

Respite Services for Family Caregivers - Survey of Agencies and Service

Introduction

Evaluation of the Lifespan Respite Care Program

IRB Protocol No.: X091222018

Explanation of Procedures: Greetings! Please reply to questions about your experiences as a respite service provider for family caregivers. 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, 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 job title?

Program coordinator or supervisor

Client or family case manager

Counselor or social worker

Therapist (OT, PT, etc.)

Agency director/administrator

Other (please specify)

Respite Services for Family Caregivers - Survey of Agencies and Service

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

- Asian
- Black
- White
- Hispanic
- Other

4. For how many years has your agency or organization provided respite care for family caregivers?

5. Estimate the number of family caregivers who have received respite services from your agency or organization during the past year.

6. Does your agency or organization accept Medicaid waivers for caregiver respite services?

- Yes
- No
- Don't Know

7. How often does your agency or organization provide caregiver respite services using a Medicaid waiver?

- Daily
- 2-3 times per week
- 2-3 times per month
- 2-3 times per year
- Never

8. What do family caregivers expect respite services to provide?

Respite Services for Family Caregivers - Survey of Agencies and Service

9. What event(s) most commonly lead family caregivers to seek respite services? (Select all that apply.)

- Change in family home situation
- Stressful family relationship
- Caregiver illness
- Health problem of a family member with a disability or chronic illness
- Family legal issues
- Caregiver need to seek or maintain employment
- Desire to participate in a support group or service
- Caregiver concerns about harm or violence
- Family alcohol or drug problems
- Other (please specify)

10. What is the average length of caregiver respite services provided by your agency or organization?

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

11. Is the average length of time of respite services sufficient for most family caregivers?

- Yes
- No
- Don't Know

12. Are you able to identify other agencies and organizations who provide respite services to family caregivers in your community?

- Yes
- No
- Don't Know

Respite Services for Family Caregivers - Survey of Agencies and Service

13. In your experience, how true is each statement about respite services for family caregivers?

	Very True	Somewhat True	Not at all True	Does Not Apply
Trained respite staff meets needs of family caregivers.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Respite offers a short-term break for family caregivers.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Respite reduces the risk of neglect or mistreatment of the family member with a disability or chronic illness.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Respite caregivers provide safe and secure care.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Respite enables family caregivers to focus on needs of others in the household.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Respite allows family caregivers to enjoy social and recreational activities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Respite reduces stress levels among family caregivers.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Respite increases family ability to effectively provide care.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Most family members with disabilities or chronic illnesses feel positively about respite.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Tell us about your experience

14. How many times have family caregivers known to you been unable to obtain respite services when needed?

- Never
- At least one time per month
- At least once per week
- Daily

15. What is the average wait to receive respite services for family caregivers known to you?

- Less than 1 week
- 1 week
- 2 weeks
- 3 weeks or more

Respite Services for Family Caregivers - Survey of Agencies and Service

16. How do families learn about respite services available in your community? (Select all that apply.)

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

17. Which agencies or organizations regularly help family caregivers to find respite services? (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 who is eligible to receive family respite services from your agency or organization.

Respite Services for Family Caregivers - Survey of Agencies and Service

18. Which age groups of individuals with disabilities or chronic illnesses are eligible for family caregiver respite services? (Select all that apply.)

- Infants
- Children
- Adults

19. In order to receive family respite services, where may the individual with a disability or chronic illness live? (Select all that apply.)

- In the parent's or guardian's home
- In the home of another family member
- In his/her own apartment or home

Other (please specify)

20. What level of supervision is your agency or organization able to provide for individuals with disabilities or chronic illnesses during family respite care?

- Occasional supervision
- Frequent supervision
- Continuous supervision
- Don't know/unsure

Other (please specify)

Respite Services for Family Caregivers - Survey of Agencies and Service

21. What level of assistance with life skills can respite caregivers from your agency or organization provide to a person with a disability or chronic illness?

	No assistance	Some assistance	Complete assistance	Don't know Does not apply
Communication (e.g., speaking, hearing)	jn	jn	jn	jn
Feeding	jn	jn	jn	jn
Dressing	jn	jn	jn	jn
Bathing and handwashing	jn	jn	jn	jn
Caring for mouth and teeth	jn	jn	jn	jn
Toileting	jn	jn	jn	jn
Cooking	jn	jn	jn	jn
Taking medication as prescribed	jn	jn	jn	jn
Transportation (driving, riding a bus)	jn	jn	jn	jn
Other	jn	jn	jn	jn

(please specify)

Thank-you for your time and effort!

Please answer these final questions.

22. What are the 3 most important training needs among employees of your agency or organization to provide family respite services ?

- A.
- B.
- C.

23. What are your additional comments about family caregiver respite services?

24. 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):

Respite Services for Family Caregivers - Survey of Agencies and Service

25. May we contact you again to request additional information?

Yes

No

Phone number or email address