

# Survey of Family Caregivers about Respite Services

## Introduction

Evaluation of the Lifespan Respite Care Program

IRB Protocol No.: X091222018

Explanation of Procedures: Greetings! Please reply to questions about your experience with respite services as a family caregiver. The Alabama Lifespan Respite Care Coalition asked evaluators from the UAB Center for Educational Accountability to assess respite services across the state. The Coalition will use the information you provide to plan improvements to lifespan respite services for caregivers of people with disabilities and chronic illness.

We will NOT collect your name or Email address without your permission. Your personal identity will not be revealed to others. It will require about 20 minutes to reply to the survey. You may refuse to answer any question or discontinue participation at any time without penalty. Responses will be automatically submitted to this online survey.

You will not receive any special consideration if you take part in this assessment. Call Dr. Brian Geiger at 205-975-5388 or Email [bgeiger@uab.edu](mailto:bgeiger@uab.edu), to answer your questions about the survey. Thanks for your participation!

If you have questions about your rights as a participant, or concerns or complaints about this activity, you may contact Ms. Sheila Moore. Ms. Moore is the Director of the Office of the Institutional Review Board for Human Use (OIRB). Ms. Moore may be reached at (205) 934-3789 or 1-800-822-8816. If calling the toll-free number, press the option for "all other calls" or for an operator/attendant and ask for extension 4-3789. (Regular hours for the Office of the IRB are 8:00 a.m. to 5:00 p.m. CT, Monday through Friday. You may also call this number in the event the research staff cannot be reached or you wish to talk to someone else.)

## Please tell us about yourself.

Please complete each of the following items.

### 1. What is your zip code?

### 2. What is your race or ethnic group? (Select all that apply.)

- Asian
- Black
- White
- Hispanic
- Other

### 3. What is your gender?

- Female
- Male

### 4. What is your age in years?

Enter a whole number, e.g. 45

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## 5. What is your marital status? (Select one response.)

- Single
- Married
- Separated
- Divorced
- Widowed

Other (please specify)

## 6. In what range is your annual family income? (Select one response.)

- \$20,000 or less
- \$20,001 - \$40,000
- \$40,001 - \$60,000
- \$60,001 - \$80,000
- More than \$80,000

## 7. How many people who live in your home have a disability or chronic illness requiring daily assistance?

## 8. Which best describes your relationship to the person with a disability or chronic illness? (Select all that apply.)

- Birth or adoptive parent
- Foster parent
- Grandparent
- Spouse or partner
- Sibling
- Son or daughter
- Close friend
- Other (please specify)

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## 9. Do you receive a Medicaid waiver for caregiver respite services?

- Yes
- No
- Don't Know

## 10. How often do you access caregiver respite services using your Medicaid waiver?

- Once each week
- Twice each month
- Two to three times each year
- Never

## 11. How do you expect respite services to help you as a caregiver?

## 12. What event(s) led you to seek respite services most recently? (Select all that apply)

- Relieve stress
- Improve relationship with my spouse or partner
- Improve relationship with other family member
- Care for myself
- Care for medical needs of another family member
- Safety issues
- Prevent alcohol or drug problems
- Care for personal business
- Participate in family support group/services
- Other (please specify)

## 13. Tell how members of your household were affected by the event(s):

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## 14. The most recent time I applied for caregiver respite services (Select all that apply.)

- I did not receive caregiver respite services
- I was placed on a waiting list for services
- I received respite services in my home
- I received respite services in an agency or community setting
- Other (please specify)

## 15. What agency or organization most recently provided caregiver respite services to you?

## 16. The most recent time I received caregiver respite services, it lasted

- Less than 1 day
- 1 day
- 2 days
- 3 or more days
- Other (please specify)

## 17. Was the length of time you received caregiver respite services enough?

- Yes
- No
- Don't Know

## 18. How would you feel if caregiver respite services were not available?

- Not at all stressed
- Somewhat stressed
- Moderately stressed
- Extremely stressed

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## 19. In your experience, how true is each statement about respite services?

	Very True	Somewhat True	Not at all True	Does Not Apply
Trained respite staff 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 level 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 for whom I provide care felt positively about respite.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Explain your answers

## Tell us about your experience

### 20. How many times have you been unable to find caregiver respite services when you needed them?

- Never
- One time
- Two times
- Three or more times

### 21. Consider your most recent experience with caregiver respite services. How long did you have to wait for respite services?

Days

Weeks

Months

### 22. Are you on a waiting list for caregiver respite services?

- Yes
- No
- Don't Know

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## 23. How did you learn about respite services in your community? (Select all that apply)

- Called a federal, state, or local agency for help
- 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)

## 24. Which agencies or organizations helped you find respite services as a caregiver? (Select all that apply.)

- Alabama Council for Developmental Disabilities (ACDD)
- Alabama Department of Education (SDE)
- Alabama Department of Human Resources (DHR)
- Alabama Department of Mental Health and Mental Retardation (MHMR)
- Alabama Department of Public Health (DPH)
- Alabama Department of Rehabilitation Services (DRS)
- Alabama Department of Senior Services (DSS)
- Alabama Department of Vocational Rehabilitation (VR)
- Alabama Respite
- Governor's Office on Disability
- United Cerebral Palsy (UCP)
- Veterans Administration (VA)
- Faith-based organizations (church, temple)
- Other (please specify)

Please tell us about the person for whom you MOST RECENTLY received respite services as a caregiver.

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**25. What is the gender of the person with a disability or chronic illness who requires daily care?**

Male

Female

**26. What is the age in years of the person with a disability or chronic illness who requires daily care?**

**27. How much assistance does the person with a disability or chronic illness require?**

No assistance

Occasional assistance

Frequent assistance

Continuous assistance

Don't know/unsure

Other (please specify)

**28. How much difficulty does the person with a disability or chronic illness have with each of the following?**

	No difficulty	Some difficulty	Much difficulty	Don't know Does not apply
Communication (e.g., speaking, hearing)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeding	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dressing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bathing and handwashing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Caring for mouth and teeth	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Toileting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cooking	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Taking medication as prescribed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transportation (driving, riding a bus)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

(please specify)

**Thank-you for your time and effort!**

Please answer these final questions.

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**29. What are your additional comments about caregiver respite services?**

  

**30. Would you like to receive a summary of the survey results? If so, please provide the following mailing information.**

Full Name:

Street Address:

City, State, Zip Code:

Email address (if available):

**31. May we contact you again to request additional information?**

Yes

No

Phone number or email address