

Caregiver Survey

Thank you for taking our survey! The information you provide will help the Texas Health and Human Services Commission (HHSC) and their partners better understand the needs of people who care for others. We ask that you complete the questions in Section I. It will take about 20 minutes. Then, if you have additional time, we invite to respond to more questions in Section II that will help us better understand your responses. Section II should take about 10 minutes.

Your responses will not affect any services or benefits you receive because we will not know who answered this questionnaire. You are not required to complete this survey and you do not need to answer any question you don't want to answer. Your individual responses are confidential. Responses will only be reported after they are combined with the responses from everyone who took the survey.

Please read each question carefully. Some questions may be skipped depending on how you answered the previous question.

Section I – Please answer questions 1 through 19 in this section.

1. What is your ZIP code? _____

2. Do you have regular access to the Internet?

- Yes, I have regular access to the Internet at home, work or another place.
- No, I do not have regular access to the Internet.

3. Please read the following statement and answer the question below:

Some people provide regular unpaid care or assistance to a family member or friend who has a health condition, long-term illness or disability. They provide this care so that their family member or friend can maintain an independent lifestyle. This family member or friend could be an adult or a child. Assistance can range from a few hours of shopping and cleaning to intensive medical or personal care. Tasks can include shopping, house cleaning, cooking, giving medications, toileting assistance and so forth.

During the past month, did you provide this kind of unpaid care or assistance to a family member or friend?

- Yes
- No

If you did NOT provide unpaid care or assistance to a family member or friend in the past month, you may stop the survey now and return it in the envelope provided. Thank you!

4. Do you consider yourself to be a caregiver for your family member or friend?

- Yes
- No

Please read the definition of respite care, below, and answer the questions that follow.

Respite care is temporary or short-term care of an individual that is provided by someone other than the person's normal caregiver. It is designed to give the caregiver brief personal time away from the daily tasks of caregiving. Respite care is provided either in-home or out-of-home. It is offered by community organizations such as mental health centers, nursing homes, churches, or private agencies. These organizations provide either a paid worker or a trained volunteer to provide respite care.

5. Before you read the definition above, did you know what respite care was?

- Yes
- No

6. Have you used respite care in the past?

- Yes
- No

7. What do you think are the biggest benefits of getting respite care services? *If you have never received respite care services, please think about what the benefits would be if you did receive respite care.*

Please mark up to 3 things that would be most beneficial to you:

- Time for me to rejuvenate, catch up on sleep, or go on vacation
- Time for me to build relationships with family or spouse
- Time for me to attend events like sports, arts, or worship
- Time for me to run errands
- Time for me to go to my own (or another family members') doctor's appointments
- Time for me to pursue hobbies or educational goals
- Helps me focus on my job and maintain employment
- Helps prevent harm to self or loved-ones because of burn-out
- Time for me to learn about techniques and skills about caregiving
- Time for me to seek assistance with caregiver stress and burnout or time for me to participate in a caregiver support group
- Other; please specify: _____

8. In your opinion, how true is each statement below? Place a ✓ in the appropriate column.

If you have never used respite care services and don't know an answer, or if you don't have an opinion, please mark the last column "I don't know."

	Very True	Somewhat True	Not Very True	Not True at All	I don't know
a. Respite care provides safe and secure care.					
b. Respite care reduces my stress level as a caregiver.					
c. Respite care increases my ability to effectively provide care for my family member or friend.					
d. Respite care reduces the risk of neglect or mistreatment of my family member or friend.					
e. Respite care allows my family member or friend to live at home rather than moving to a residential facility, which could help reduce costs of care.					
f. I don't trust respite care providers.					
g. I am uncomfortable with having strangers in my home.					
h. My family member or friend would not allow someone else to assist him or her.					

9. What types of respite care do you think are available in your area? Please mark all of the types of services that you think are available in your area.

- In-home respite care
- Residential respite care
- Day activity programs
- I don't know what types of respite care programs are available in my area.

10. If you have received information about respite care services in the past, where did you get the information? Mark all that apply.

- Friend, family, or word of mouth
- Referral from a medical provider
- Referral from an Area Agency on Aging (AAA)
- Referral from an Aging and Disability Resource Center (ADRC)
- Referral from another social service agency
- Pamphlets from service agencies
- Website for the Department of Aging and Disability Services
- Website for Take Time Texas
- Other website
- 211 referral line
- Phone book
- Other; please specify: _____
- I don't remember.
- I have never received information about respite services before.

11. Has anyone ever helped you in the process of getting respite care services, such as provide you contact information for service providers and help you schedule the services?

- Yes *(Please go to question 11a.)*
- No *(Please skip to question 12.)*
- I'm not sure *(Please skip to question 12.)*

11a. If yes, who helped you?

- Friend or family member
- A medical provider
- Someone at an Area Agency on Aging (AAA)
- Someone at an Aging and Disability Resource Center (ADRC)
- Someone at another social service agency (such as a mental health agency)
- Someone at a religious organization (such as a church)
- Other; please specify: _____

12. Do you know how to find a respite provider that is licensed and reputable?

- Yes
- No

13. Do you know how to find out if a potential respite provider is a good fit for your needs?

- Yes
- No

14. Have you ever been unable to get respite care when you looked for it?

- Yes, I have looked for respite care in the past but was unable to find the right service. *(Please answer question 14a.)*
- No, I have always been able to get respite care when I needed it. *(Please skip to question 15.)*
- No, I have never tried to get respite care. *(Please skip to question 15.)*

14a. If you have looked for respite care and NOT been able to get it, why were you not able to get it? (Choose the top 3 reasons.)

- I could not afford it and no financial assistance was available.
- Language barriers – I could not find a provider who spoke my friend or family member’s language.
- I was placed on a wait list for services.
- Schedule availability of agency services did not meet my needs.
- Respite care was not available for the age or the special needs of my family member or friend.
- I could not get to the respite care provider because I had no transportation or it was too far away.
- Other, describe: _____

15. In a typical 6-month time period, about how often do you feel you need respite care?

Even if you have never used respite care, please think about how often you could use it.

- I don’t need any respite care.
- Less than once a month
- 1 to 2 times per month
- At least three times per month

16. How often have you actually received respite care in the past 6 months?

- I have not received any respite care.
- Less than once a month
- 1 to 2 times per month
- At least three times per month

17. When you use respite care, is it easy or difficult to arrange?

- Very easy *(Skip to question 18.)*
- Somewhat easy *(Skip to question 18.)*
- Unsure *(Skip to question 18.)*
- Somewhat difficult *(Please answer question 17a.)*
- Very difficult *(Please answer question 17a.)*
- Not applicable – I have never used respite care in the past. *(Please skip to question 18.)*

17a. If it is sometimes difficult to arrange respite care services, why is it difficult?

18. If you were to receive respite care services when you need it, how would it affect the amount of stress you feel about your caregiving responsibilities?

- I would feel a lot less stress.
- I would feel a little less stress.
- I would feel the same amount of stress.
- I would feel more stress.

19. Is there any information or advice you wish you had that would help you access respite services?

Thank you for completing Section I!

If you have a little more time, we'd like to ask a few more questions about you and your family member or friend and about respite services. Your responses to these questions will help us better understand the information you already provided us. However, if you need to, you may stop here and return the survey to us now.

Section II – *Optional Questions*

Now we'd like to ask you some questions about the person you care for. Please leave blank any questions you do not wish to answer.

20. How many people do you provide unpaid care or assistance for?

- 1
- 2
- 3 or more

If you provide care or assistance for more than one person, please think about the person for whom you provide the most care and answer the following questions for that person.

21. How long have you been providing care for your family member or friend?

- Less than one year
- 1 to 3 years
- 4 to 10 years
- More than 10 years

22. What kinds of care do you provide for your family member or friend? (Mark all that apply.)

- Companionship (talking, reading, keeping company) or supervision
- Transportation (driving to doctor's appointments, driving for errands)
- Homemaking (shopping, cleaning, preparing meals)
- Personal care assistance (feeding, bathing, toileting, dressing, grooming)
- Healthcare assistance (help with medications, wound care)
- Financial assistance (paying bills, managing budget)
- None of these activities – please specify other activity: _____

23. How much time do you spend each week helping this friend or family member?

- 5 hours per week or less
- 6 to 20 hours per week
- 21 to 40 hours per week
- More than 40 hours per week

*If you have used respite care services in the past, please answer questions 23 and 24.
If you have NEVER USED respite care services, please skip to question 25.*

24. If you used respite care in the past, who provided the service? (Check all that apply.)

- A relative or close friend
- A volunteer
- Home health care agency
- Private nursing care
- Mental health agency
- Emergency room
- Place of worship
- Adult daycare facility
- Day camp or overnight camp for children
- Specialized childcare center
- Foster care
- Other; please describe: _____

25. Where was the respite care provided?

- At home (my home or the home of my family member or friend)
- At a residential respite care center
- At a day activity program
- Other: _____

If you provide care or assistance for more than one person, please think about the person for whom you provide the most care and answer the following questions for that person.

26. What is your relationship to the person for whom you provide care?

I am the person's:

- spouse or partner
- adult child
- parent
- family member
- friend
- other: _____

27. What is the primary condition of the person you care for?

- Alzheimer's Disease or dementia
- Traumatic Brain Injury
- Cancer or lymphoma
- Intellectual, cognitive, or developmental disability
- Physical disability
- Heart or lung disease
- Chronic health condition
- No diagnosis
- Other: _____
- I prefer not to say.

Please provide the following information for both yourself and the person you care for. Please leave blank any information you do not wish to answer.

	<i>You</i>	<i>The Person You Care For</i>
<i>Gender</i>	<input type="checkbox"/> Female <input type="checkbox"/> Male	<input type="checkbox"/> Female <input type="checkbox"/> Male
<i>Age Group</i>	<input type="checkbox"/> 19 years or younger <input type="checkbox"/> 20 to 29 years <input type="checkbox"/> 30 to 39 years <input type="checkbox"/> 40 to 49 years <input type="checkbox"/> 50 to 59 years <input type="checkbox"/> 60 to 69 years <input type="checkbox"/> 70 to 79 years <input type="checkbox"/> 80 years or older	<input type="checkbox"/> 19 years or younger <input type="checkbox"/> 20 to 29 years <input type="checkbox"/> 30 to 39 years <input type="checkbox"/> 40 to 49 years <input type="checkbox"/> 50 to 59 years <input type="checkbox"/> 60 to 69 years <input type="checkbox"/> 70 to 79 years <input type="checkbox"/> 80 years or older
<i>Race</i>	<input type="checkbox"/> American Indian or Alaskan Native <input type="checkbox"/> Asian or Pacific Islander <input type="checkbox"/> Black (not of Hispanic origin) <input type="checkbox"/> Hispanic or Latino <input type="checkbox"/> White (not of Hispanic origin) <input type="checkbox"/> Other or multiple race	<input type="checkbox"/> American Indian or Alaskan Native <input type="checkbox"/> Asian or Pacific Islander <input type="checkbox"/> Black (not of Hispanic origin) <input type="checkbox"/> Hispanic or Latino <input type="checkbox"/> White (not of Hispanic origin) <input type="checkbox"/> Other or multiple race

Thank you!

Thank you for your help! Your responses will help us better understand the needs of caregivers and the ways they access respite care services.