

### Nebraska Lifespan Respite Caregiver Survey

Welcome to the Nebraska Lifespan Caregiver Survey! Respite is planned or emergency care provided to a child or adult with special needs in order to provide temporary relief to family caregivers who are caring for that child or adult. (*Definition taken from ARCH website*) Your feedback and participation in completing this survey is appreciated and vital. Results from the survey will be shared with the Nebraska Department of Health and Human Services as part of an overall evaluation through the University of Nebraska Medical Center/Munroe Meyer Institute. Your participation and completion of the survey is appreciated and could help to improve the current system. The survey should take about 15 minutes to complete. At the conclusion of the survey you will have the option of providing contact information for a possible incentive (\$25 gift card). Thank you!

Items on this survey were adapted from the following sources: *ARCH, REST Caregiver Survey, George & Gwyther, 1986 and Perline, et al., 1990*. Thank You!

1. Please rate your level of satisfaction with the respite care services.

	Strongly Disagree	Disagree	Agree	Strongly Agree
I am satisfied with the overall level of respite care services I have received.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am satisfied with the ease of finding a respite care provider.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am satisfied with the care provided to the care recipient.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

2. How long have you been receiving respite care services?

Less than 2 Months       2-6 Months       6-11 Months  
 1-5 Years       More than 5 Years

3. On average, how many hours of paid respite care do you receive per month?

1-3 Hours       4-6 Hours       7-10 Hours  
 10-15 Hours       More than 15 Hours

4. How many hours of respite care that you receive are unpaid (volunteers, family members, etc.)?

\_\_\_\_\_

5. Is the amount of time you receive respite care sufficient to meet your needs?

Not at all       Slightly       Somewhat       Moderately  
 Quite       Very       Extremely

6. How many hours of respite care per month would be ideal? \_\_\_\_\_

7. Please rate your experiences for the following items.

	Not at all stressed	Slightly stressed	Moderately stressed	Very stressed	Extremely stressed
<i>Before</i> receiving respite, how “stressed” were you as a result of caring for your family member?	<input type="radio"/>				
<i>Now</i> that you are receiving respite care services, how “stressed” are you as a result of caring for your family member?	<input type="radio"/>				
If respite care were to end, how “stressed” would you be as a result of caring for your family member?	<input type="radio"/>				

8. Individuals who are stressed can experience any of the following symptoms: headache, muscle tension or pain, chest pain, fatigue, change in sex drive, stomach upset, sleep problems, anxiety, restlessness, lack of motivation or focus, irritability or anger, sadness or depression.

	Headache	Muscle tension or pain	Chest pain	Fatigue	Change in sex drive	Stomach upset	Sleep problems	Anxiety	Restlessness	Lack of motivation	Irritability or anger	Sadness or depression
<i>Before</i> receiving respite care which symptoms did you experience?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>Now</i> that you are receiving respite care which symptoms do you experience?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

9. Please tell us about your health in relationship to your caregiving responsibilities. "Health" refers to physical, mental and/or emotional health?

	Not at all	Slightly	Moderately	Greatly	Extremely
<i>Before</i> receiving respite, did your caregiving responsibilities contribute to any health problems you may have?	<input type="radio"/>				
<i>Now</i> that you are receiving respite, do your caregiving responsibilities contribute to any health problems you may have?	<input type="radio"/>				
If respite were to end, would your caregiving responsibilities contribute to any health problems you may have?	<input type="radio"/>				

10. If you are in a relationship, please tell us about your relationship with your spouse/partner.

	Not at all	Slightly	Moderately	Very	Extremely
<i>Before</i> receiving respite, was your relationship with your spouse/partner in any way strained due to your caregiving responsibilities?	<input type="radio"/>				
<i>Now</i> that you are receiving respite, is your relationship with your spouse/partner in any way strained due to your caregiving responsibilities?	<input type="radio"/>				
If respite ended, would your relationship with your spouse/partner become strained due to your caregiving responsibilities?	<input type="radio"/>				

11. Please tell us about your relationship with your family member needing care (Care Recipient).

	Not at all	Slightly	Moderately	Very	Extremely
<i>Before</i> receiving respite, was your relationship with the care recipient in any way strained due to your caregiving responsibilities?	<input type="radio"/>				
<i>Now</i> that you are receiving respite, is your relationship with care recipient in any way strained due to your caregiving responsibilities?	<input type="radio"/>				
If respite ended, would your relationship with the care recipient become strained due to your caregiving responsibilities?	<input type="radio"/>				

12. Please tell us about your opportunities and time to engage in social/recreational activities of your choice.

	Not at all	Slightly	Moderately	Very	Extremely
<i>Before</i> receiving respite, were your opportunities and time to engage in social/recreational activities of your choice sufficient?	<input type="radio"/>				
<i>Now</i> that you are receiving respite, are your opportunities and time to engage in social/recreational activities of your choice sufficient?	<input type="radio"/>				
If respite ended, would your opportunities and time to engage in social/recreational activities of your choice sufficient?	<input type="radio"/>				

13. Please share your thoughts on possible out-of-home placement for Care Recipient.

	No	Yes
<i>Before</i> receiving respite, did you consider adoption or an out-of-home placement such as extended family, foster care, group home, nursing home or assisted living facility for the care recipient?	<input type="radio"/>	<input type="radio"/>
<i>Now</i> that you are receiving respite, do you consider adoption or an out-of-home placement such as extended family, foster care, group home, nursing home or assisted living facility for the care recipient?	<input type="radio"/>	<input type="radio"/>
If respite <i>were to end</i> , would you consider adoption or an out-of-home placement such as extended family, foster care, group home, nursing home or assisted living facility for the care recipient?	<input type="radio"/>	<input type="radio"/>
Sometimes an out-of-home placement may be desirable or inevitable for a family or family member who receives care. Would you say that an out-of-home placement is desirable or inevitable for your family member in the next six months?	<input type="radio"/>	<input type="radio"/>

14. Now you will be asked some questions about your finances.

	Better	About the same	Worse	Choose to not answer
<i>Before</i> receiving respite, how well do you think you (and your family) were doing financially as compared to other people your age?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>Now</i> that you are receiving respite, how well do you think you (and your family) were doing financially as compared to other people your age?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If respite <i>were to end</i> , how well do you think you (and your family) were doing financially as compared to other people your age?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

15. These questions ask about your household expenses and standard of living. Think back over your financial status as it was *just* before you began to take care of your family member.

	Much less than now	Somewhat less than now	About the same	Somewhat more now	Much more now
Compared to that time, how would you describe your total household income from all sources?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Compared to that time, how would you describe your monthly expenses?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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

- Not enough to make ends meet
- Just enough to make ends meet
- Some money left over

17. What are your total non-reimbursable respite costs per month? \_\_\_\_\_

18. What are your total caregiving out-of-pocket expenses (not including respite) per month? Examples include adult day care, paid in home caregiving, transportation for care, out of pocket medical expenses.

---



---



---



---



---

19. My family receives respite care services through?

- |  |  |
|--|--|
| <input type="radio"/> Lifespan Respite Subsidy               | <input type="radio"/> Veteran's Administration           |
| <input type="radio"/> Developmental Disabilities (DD Waiver) | <input type="radio"/> SSI/Disabled Children's Program    |
| <input type="radio"/> Alzheimer's Scholarship                | <input type="radio"/> Church or Faith-Based Organization |
| <input type="radio"/> Medicaid                               | <input type="radio"/> Local Area Agency on Aging         |
| <input type="radio"/> Private Health Insurance               | <input type="radio"/> Private Pay                        |
| <input type="radio"/> Long Term Care Insurance               | <input type="radio"/> Aged and Disabled Waiver (A&D)     |
| <input type="radio"/> Other (please specify) _____           |  |

20. I am the family caregiver for my

- |                                      |  |                               |
|--------------------------------------|--|-------------------------------|
| <input type="radio"/> Spouse/Partner | <input type="radio"/> Daughter/Son                 | <input type="radio"/> Parent  |
| <input type="radio"/> Grandparent    | <input type="radio"/> Foster Child                 | <input type="radio"/> Sibling |
| <input type="radio"/> Friend         | <input type="radio"/> Other (please specify) _____ |                               |

21. What is the age of the primary Family Caregiver?

- |                                   |  |                                   |
|-----------------------------------|--|-----------------------------------|
| <input type="radio"/> 14-19 Years | <input type="radio"/> 19-25 Years                          | <input type="radio"/> 25-30 Years |
| <input type="radio"/> 30-35 Years | <input type="radio"/> 35-40 Years                          | <input type="radio"/> 40-45 Years |
| <input type="radio"/> 45-50 Years | <input type="radio"/> 50-55 Years                          | <input type="radio"/> 55-60 Years |
| <input type="radio"/> 65+ Years   | <input type="radio"/> Same age as the Care Recipient _____ |                                   |

22. What is the age of the primary Care Recipient?

- |                                      |  |                                   |
|--------------------------------------|--|-----------------------------------|
| <input type="radio"/> Under 19 Years | <input type="radio"/> 19-25 Years                            | <input type="radio"/> 25-30 Years |
| <input type="radio"/> 30-35 Years    | <input type="radio"/> 35-40 Years                            | <input type="radio"/> 40-45 Years |
| <input type="radio"/> 45-50 Years    | <input type="radio"/> 50-55 Years                            | <input type="radio"/> 55-60 Years |
| <input type="radio"/> 65+ Years      | <input type="radio"/> Same age as the Family Caregiver _____ |                                   |

23. What is your total annual family income (from all sources)?

- \$0-\$9,999
- \$10,000 to \$19,999
- \$20,000 to \$29,999
- \$30,000 to \$39,999
- \$40,000 to \$49,999
- \$50,000 to \$59,999
- Over \$60,000

24. Please check medical diagnosis of Care Recipient? (Check all that apply)

- |   |   |
|---|---|
| <input type="radio"/> Alzheimer's/Dementia            | <input type="radio"/> AIDS                      |
| <input type="radio"/> Hearing Impairment/Hearing Aids | <input type="radio"/> Arthritis                 |
| <input type="radio"/> Autism/Autism Spectrum Disorder | <input type="radio"/> Developmental Delay       |
| <input type="radio"/> Coronary Heart Disease          | <input type="radio"/> Intellectual Disability   |
| <input type="radio"/> Cancer                          | <input type="radio"/> Cerebral Palsy            |
| <input type="radio"/> Congestive Heart Failure        | <input type="radio"/> Cystic Fibrosis           |
| <input type="radio"/> Chromosomal Abnormality         | <input type="radio"/> Depression                |
| <input type="radio"/> Brain Injury-Stroke/CVA         | <input type="radio"/> Digestive System disorder |
| <input type="radio"/> Brain Injury-TBI                | <input type="radio"/> Fetal Alcohol Syndrome    |
| <input type="radio"/> Heart Condition                 | <input type="radio"/> Multiple Sclerosis        |
| <input type="radio"/> Muscular Dystrophy              | <input type="radio"/> Neurodegenerative Disease |
| <input type="radio"/> Orthopedic Impairments          | <input type="radio"/> Parkinson's Disease       |
| <input type="radio"/> Renal Failure                   | <input type="radio"/> Seizure Disorder          |
| <input type="radio"/> Speech and Language Disorder    | <input type="radio"/> Spinal Injury/Disorder    |

25. Please check the behavioral and/or emotional needs of the Care Recipient requiring supervision. (Check all that apply)

- |  |                                      |  |
|--|--------------------------------------|--|
| <input type="radio"/> ADD/ADHD         | <input type="radio"/> Anxiety        | <input type="radio"/> Reactive Attachment Disorder |
| <input type="radio"/> Bipolar Disorder | <input type="radio"/> Depression     | <input type="radio"/> Self-Abusive                 |
| <input type="radio"/> Hyperactivity    | <input type="radio"/> Mental Illness | <input type="radio"/> Physically Aggressive        |
| <input type="radio"/> Non-Verbal       | <input type="radio"/> Wandering      | <input type="radio"/> Temper Tantrums              |

26. Ethnicity of Family Care Giver

- |                                       |  |                                 |
|---------------------------------------|--|---------------------------------|
| <input type="radio"/> Native American | <input type="radio"/> African American             | <input type="radio"/> Hispanic  |
| <input type="radio"/> Asian           | <input type="radio"/> Pacific Islander             | <input type="radio"/> Caucasian |
| <input type="radio"/> Bi-racial       | <input type="radio"/> Other (please specify) _____ |                                 |

27. Marital Status of the Family Caregiver

- |  |                               |                                 |
|--|-------------------------------|---------------------------------|
| <input type="radio"/> Married                      | <input type="radio"/> Single  | <input type="radio"/> Divorced  |
| <input type="radio"/> Life Partner living together | <input type="radio"/> Widowed | <input type="radio"/> Separated |
| <input type="radio"/> Other (please specify) _____ |                               |                                 |

**\*Supported in part by a federal DHHS Administration for Community Living, CDAP-Lifespan Respite Integration Program grant awarded to the NE Department of Health & Human Services (09LI008-02-00).**

