

## **Delaware Lifespan Respite Care Network Caregiver Survey**

July 20, 2004

Dear Delaware Caregiver:

Do you need help in caring for a loved one? If so, you may be in need of respite care services.

Respite care gives temporary relief to caregivers like you who have the ongoing responsibility of caring for an individual with any form of disability or other special need, including someone with chronic or terminal illness. If you need temporary help caring for someone with disabilities or other special needs, then you may need respite services.

You have received this survey because your help is needed to improve respite services and make them more available in Delaware.

The Delaware Caregivers Support Coalition is a recently formed group of caregivers, health care providers, professionals, and disability advocates who are working on a project to expand respite services in the state. This group needs your help to understand the circumstances and needs of caregivers in Delaware so they can develop a plan to make respite services more available.

Please take a few minutes to fill out the enclosed survey to describe the challenges you face as a caregiver. Your answers will be reported along with those of other caregivers. You do not have to put your name on the survey; the survey is completely anonymous. **If you receive more than one copy of the survey, please return only one per each person that you care for.**

**Please return the survey in the enclosed postage paid envelope by August 2<sup>nd</sup>.**

This is an important survey and your views are extremely important! If you have questions about the survey or the coalition, please call Sara Whitehead at 1-800-677-3800.

Sincerely,

Sara Whitehead

Delaware Caregivers:

Thank you for taking time to fill out this survey. Your views are very important to help improve respite care in Delaware. **Please return this survey in the enclosed postage paid envelope by August 9<sup>th</sup>.** If you need additional copies of the survey or have questions, contact Sara Whitehead at 1-800-677-3800.

- 1) Is the person you help care for related to you?  
 Yes If so, how are they related? \_\_\_\_\_  
 No
  
- 2) Where does the person that you care for live?  
 a. Alone  
 b. In your home  
 c. With a spouse/family member  
 d. In a boarding or group home or assisted living facility  
 e. In a nursing home  
 f. Other (specify): \_\_\_\_\_
  
- 3) What are the main illnesses or problems of the person that you help? (Check all that apply.)  
 a. Alzheimer's/ Dementia/ Senility  
 b. AIDS  
 c. Developmental Disabilities/ Mental Retardation  
 d. Blindness/ Vision Loss  
 e. Chronic Disease (Cancer, Diabetes, Heart Disease, High Blood Pressure, Lung Disease, Multiple Sclerosis, Arthritis)  
 f. Mental Illness/ Emotional Disturbance  
 g. Mobility (Physical Limitations)  
 h. Stroke  
 i. Traumatic Brain Injury  
 j. Autism  
 k. Don't Know  
 l. Other (Specify): \_\_\_\_\_
  
- 4) In your view, how disabled is the person that you care for?  
 a. Mildly disabled (needs occasional help or supervision)  
 b. Moderately disabled (needs routine help or supervision)  
 c. Severely disabled (needs extensive/continuous help)
  
- 5) About how old is the person you care for?  
\_\_\_\_\_ years  
 Don't know
  
- 6) How old are you? \_\_\_\_\_

- 7) How long have you been helping to care for this person?
- a. Less than six months
  - b. Six months to a year
  - c. More than a year
  - d. \_\_\_ years
- 8) About how many hours do you spend caring for this person in an average week?
- Hours per week
  - Constant care
  - Don't know
- 9) Place a mark next to each area that describes the kind of help that you give to this person. (Check all that apply):
- a. Get in and out of bed and chairs
  - b. Get dressed
  - c. Get to and from the toilet
  - d. Bathe or shower
  - e. Help with diapers or remind to go to the bathroom
  - f. Feed
  - g. Give medications, pills, or injections
  - h. Manage finances (pay bills, fill out insurance forms)
  - i. Grocery shop
  - j. Do household work (wash dishes, do laundry)
  - k. Prepare meals
  - l. Transport by driving or help with public transportation
  - m. Provide companionship
  - n. Specialized medical care (suctioning, tube-feeding, physical therapy)
  - o. Run errands
  - p. Manage challenging behaviors
  - q. Help with communication skills
  - r. Other (specify): \_\_\_\_\_
- 10) Due to the behavior of the person that you help, have you ever been concerned:  
(check yes or no)
- a. For your own safety?  Yes  No
  - b. For the safety of others in the household?  Yes  No
  - c. For the safety of the person you help?  Yes  No
- 11) Do you receive any financial assistance that helps you care for this person?
- Yes
  - No
- 12) Is the person you care for covered by Medicaid or private health insurance?
- Covered by Medicaid
  - Covered by private insurance
  - Not covered by Medicaid or private insurance

13) What problems do you have in providing care? (Check all that apply.)

- a. Financial strain
- b. Not having enough time for other activities
- c. Conflict with my job
- d. Conflict with school
- e. Conflict with state or local agency
- f. Legal problems
- g. Conflict in my family
- h. Emotional strain/burnout
- i. Physical health strain
- j. Other: \_\_\_\_\_

14) Of all of the items that you checked, what is your greatest difficulty?

Choose one: \_\_\_\_\_

15) How often do you **currently get** help caring for this person?

- a. Every day
- b. Once or twice a week
- c. On an emergency basis
- d. Other (specify): \_\_\_\_\_

16) How often do you **need** help caring for this person?

- a. Every day
- b. Once or twice a week
- c. On an emergency basis
- d. Other (specify): \_\_\_\_\_

17) Approximately how much would you be willing to pay for respite care?

- \$ \_\_\_\_\_ Per hour
- \$ \_\_\_\_\_ Per day
- \$ \_\_\_\_\_ Overnight
- Not able to pay at this time

18) As a caregiver, what are you most concerned about in finding help to care for your loved one? (Feel free to attach additional sheets to share your concerns.)

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**Please return this completed survey to Sara Whitehead at Easter Seals, 61 Corporate Circle, New Castle, DE 19720, or use the enclosed postage paid envelope.**

**OPTIONAL: Please list the following information if you would like to receive a copy of the results of this survey:**

Name: \_\_\_\_\_  
Address: \_\_\_\_\_

Phone: \_\_\_\_\_  
Email: \_\_\_\_\_