

## Lifespan Respite Care Caregiver Needs Assessment

We are reaching out to caregivers across New Hampshire to determine the statewide need of Respite services. Please take about 10 minutes to complete this survey about your life as a caregiver, including the role respite services may play in it. All of your responses will be confidential and will not affect the receipt of services. If you need this survey to be translated into another language, this service can be provided over the phone with a third party translator. If you would like this service, please call Martha Bose at 603-271-4497 or send her an email request at Martha.Bose@dhhs.state.nh.us.

Here are some definitions and examples that may help you answer questions throughout the survey:

Respite means a time of rest or relief. Respite care provides a family caregiver a temporary, short-term break from the constant responsibilities of caring for a dependent child or adult. Examples of respite providers can include but are not limited to family members, friends, and community members (from churches, clubs, etc).

A caregiver is the primary person or persons responsible for the day-to-day care of a dependent child or adult. An example of a caregiver is an adult visiting her aging mother daily to help with meals or other daily living activities; or a parent's consistent supervision and/or medical care of a young or grown up son/daughter.

### Caregiver Information

#### \* 1. How old are you? (Caregiver)

- |   |   |                                     |
|---|---|-------------------------------------|
| <input type="radio"/> 18 - 24 years old | <input type="radio"/> 45 - 54 years old | <input type="radio"/> 75+ years old |
| <input type="radio"/> 25 - 34 years old | <input type="radio"/> 55 - 64 years old |                                     |
| <input type="radio"/> 35 - 44 years old | <input type="radio"/> 65 - 74 years old |                                     |

#### \* 2. Please indicate your gender.

- Male  Female

#### \* 3. What is your zip code?

ZIP:

#### \* 4. Which county do you live in?

- |                                |                                    |                                  |
|--------------------------------|------------------------------------|----------------------------------|
| <input type="radio"/> Belknap  | <input type="radio"/> Grafton      | <input type="radio"/> Sullivan   |
| <input type="radio"/> Carrol   | <input type="radio"/> Hillsborough | <input type="radio"/> Rockingham |
| <input type="radio"/> Cheshire | <input type="radio"/> Merrimack    |                                  |
| <input type="radio"/> Coos     | <input type="radio"/> Strafford    |                                  |

### Information about the individual(s) you provide care for

#### \* 5. How many people requiring daily assistance (e.g. disabled, chronic illness, elderly, etc) are you a primary caregiver for?

**\* 6. What is the age of the person you provide care for?**

- |                                      |                                    |                                       |
|--------------------------------------|------------------------------------|---------------------------------------|
| <input type="checkbox"/> Under Age 1 | <input type="checkbox"/> Age 16-18 | <input type="checkbox"/> Age 51-60    |
| <input type="checkbox"/> Age 1-6     | <input type="checkbox"/> Age 19-21 | <input type="checkbox"/> Age 61-64    |
| <input type="checkbox"/> Age 7-12    | <input type="checkbox"/> Age 22-30 | <input type="checkbox"/> Age 65-80    |
| <input type="checkbox"/> Age 13-15   | <input type="checkbox"/> Age 31-50 | <input type="checkbox"/> Above Age 81 |

**\* 7. What are the primary conditions of the persons you provide care for? (Please limit your selection to three or fewer)**

- |   |  |
|---|--|
| <input type="checkbox"/> Developmental Disability                                     | <input type="checkbox"/> Vision/hearing loss or blindness/deafness |
| <input type="checkbox"/> Mental illness/emotional disturbance                         | <input type="checkbox"/> Dementia/Alzheimer's Disease              |
| <input type="checkbox"/> Autism   | <input type="checkbox"/> Stroke and related disorders              |
| <input type="checkbox"/> Mobility assistance  | <input type="checkbox"/> Traumatic Brain Injury                    |
| <input type="checkbox"/> Physical disability  | <input type="checkbox"/> Personal Care/Safety                      |
| <input type="checkbox"/> Other (please specify if primary diagnosis not listed above) |  |
- 

**8. In which of the following ways do you assist the person you care for? (Select all that apply)**

- |  |   |
|--|---|
| <input type="checkbox"/> Transportation (driving, arranging)                     | <input type="checkbox"/> Feeding  |
| <input type="checkbox"/> Housework   | <input type="checkbox"/> Getting dressed                                      |
| <input type="checkbox"/> Toileting   | <input type="checkbox"/> Arranging or supervising other caretakers            |
| <input type="checkbox"/> Managing and/or giving medications, pills or injections | <input type="checkbox"/> Managing finances (bills, insurance paperwork, etc)  |
| <input type="checkbox"/> Incontinence  | <input type="checkbox"/> Grocery shopping                                     |
| <input type="checkbox"/> Bathing or showering                                    | <input type="checkbox"/> Transferring (Getting in and out of beds and chairs) |
| <input type="checkbox"/> Preparing meals   | <input type="checkbox"/> Mobility help  |
| <input type="checkbox"/> Other (please specify)                                  |   |
- 

**Caregiver Stress**

Although not all caregivers experience overwhelming stress, research has documented that caregivers are at a greater risk for experiencing stress and stress related problems. Please think of your experiences as a caregiver and how you have ever felt or feel in response to the statements below.

## 9. Are you experiencing any of the following problems in relation to your caregiving role?

- |   |  |
|---|--|
| <input type="checkbox"/> Depression                           | <input type="checkbox"/> Loss of income  |
| <input type="checkbox"/> Guilt, anger, resentment and denial  | <input type="checkbox"/> More negative attitude toward the person you provide care for |
| <input type="checkbox"/> Declines in physical health          | <input type="checkbox"/> Loss of free time   |
| <input type="checkbox"/> Strained social and family relations | <input type="checkbox"/> Abuse of self or others                                       |
| <input type="checkbox"/> Sleep disorders                      | <input type="checkbox"/> Sleeplessness   |
| <input type="checkbox"/> Anxiety about aging                  | <input type="checkbox"/> Exhaustion  |
| <input type="checkbox"/> Neglect of self and others           | <input type="checkbox"/> Loss of enjoyable activities                                  |
| <input type="checkbox"/> Less marital closeness               | <input type="checkbox"/> Loss of friendships   |
| <input type="checkbox"/> Work absenteeism and job loss        | <input type="checkbox"/> Feeling overwhelmed   |

## 10. How often do you feel...

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
I feel that I am missing out on life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I wish I could escape from this situation.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My social life has suffered.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel emotionally drained due to caring for him/her.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I expected that things would be different at this point of my life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I'm not getting enough sleep.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My health has suffered.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Caregiving has made me physically sick.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I'm physically tired.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I don't get along with other family members as well as I used to.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My caregiving efforts aren't appreciated by others in my family.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've had problems in my marriage (or other significant relationships).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I don't get along as well as I used to with others.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel resentful of other relatives who could but do not help.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel embarrassed over his/her behavior.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel ashamed of him/her.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I resent him/her.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel uncomfortable when I have friends over.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel angry about my interactions with him/her.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I do pretty much what I have to do, not what I want to do, for him/her.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Although caregiving presents challenges and difficulties, it can also be rewarding as well. Please think of your experiences as a caregiver and how you have ever felt or feel in response to the statements below.

**11. Which best describes your relationship to the persons you provide care for? (Select all that apply)**

- |  |   |
|--|---|
| <input type="checkbox"/> Birth or adoptive parent        | <input type="checkbox"/> Sibling                        |
| <input type="checkbox"/> Foster parent                   | <input type="checkbox"/> Son or daughter                |
| <input type="checkbox"/> Grandparent                     | <input type="checkbox"/> Close friend or other relative |
| <input type="checkbox"/> Spouse or partner               |   |
| <input type="checkbox"/> Other (please specify)          |   |
| <input style="width: 200px; height: 15px;" type="text"/> |   |

**12. How often do you feel...**

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
You really enjoy being with the person you care for.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Helping this person has made you feel closer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You take care of him/her more because you want to than out of a sense of duty.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The person you care for can show his/her old self in spite of his/her current condition.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The person you care for shows real appreciation for what you do.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The knowledge that you are doing your best gets you through the rough times with the person you care for.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The person you care for gets pleasure out of some little thing that gives you pleasure.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
That it makes you happy that the person you care for is being cared for by family.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Type and Time of Care Provided**

**\* 13. How many hours, on average, do you spend caring for this person per WEEK?**

- |                                   |   |
|-----------------------------------|---|
| <input type="radio"/> 0-10 hours  | <input type="radio"/> 41-50 hours           |
| <input type="radio"/> 11-20 hours | <input type="radio"/> 51-60 hours           |
| <input type="radio"/> 21-30 hours | <input type="radio"/> 61-70 hours           |
| <input type="radio"/> 31-40 hours | <input type="radio"/> Greater than 71 hours |

**14. How often do you feel...**

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
The person you care for needs my help to perform many daily tasks.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
He/she is dependent on me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have to watch him/her constantly.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have to help him/her with many basic functions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I don't have a minute's break from his/her chores.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**15. How would you spend your time when using respite care? (Select all that apply)**

- |   |   |
|---|---|
| <input type="checkbox"/> Personal relaxation time | <input type="checkbox"/> Spend time with other family members |
| <input type="checkbox"/> Going to work            | <input type="checkbox"/> Attend support meetings              |
| <input type="checkbox"/> Errands/housework        | <input type="checkbox"/> Watch TV                             |
| <input type="checkbox"/> Visiting friends         |   |
| <input type="checkbox"/> Other (please specify)   |   |
- 

**16. Are there any activities that you used to do before becoming a caregiver that you wish you could continue to do now?**

**17. In your experience, how true is each statement about respite services?**

	Very true	Somewhat true	Not true at all	Does not apply
Trained respite providers met caregiving needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Respite offered a short-term break from caregiving.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Respite reduced the risk of neglect or mistreatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Respite provided safe and secure care.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Respite enabled me to focus on needs of others in my household.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Respite allowed me to enjoy social and recreational activities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Respite reduced my stress as a caregiver.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Respite increased my ability to effectively provide care.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The person whom I provide care felt positively about respite.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Thus far, I have been very satisfied with my use of respite services.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**\* 18. How long have you been receiving respite care?**

**If you answer "Never", please skip questions 19-23.**

- Never
- Less than 6 months
- 6 months - 1 year
- More than 1 year

**Respite Provider Information**

**19. As a caregiver, where does your respite care take place?**

- In your home
- In the home of the person receiving care (if different from your home)
- Some where else (please specify)

**20. What is your relationship to your primary respite providers? (Select all that apply)**

- Family
- Friend/neighbor
- Community member (e.g. church, women's club, etc)
- Day facility
- Over night facility
- Hired in home service provider
- Other (please specify)

**21. How have you found respite providers? (Check all that apply)**

- Called a federal, state, or local agency for help
- Service link
- Recommendation from a support group
- Recommendation from a church or faith organization
- Referred by a physician or other clinical service provider
- Recommendation from a friend or family member
- Internet website
- Other (please specify)

**22. What type of training or experience does your respite provider have? (Check all that apply)**

- |   |   |
|---|---|
| <input type="checkbox"/> None   | <input type="checkbox"/> Red Cross Training                     |
| <input type="checkbox"/> Alzheimer Training                             | <input type="checkbox"/> Seizure Training                       |
| <input type="checkbox"/> Autism Training                                | <input type="checkbox"/> Foster Parent Training                 |
| <input type="checkbox"/> Baby Sitting                                   | <input type="checkbox"/> Formal Training/Education              |
| <input type="checkbox"/> Basic First Aid                                | <input type="checkbox"/> Parent/Caretaker (Personal Experience) |
| <input type="checkbox"/> CPR  |   |
| <input type="checkbox"/> Other (please specify)<br><input type="text"/> |   |

**23. How is your respite provider paid for? (Select all that apply)**

- Pay out of pocket
- Paid through area agency or other agency
- Covered by insurance
- Paid by Medicaid
- No charge
- Other (please specify)

**Respite Care Preferences**

**24. Please rate what characteristics you think would be ideal for a respite provider.**

	Very important	Somewhat important	Not important at all
Alzheimer Training	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Autism Training	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Baby Sitting Experience	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Basic First Aid Training	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
CPR Training	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Red Cross Training	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Seizure Training	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Foster Parent Training	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Formal Training/Education	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Parent/Caretaker (Personal Experience)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Available 24/7	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Consumer friendly and easy to use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Provides me with multiple options for care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Quality of care services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Options for financial assistance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pre-screening or training requirements	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Barriers in Using Respite Care**

**\* 25. Caregivers can face several problems when trying to use informal and formal respite care. Please check any problem below that you have encountered when considering respite care.**

- I am not comfortable with someone else assisting the person I care for.
- The person I care for is uncomfortable and/or uncooperative when someone else assists them.
- The medical needs of the person I care for are very complex.
- There are no respite providers available to me in my area.
- Do not have enough funds to pay for respite care.
- Not eligible for financial assistance.
- There is a high turn over rate of respite providers who will work with us.
- The respite provider may not have the knowledge or appropriate training about the special health care needs of the person I care for.
- Lack of Information/do not know who to talk to.
- Reluctant to ask for help.
- Other (please specify)



**26. If you were to work with a new respite provider, would you prefer to train them yourself?**

- Yes
- No
- No preference

### **Respite Care Funding**

**\* 27. Do you have short term funding available to you for respite care?**

**If you answer "No" or "Don't Know", please skip questions 28 and 29.**

- Yes
- No
- Don't Know

### **Use of Short Term Funding**

**\* 28. Even though short term funding for respite services is available to you, do you actually use the funding for respite care?**

**If you answer "Yes", please skip question 29.**

- Yes
- No

### **Short Term Funding**

**\* 29. Why do you not use these funds for respite care? (Select all that apply)**

- I don't know how to use the funds.
- I am not comfortable with someone else assisting the person I care for.
- The person I care for is uncomfortable and/or uncooperative when someone else assists them.
- The medical needs of the person I care for are very complex.
- There are no respite providers available to me in my area.
- There is a high turn over rate of respite providers who will work with us.
- Use the funding for other medical expenses.
- Funds available and cost of care do not match.
- Reluctant to ask for help.
- Other (please specify)

**Interest in Receiving Additional Information about Respite Services**

**\* 30. Are you interested in joining other caregivers and respite providers for more information about respite care services that are available in New Hampshire?**

**If you answer "Yes", please SKIP question 31. If you answer "NO", please ANSWER question 31 and the survey will then be complete.**

- Yes
- No

**Disinterest in Receiving More Information**

**31. Why are you not interested in receiving more information?**

**Contact Information**

**32. In what ways would you like to receive information? (Select all that apply)**

- Postal mail
- E-mail
- Community gatherings (such as church or town meetings)
- Statewide seminars, conferences, or summits

Other (please specify)

**33. Please provide your preferred email address and/or mailing address for future contact about respite care resources in New Hampshire.**

**Name:**

**Address:**

**Address 2:**

**City/Town:**

**State:**

**ZIP:**

**Email Address:**

**Thank you**

Thank you for taking the time to complete this survey. Your feedback is very important to us.