Family Caregiver Respite Service Needs Questionnaire

Respite services provide family caregivers with a needed break from ongoing responsibilities, enabling them to help keep the person they care for at home or in another setting. We are interested in learning about caregivers who provide a few hours to around the clock assistance for a family member with a disability, chronic illness, life changing injury or other limitation of daily activities.

We would appreciate your taking a few minutes to complete this anonymous survey. Your responses will help the Massachusetts Lifespan Respite Coalition develop a vision to improve family caregiver respite services.

When completing the survey, click once on the item to mark your response and double click to undo a response. Press the "Next" button to go to the next screen; the "Back" button to return to a previous screen. Press the "Submit" button in the last screen to send your completed survey.

Thank you.

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SECTION I: Respite Care

1. Have you ever used or sought respite services?

Please pick one of the answers below.

- ○ Yes
- ○ No

1.a Why did you most recently seek respite services? (Check all that apply.)

Please check all that apply and/or add your own variant.

- ☐ Enable to work
- ☐ Relieve emotional stress/prevent burnout
- ☐ Attend to needs of other family members
- ☐ Attend to personal need (social/business/recreation/medical)
- ☐ Complete household tasks/chores
- ☐ Participate in caregiver support group/training

Other (please specify)

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1.b I have not used or sought respite services because: (Check all that apply.)

Please check all that apply and/or add your own variant.

- ☐ I am able to provide adequate care to my loved one without assistance.
- ☐ I have enough assistance and do not need respite services.
- ☐ I have no family or friends to ask for help.
- ☐ My loved one(s) refuses help from others.
- ☐ I am concerned about outsiders caring for my loved one(s).
- ☐ I do not know where to find services.
- ☐ I cannot afford services.
- ☐ I think I do not qualify.
- ☐ Services are too difficult to obtain.
- ☐ I cannot find qualified people or agencies.
- ☐ Care is not available when I need it.
- ☐ I do not qualify for respite.

Other (please specify)

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2. How often do you NEED respite care services? (Select one choice.)

Please pick one of the answers below or add your own.

- ○ Daily
- ○ Weekly
- ○ Monthly
- ○ Occasionally (e.g., vacation, emergency situation)

Other (please specify)

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3. What days and time of day do you need respite services? (Check all that apply.)

Please check all that apply.

- ☐ Weekdays -- daytime hours
- ☐ Weekdays -- evening hours
- ☐ Weekends -- daytime hours
- ☐ Weekends -- evening hours
- ☐ Overnight

4. In what setting do you seek to receive respite services? (Select one choice.)

Please note: Out-of-home includes but not limited to a day health program, respite facility, respite in a family/friend/neighbor's home.

Please pick one of the answers below or add your own.

- ○ In home
- ○ Out-of-home

Other (please specify)

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5. When seeking respite services, please tell us from the listed items which is most important, second most important, third most important, and least important to you. Indicate your ranking of the item by marking the circle under the applicable column header. (Double click on the circle to undo a response. Only one response is recorded under each column.)

Please mark the corresponding circle - only one per line.

	Most important	Second most important	Third most important	Least important
Respite service is affordable.	○	○	○	○
Respite service is available when needed.	○	○	○	○
Respite service is easily accessible.	○	○	○	○
A person or an agency is able to meet the specific needs of my loved one.	○	○	○	○

6. The safety of those providing care and those in need of care is ongoing. Taking into consideration the behavior of the person you care for, have you been concerned in the past 12 months:

Please mark the corresponding circle - only one per line.

	Yes	No
for their safety.	○	○
for your own safety.	○	○
for the safety of family members.	○	○
for the safety for others outside the family.	○	○

7. Within the last 12-months, which of the following best describes your experience with respite services? (Select one option.)

Please pick one of the answers below or add your own.

- ○ Received respite as scheduled from a paid or unpaid person or agency.
- ○ Did not receive respite as scheduled from a paid or unpaid person or agency.
- ○ Placed on a waiting list for services.
- ○ Had funding, however could not find a qualified provider.
- ○ Was eligible for respite services, however funding unavailable.
- ○ Referred to another agency/program.

Other (Please specify)

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8. In general, how did you learn about the respite services that you received? (Check all that apply.)

Please check all that apply and/or add your own variant.

- ☐ Federal, state or local government agency
- ☐ Community social service agencies
- ☐ Physician or other medical professional
- ☐ Informal networking (friends, family, faith based organization, support group, etc.)
- ☐ Internet, telephone directory

Other (please specify)

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9. In general, who provided you with respite services? (Check all that apply.)

Please check all that apply and/or add your own variant.

- ☐ Paid family member
- ☐ Unpaid family member
- ☐ Paid friend/neighbor
- ☐ Unpaid friend/neighbor
- ☐ Volunteer
- ☐ Paid staff

Other

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10. In general, how often do you RECEIVE respite services? (Select one choice.)

Please pick one of the answers below or add your own.

- ○ Daily
- ○ Weekly
- ○ Monthly
- ○ Occasionally (e.g., vacation, emergency situations)
- ○ Did not receive respite service in the last 12-months

Other (please specify)

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11. What financial sources do you use for your respite services? (Check all that apply.)

Please check all that apply and/or add your own variant.

- ☐ Out of pocket personal account
- ☐ Community social service agency
- ☐ Federal, state, or local government agency
- ☐ Coverage from care recipient's insurance policy
- ☐ Volunteer program

Other (please specify)

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11.a Please indicate your estimated annual out-of-pocket respite expenses that you incur as a caregiver.

Please pick one of the answers below.

- ○ Under $500
- ○ $500 to $1,499
- ○ $1,500 to $2,999
- ○ $3,000 to $4,999
- ○ $5,000 and over

12. Is the amount of respite services you receive meeting your needs?

Please pick one of the answers below.

- ○ Yes
- ○ No

13. Does having respite enable you to care for your loved one(s)?

Please pick one of the answers below.

- ○ Yes
- ○ Unsure
- ○ No

SECTION II: Care Recipient Information

This section seeks information about the person or persons that you care for (also known as care recipient).

1. For each care recipient, indicate the age range, gender, the level of assistance provided to him/her, your relationship to the care recipient, and the amount of caregiving hours provided to him/her on a weekly basis. Click on the down arrow under each column to view and select your response.

Begin with Person A (row 1) then repeat for the second and third persons, if applicable.

Please fill in the answers in the table below (mark appropriate circles and squares and fill in the blank spaces).

Matrix: part 1 of 2

	Age range	Gender	Level of Assistance	Your relationship to care recipient
Person A	○ Under 5 years of age ○ 5-12 years of age ○ 13-17 years of age ○ 18-24 years of age ○ 25-39 years of age ○ 40-59 years of age ○ 60-74 years of age ○ 75-84 years of age ○ 85 years and older	○ Male ○ Female	○ Occasional assistance ○ Frequent assistance ○ Continous assistance	○ Sibling ○ Parent ○ Spouse/partner ○ Child ○ Grandchild ○ Other relative ○ Other non-relative ○ Other
Person B	○ Under 5 years of age ○ 5-12 years of age ○ 13-17 years of age ○ 18-24 years of age ○ 25-39 years of age ○ 40-59 years of age ○ 60-74 years of age ○ 75-84 years of age ○ 85 years and older	○ Male ○ Female	○ Occasional assistance ○ Frequent assistance ○ Continous assistance	○ Sibling ○ Parent ○ Spouse/partner ○ Child ○ Grandchild ○ Other relative ○ Other non-relative ○ Other
Person C	○ Under 5 years of age ○ 5-12 years of age ○ 13-17 years of age ○ 18-24 years of age ○ 25-39 years of age ○ 40-59 years of age ○ 60-74 years of age ○ 75-84 years of age ○ 85 years and older	○ Male ○ Female	○ Occasional assistance ○ Frequent assistance ○ Continous assistance	○ Sibling ○ Parent ○ Spouse/partner ○ Child ○ Grandchild ○ Other relative ○ Other non-relative ○ Other

This section seeks information about the person or persons that you care for (also known as care recipient).

1. For each care recipient, indicate the age range, gender, the level of assistance provided to him/her, your relationship to the care recipient, and the amount of caregiving hours provided to him/her on a weekly basis. Click on the down arrow under each column to view and select your response.

Begin with Person A (row 1) then repeat for the second and third persons, if applicable.

Please fill in the answers in the table below (mark appropriate circles and squares and fill in the blank spaces).

Matrix: part 2 of 2

	Weekly caregiving hours
Person A	○ Less than 10 hours ○ 10-19 hours ○ 20-29 hours ○ 30-39 hours ○ 40 or more hours ○ Constant care (24/7)
Person B	○ Less than 10 hours ○ 10-19 hours ○ 20-29 hours ○ 30-39 hours ○ 40 or more hours ○ Constant care (24/7)
Person C	○ Less than 10 hours ○ 10-19 hours ○ 20-29 hours ○ 30-39 hours ○ 40 or more hours ○ Constant care (24/7)

2. For each care recipient identified earlier, indicate the type or types of conditions she or he copes with on a daily basis? (Check all that apply.)

Please fill in the answers in the table below (mark appropriate circles and squares and fill in the blank spaces).

	Person A	Person B	Person C
Short term (acute) health/medical conditions	☐	☐	☐
Long term (chronic) health/medical conditions	☐	☐	☐
Behavioral disorder	☐	☐	☐
Cognitive impairment (e.g., confusion, forgetfulness) other than dementia and Alzheimer's Disease	☐	☐	☐
Dementia and Alzheimer's Disease	☐	☐	☐
Intellectual or developmental disabilities (including Autism Spectrum disorder)	☐	☐	☐
Mental health	☐	☐	☐
Mobility (e.g., walking), transfer (e.g., from bed to chair), and position (e.g., sitting in a chair) limitations	☐	☐	☐
Visual, hearing and other sensory conditions	☐	☐	☐

SECTION III: Demographic Information

Would you kindly share some demographic characteristics about yourself, NOT the individual needing care.

Massachusetts county of residence:

Please pick one of the answers below.

- ○ Barnstable
- ○ Berkshire
- ○ Bristol
- ○ Dukes
- ○ Essex
- ○ Franklin
- ○ Hampden
- ○ Hampshire
- ○ Middlesex
- ○ Nantucket
- ○ Norfolk
- ○ Suffolk
- ○ Plymouth
- ○ Worcester
- ○ Out of state

Gender:

Please pick one of the answers below.

- ○ Male
- ○ Female

Marital status:

Please pick one of the answers below.

- ○ Married/living with a partner
- ○ Single
- ○ Divorced or separated
- ○ Widowed

Age range:

Please pick one of the answers below.

- ○ 18-24 years of age
- ○ 25-34 years of age
- ○ 35-44 years of age
- ○ 45-54 years of age
- ○ 55-64 years of age
- ○ 65-74 years of age
- ○ 75-84 years of age
- ○ 85 years and over

Race:

Please pick one of the answers below.

- ○ One race: White
- ○ One race: Black or African American
- ○ One race: Asian
- ○ One race: American Indian or Alaskan Native
- ○ One race: Native Hawaiian or Other Pacific Islander
- ○ One race: Some other race
- ○ Two or more races

Hispanic, Latino or Spanish heritage:

Please pick one of the answers below.

- ○ Yes
- ○ No

Employment status:

Please pick one of the answers below.

- ○ Employed full time
- ○ Employed part time
- ○ Unemployed or looking for work
- ○ Not employed and no longer in the labor force (retired)
- ○ Not employed and not seeking employment
- ○ Skip question

In what manner has caregiving affected your employment in the past 12 months? (Check all that apply.)

Please check all that apply and/or add your own variant.

- ☐ No impact on my employment
- ☐ Arrived late or left work early
- ☐ Missed work days
- ☐ Used your vacation or other personal time to provide care
- ☐ Arranged for flexible work hours
- ☐ Reduced your official work hours
- ☐ Changed from full-time to part-time work
- ☐ Taken a leave of absence to provide care
- ☐ Taken a less demanding job
- ☐ Lost a promotional opportunity
- ☐ Considered taking early retirement or leaving the labor force

Other (please specify)

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Please share any additional comments regarding respite services that are important to you.

Please write your answer in the space below.

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If you would like information regarding the Massachusetts Lifespan Respite Coalition, please provide your email or other contact information.

Please use the blank space to write your answers.

Email

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Name

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Street

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PO Box

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City/Town

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State

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Zip

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