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.

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**Caregiver Information**

1. **How old are you? (Caregiver)**
   - 18 - 24 years old
   - 25 - 34 years old
   - 35 - 44 years old
   - 45 - 54 years old
   - 55 - 64 years old
   - 65 - 74 years old
   - 75+ years old

2. **Please indicate your gender.**
   - Male
   - Female

3. **What is your zip code?**
   - ZIP: [ ]

4. **Which county do you live in?**
   - Belknap
   - Carroll
   - Cheshire
   - Coos
   - Grafton
   - Hillsborough
   - Merrimack
   - Strafford
   - Sullivan
   - Rockingham

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**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?

- Under Age 1
- Age 1-6
- Age 7-12
- Age 13-15
- Age 16-18
- Age 19-21
- Age 22-30
- Age 31-50
- Age 51-60
- Age 61-64
- Age 65-80
- Above Age 81

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

- Developmental Disability
- Mental illness/emotional disturbance
- Autism
- Mobility assistance
- Physical disability
- Vision/hearing loss or blindness/deafness
- Dementia/Alzheimer's Disease
- Stroke and related disorders
- Traumatic Brain Injury
- Personal Care/Safety

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)

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

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?

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

10. How often do you feel...

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

Rewarding Experiences from Caregiving
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)**

- Birth or adoptive parent
- Foster parent
- Grandparent
- Spouse or partner
- Other (please specify)

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

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

**Type and Time of Care Provided**

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

- 0-10 hours
- 11-20 hours
- 21-30 hours
- 31-40 hours
- 41-50 hours
- 51-60 hours
- 61-70 hours
- Greater than 71 hours
14. How often do you feel...

<table>
<thead>
<tr>
<th>Statement</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Quite Frequently</th>
<th>Nearly Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>The person you care for needs my help to perform many daily tasks.</td>
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<tr>
<td>He/she is dependent on me.</td>
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<tr>
<td>I have to watch him/her constantly.</td>
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<tr>
<td>I have to help him/her with many basic functions.</td>
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<tr>
<td>I don’t have a minute’s break from his/her chores.</td>
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</table>

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

- Personal relaxation time
- Going to work
- Errands/housework
- Visiting friends
- 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?

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

- None
- Alzheimer Training
- Autism Training
- Baby Sitting
- Basic First Aid
- CPR
- Red Cross Training
- Seizure Training
- Foster Parent Training
- Formal Training/Education
- Parent/Caretaker (Personal Experience)
- Other (please specify)

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

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

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.