregiving (e.g., tasks, hours/week)
- Impacts on work (e.g., arrive late/leave early; feeling unfocused; turned down promotion)
- Topics about which they want more information

Example: Acme Widget Corporation (AWC)

- 65% of respondents were caregivers
- Most common activities:
 - Driving to appointments (56%)
 - Home maintenance, repairs, yard work (51%)
- Significant subset engages in intensive care tasks:
 - Personal care (bathing, feeding): 23%
 - Assisting with medications (19%)
- 44% were the primary caregiver
- Work impacts in the past year
 - Two-thirds left work early to provide care
 - 54% missed days of work
 - 50% unable to focus
 - 13% turned down work-related travel
 - 13% considered changing employer
 - 16% considered leaving work entirely
- Topics they'd like to learn more about
 - 50% caregiving benefits offered through employer

Facilitating employer self-reflection

- Response to the report
 - Was the number of employee caregivers higher or lower than expected?
 - Increase employer's awareness of issues faced by caregiving employees?
 - Change awareness of the work-related impacts of caregiving?
- Checklist of workplace supports
 - Offered?
 - How often used?
- Intentions
 - Offer additional workplace supports
 - Provide caregiving information

Connecting employers and caregivers with resources

- <https://fyi.extension.wisc.edu/balancingcare/home/>
 - Videos
 - Blog posts
 - Success stories
 - Resources

What's next

- Updating the resources
- Connecting with other initiatives
- Continuing to connect the dots for employers and employed caregivers

Questions?

Learn more:

[https://articles.extension.org/pages/27975/
employed-family-caregiver-survey](https://articles.extension.org/pages/27975/employed-family-caregiver-survey)

Contact me: Litzelman@wisc.edu

Nebraska's Respite Employer Engagement Initiative



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Helping People Live Better Lives.

Respite Employer Engagement Initiative Presenters



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Respite Employer Engagement Development

- ACL Respite Grant 2015 Pilot Project initiated
- Nebraska Department of Health and Human Services wanted to address respite needs for working family caregivers
- University of Nebraska Medical Center (UNMC) and Nebraska Medicine lead the way as major employers in Omaha

Respite Employer Engagement Development

- Pilot Project Goals:
 - Prepare employers for the aging of the baby boomer population;
 - Create a way for employers to provide respite resources for working caregivers when needed; and
 - Develop a replicable model for employers across the state and nation.

UNMC/Nebraska Medicine Respite Projects

**3 year grant with the Administration for Community Living
and contracted through Nebraska DHHS**

- Respite Evaluation**
- Employer Engagement**
- College Curriculum**

**University of Nebraska
Medical Center**



**Nebraska
Medicine**

Family Caregiving in the U.S.

- 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.

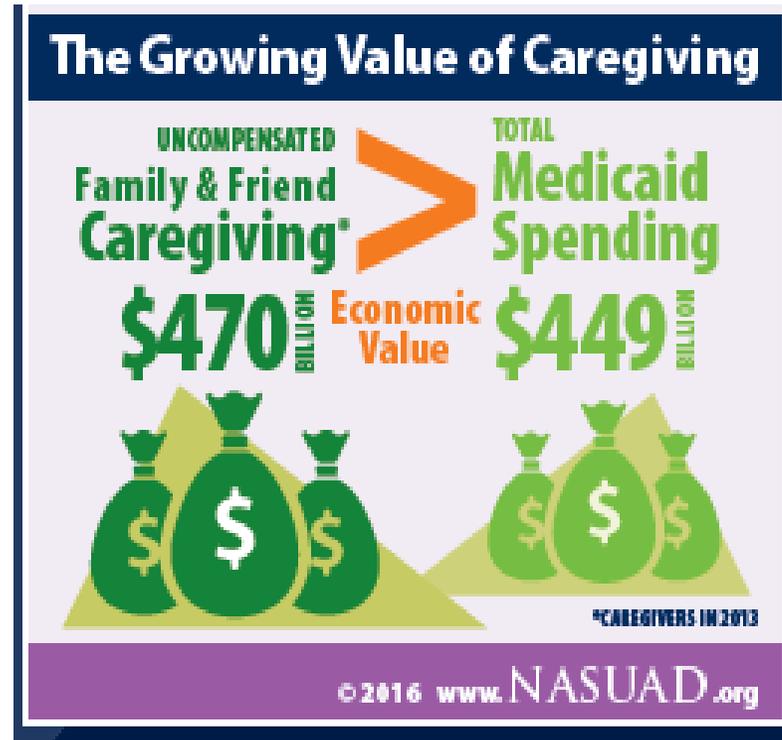


Sources: 1) National Alliance for Caregiving and AARP Public Policy Institute
Caregiving in the US 2015
2) Congressional Budget Office (2013)
Rising Demand for Long-Term Services and Supports for Elderly People

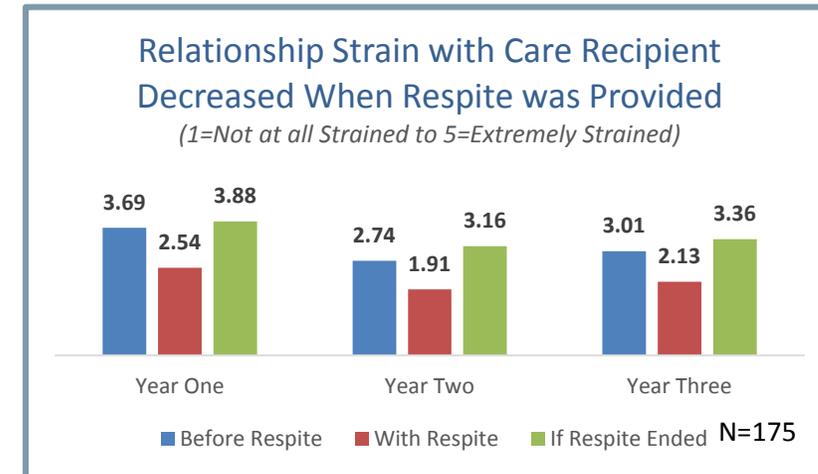
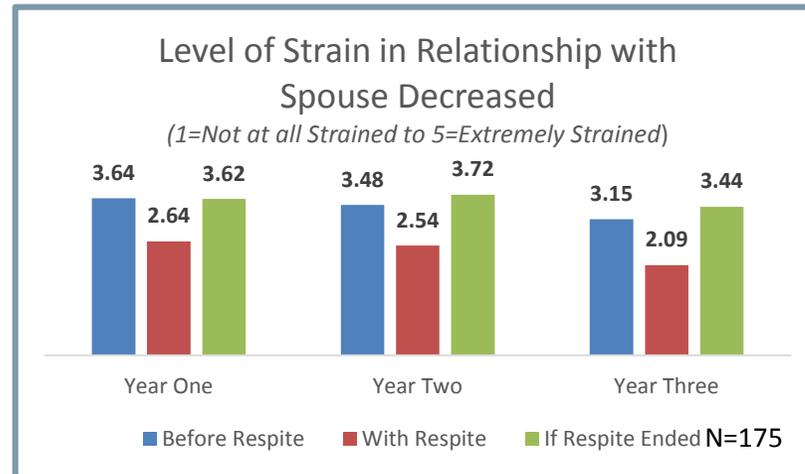


Background:

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



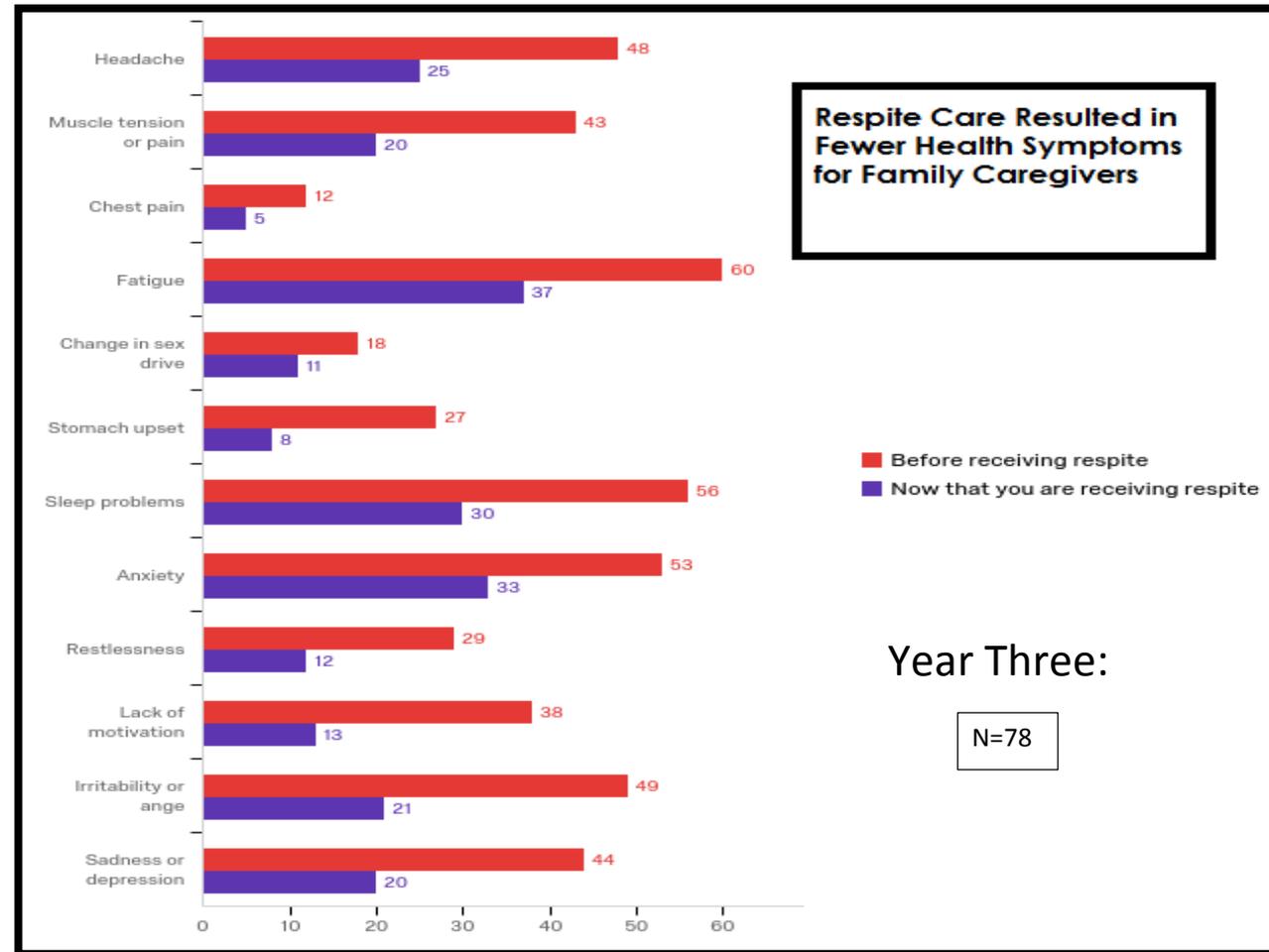
Nebraska Evaluation: Respite Decreases Caregiver and Care Recipient Stress



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



Nebraska Evaluation: Respite Improves Caregiver Health

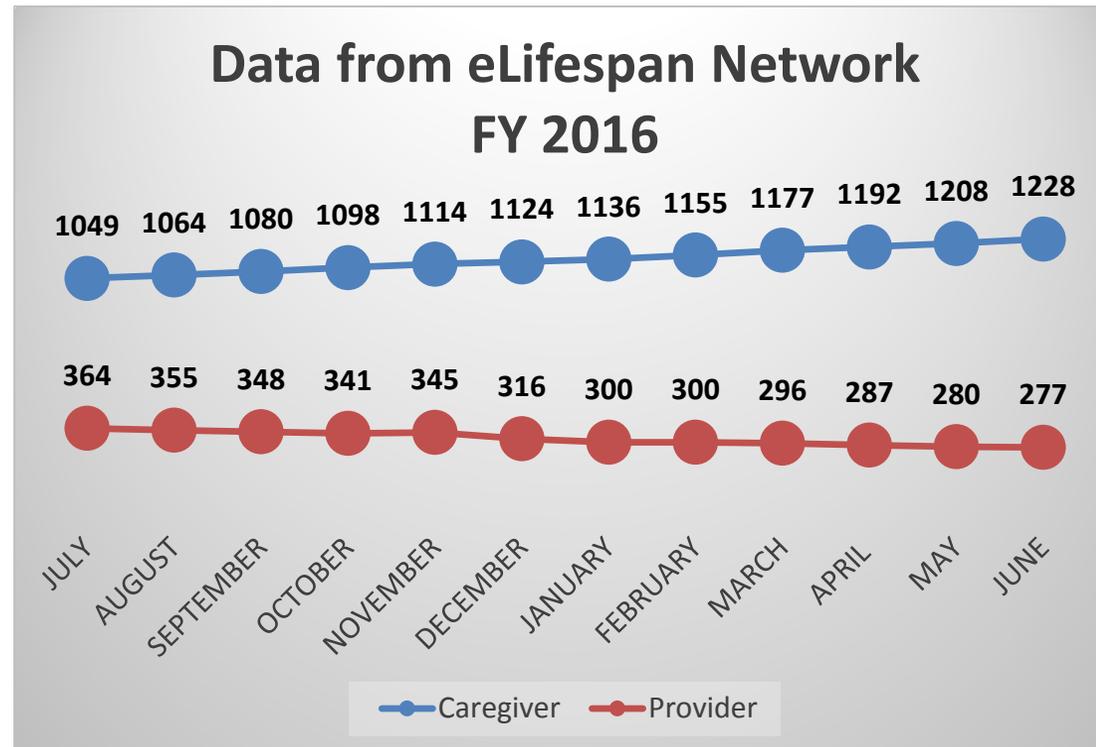


Source: Dr. Jolene Johnson, UNMC/MMI Respite Evaluation 2016-2017



Nebraska Evaluation:

Increasing Caregivers vs. Decreasing Providers



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



Caregiver Support Ratio

Year	Person in Need of LTSS	Number of Caregivers Available
2010		
2030		
2050		

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'



Employer Role

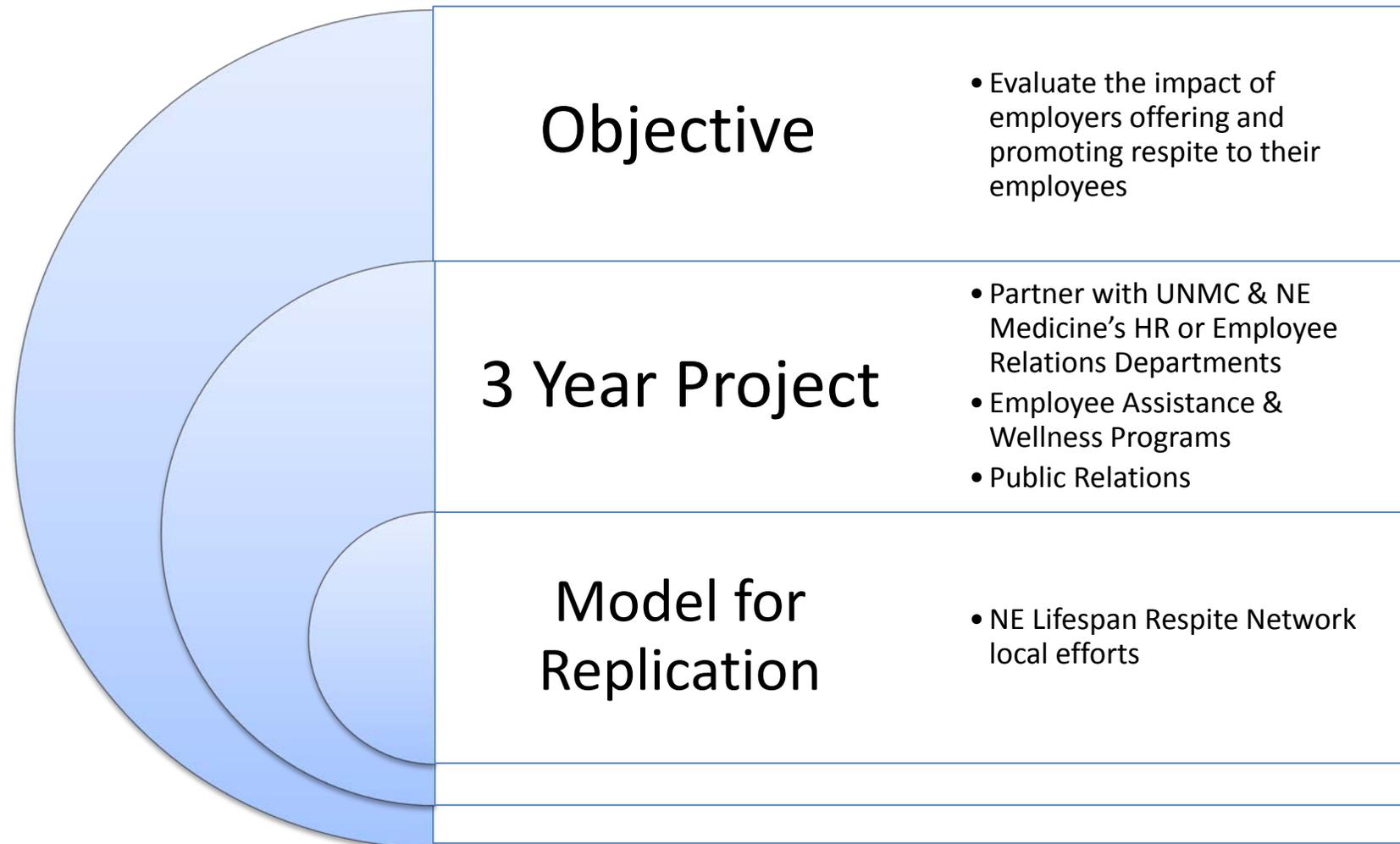
- Employers need to recognize their role in supporting working family caregivers

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.

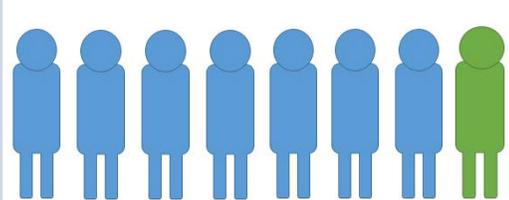
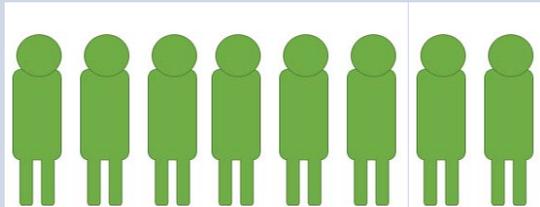
(AARP, 2015)



UNMC/Nebraska Medicine Respite Employer Engagement Pilot



Respite Employer Engagement Baseline Questions

Baseline Questions of Respite	Answers
What is your current understanding of Respite Care?	 <p>7 out of 8 had a general understanding of Respite.</p>
What respite information are you currently providing to UNMC/Nebraska Medicine employees?	 <p>4 had knowledge of EAP's dissemination of Respite Resources and 4 had no knowledge of this.</p>
Approximately how many Respite referrals have you made in the past year and to what organization do you send referrals?	 <p>Nobody knew of any referrals and EAP does not track that information.</p>



Respite Employer Engagement Pilot Program Steps

- Attend all New Hire Orientations
 1. Explain Respite Care Resources and share brochures including:
 - Nebraska Lifespan Respite Network brochures
 - Nebraska Lifespan Respite Subsidy applications
 - Nebraska Lifespan Respite Provider applications
 2. Collect contact information for further follow up and data collection.
- Create a Respite Resources website or link on our campus website including links to Department of Health and Human Services, Nebraska Resource and Referral System and other Respite Resources
- Lunch and Learn opportunities and attend Wellness Events and Health Fairs
- Present Respite to Managers, Department Heads and Supervisors
- Partnership with Nebraska Respite Network
 1. Consistent referral source for our employees.
 2. Collect data on numbers of employees that are using the referral.
 3. Continue to expand resources and supports of Respite Care!



Impact of Attendance at UNMC-Nebraska Medicine New Hire Orientations



UNMC Respite Resource Webpage

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.

<https://www.unmc.edu/mmi/faculty-staff/respite-resources.html>



Respite Employer Engagement Next Steps

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.*





Statewide Respite Employer Engagement Initiative *Employer Presentation



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Statewide Respite Employer Engagement Initiative



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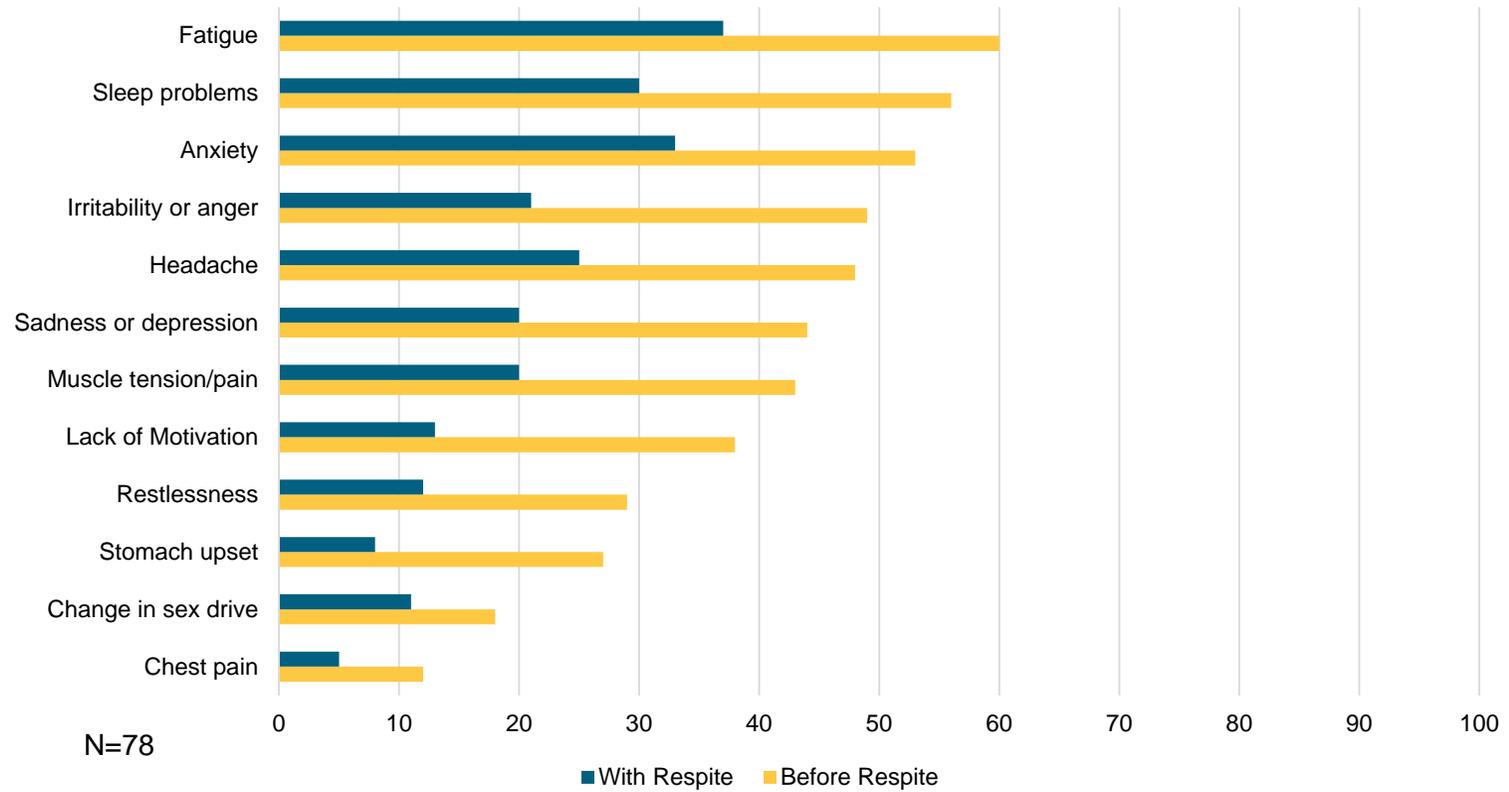
Who Needs Respite?

- **Do you know there are over 200,000 caregivers in Nebraska?**
- **How many of your employees are caregivers?**
- **How could employers offer support to caregivers?**

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Nebraska Respite Evaluation Data

Respite Care Resulted in Fewer Health Symptoms Reported by Family Caregivers



Nebraska Respite Evaluation By: Jolene Johnson, Ed. D.
Associate Director, Department of Education and Child Development, Munroe-Meyer Institute/University of NE Medical Center



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Family Caregiving in Nebraska

In 2013, nearly 200,000 family caregivers in **Nebraska** provided 182 million hours of care. The value of their caregiving is estimated at \$2.5 billion.

It is from AARP's [Valuing the Invaluable, 2015 Update](#)

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.



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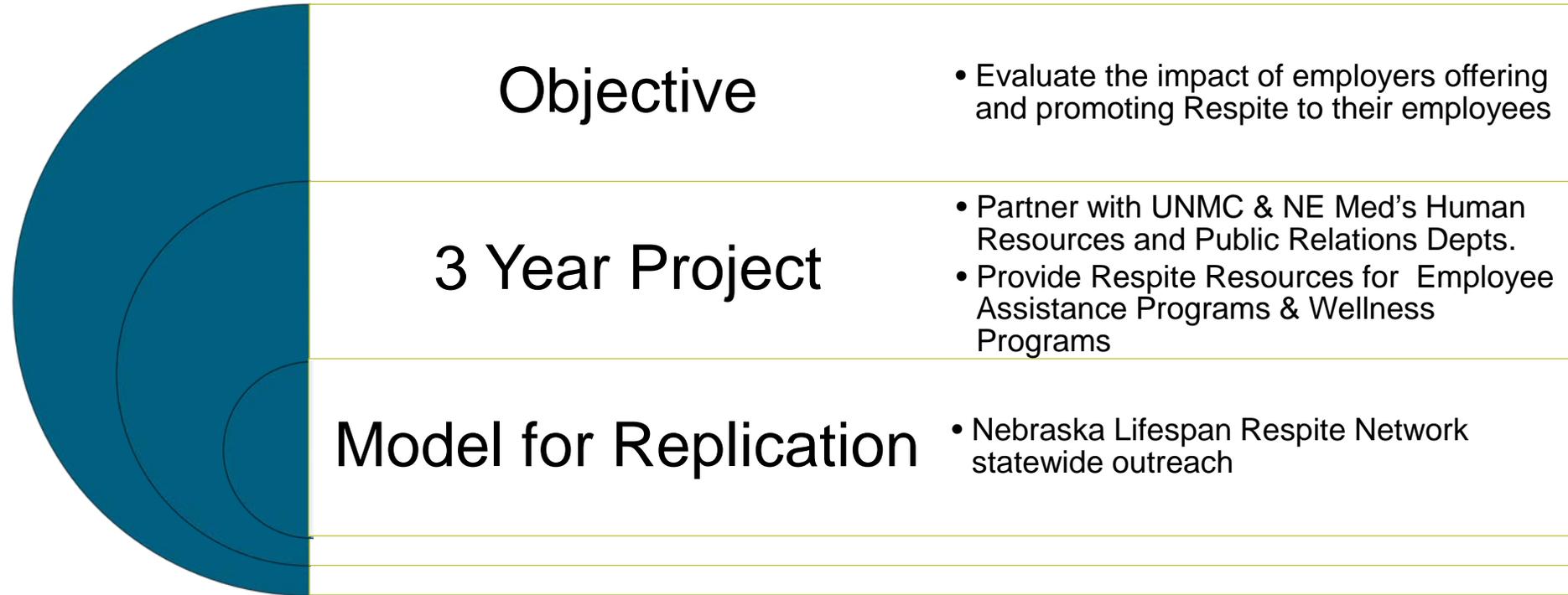
Employer Role

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)

University of Nebraska Medical Center ~ Nebraska Medicine Respite Employer Engagement Pilot





RESPIRE EMPLOYER ENGAGEMENT INITIATIVE STEPS

Respite Care Resources Website

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[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.



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RESPITE EMPLOYER ENGAGEMENT INITIATIVE STEPS

Impact of Attendance at UNMC/NE Medicine New Hire Orientations



RESPITE EMPLOYER ENGAGEMENT INITIATIVE STEPS

Offer additional presentations for employee outreach

Department Heads

Managers

Supervisors

Employees in need of Respite

RESPIRE 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 INITIATIVE STEPS

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.*

Nebraska Lifespan Respite Programs*

***Funded with state and/or federal funds**

Respite is providing a short-term break to those caring for family members with special needs.

March 2019

Respite email: DHHS.Respite@Nebraska.gov

Name of Program	Eligibility	Contact Information	Website
Lifespan Respite Subsidy Program	Individual of any age with a special need requiring ongoing supervision; lives with an unpaid caregiver in a non-institutional setting; & meets financial criteria. Planned respite of \$125/month and Exceptional Circumstances of up to additional \$1,000/eligibility year.	Lifespan Respite Subsidy email: DHHS.Respite@nebraska.gov Social Services Worker at (402) 471-9188 Respite Coordinators at 1-866-RESPITE (1-866-737-7483)	nrrs.ne.gov/respite or http://dhhs.ne.gov/Pages/hcs_programs_lifespan-respite.aspx
SSI/DCP (Supplemental Security Income/Disabled Children's) Program	Children ages birth to 16 active pay SSI (Social Security Insurance).	Call the nearest local office or DHHS.MHCP@nebraska.gov Lincoln (402) 471-5379, North Platte (308) 530-3087	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.	Sub-Adopt Program Specialist or Assigned DHHS Worker	http://dhhs.ne.gov/children_family_services/Pages/adoption.aspx



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Name of Program	Eligibility	Contact Information	Website
<p>HCBS Waivers for People with Developmental Disabilities *To be eligible for any waiver, an applicant must: 1) Be a citizen of the United States of America or a qualified alien under the federal Immigration and Nationality Act and be lawfully present in the United States; 2) Be a resident of the State of Nebraska; and 3) Have active Medicaid.</p>	<p>A developmental disability is defined in Nebraska Revised Statute 83-1205. It is a severe, chronic disability, including intellectual disability, other than mental illness that: 1) Is due to a mental or physical impairment; 2) Began before age 22; 3) Is likely to continue; 4) Results in substantial limitations in three areas: a) Conceptual skills; b) Social skills; and c) Practical skills; and 5) Results in need for special services and supports.</p> <p>Comprehensive Developmental Disabilities (CDD) Waiver Allows persons of all ages with developmental disabilities to maximize their independence as they live, work, socialize, and participate to the fullest extent possible in their communities. A participant must have a developmental disability and needs that require services like those provided by an intermediate care facility for persons with developmental disabilities (ICF/DD).</p> <p>Developmental Disabilities Adult Day (DDAD) Waiver Allows persons ages 21 and over with developmental disabilities to maximize their independence as they live, work, socialize, and participate to the fullest extent possible in their communities. A participant must have a developmental disability and needs that require services like those provided by an intermediate care facility for persons with developmental disabilities (ICF/DD).</p>	<p>1-877-667-6266 Lincoln (402) 471-8501 apply anytime at: http://dhhs.ne.gov/Children_Family_Services/AccessNebraska/Pages/accessnebraska_ind ex.aspx</p>	<p>http://dhhs.ne.gov/developmental_disabilities/Pages/aDDIF.aspx</p>

Name of Program	Eligibility	Contact Information	Website
Aged and Disabled (AD) Waiver	Provides aged persons and persons of all ages with disabilities options for services and community supports, other than a nursing facility. A participant must have physical and health needs that require services like those provided by a nursing facility.	1-800-358-8802 all ages OR children ages 4-17 call Health & Human Services (855) 632-7633; adults 18 & older with physical disabilities contact closest League of Human Dignity; adults 65 and older contact Area Agency on Aging or 1-844-843-6364	www.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 DHHS State Unit on Aging (402) 471-2307	http://dhhsemployees/sites/mltc/Pages/MLTCHome.aspx



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Name of Program	Eligibility	Contact Information	Website
Foster Care/Child Protective Services	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 themselves as caregivers using foster care maintenance funds.	ACCESS Nebraska Customer Services (800) 383-4278 OR 1-866-RESPITE (1-866-737-7483) OR dhhs.childrenandfamilyservices@nebraska.gov	http://dhhs.ne.gov/children_family_services/Pages/jus_jusindex.aspx
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.	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	http://dhhs.ne.gov/Children_Family_Services/AccessNebraska/Pages/accessnebraska_index.aspx



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Name of Program	Eligibility	Contact Information	Website
Adult Protective Services (Title XX)	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.	Call the 24-hour toll-free Adult & Child Abuse and Neglect Hotline at 1-800-652-1999 OR Local Law Enforcement	http://dhhs.ne.gov/children_family_services/Pages/nea_aps_apsindex.aspx#Eligibility
Alternative Response	Intake accepted for assessment per program guidelines. DHHS conducts family assessments to determine family's strengths and needs as well as assess for child safety. Families are connected to the supports and services they need, including respite.	Call the 24-hour toll-free Adult & Child Abuse and Neglect Hotline at 1-800-652-1999. DHHS.AlternativeResponse@nebraska.gov	http://dhhs.ne.gov/children_family_services/Pages/children_family_services_alternative-response.aspx



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Name of Program	Eligibility	Contact Information	Website
<p>Nebraska Western Iowa Veterans Administration Caregiver Support Program: General Caregiver Support Services and Comprehensive Assistance for Family Caregivers</p>	<p>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 range of services available to veterans that may help ease Caregiver burden. Identifies and creates support resources to help educate Caregivers, alleviate 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. Joni S. Morin, MSW, LCSW, Caregiver Support Coordinator, Nebraska Western Iowa / VA Health Care System / (402) 995-4618</p>	<p>www.caregiver.va.gov</p>



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Name of Program	Eligibility	Contact Information	Website
U.S. Air Force (USAF) Exceptional Family Member Program (EFMP)	The Exceptional Family Member Program (EFMP) supports military families with special medical and educational needs. The program has three components: 1. Identification and Enrollment 2. Assignment Coordination 3. Family Support. A family member who has special needs is a: 1. Spouse, child, or dependent adult who, regardless of age, has special medical needs and 2. Requires medical services for a chronic condition such as asthma, attention deficit disorder, diabetes, multiple sclerosis, etc.3. Receives ongoing services from a medical specialist or 4. has significant behavioral health concerns. A child (birth through 21 years) with special educational needs who is eligible for, or receives 1. special education services through an Individualized Education Program (IEP) or 2. Early Intervention Services (EIS) through an Individualized Family Service Plan (IFSP)	(402) 417-9331	http://www.offuttafrfc.com/cms/index.php/programs/efmp



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Respite Employer Engagement Sustainability

- Pilot funded with ACL respite grant funds then transitioned to state dollars
- Statewide technical assistance of approved outcome-based model
 - Workplace wellness, employee assistance and human resource supports
- Increase number of employers per six local networks sharing respite resources
- Strategic planning with local job centers to engage business community

Respite Employer Engagement Lessons Learned

- Consistent sustainability priority
- Strategic technical assistance essential
- Targeted outreach

Respite Employer Data Collection & Evaluation

- Tracking employer outreach activities
 - Verified actions by business to inform employee caregivers of respite resources;
 - Listing of caregiver support benefits offered as company's well-being strategy;
 - Employee caregiver stories; and
 - Respite utilization data of employee caregivers impacted by employer engagement activities to support **return on investment of employer engagement obligated funding.**

Respite Employer Engagement Initiative

Questions & Answers

*Thank you for joining the Respite
Employer Engagement Initiative Webinar!*