



U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy

SURVEY FOR CAREGIVERS SUPPORTING A PERSON WITH A DISABILITY OUTSIDE OF THE DISABILITY SUPPORT SERVICE SYSTEM

ABT ASSOCIATES

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The opinions and views expressed in this report are those of the authors. They do not necessarily reflect the views of the Department of Health and Human Services, the contractor or any other funding organization.

TABLE OF CONTENTS

ACRONYMS ii

STATEMENT OF INFORMED CONSENT 1

DOMAIN 1: CAREGIVING RESPONSIBILITIES 3

DOMAIN 2: NEEDS OF CARE RECIPIENT AND CAREGIVERS 10

DOMAIN 3: EXPERIENCE WITH THE FORMAL SERVICES SYSTEM 15

DOMAIN 4: COMPENSATION STRATEGIES 18

DOMAIN 5: EXPECTATIONS AND PLANNING TOWARDS THE FUTURE 22

DOMAIN 6: DEMOGRAPHICS 25

ACRONYMS

The following acronyms are mentioned in this survey.

ABA	Applied Behavioral Analysis
ASPE	Office of the Assistant Secretary for Planning and Evaluation
CHAMP-VA	Civilian Health and Medical Program of the Department of Veterans Affairs
CHIP	Children's Health Insurance Program
CR	Care Recipient
IEP	Individualized Education Program
IRB	Institutional Review Board
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Income
VA	U.S. Department of Veterans Affairs

STATEMENT OF INFORMED CONSENT

Hello,

Thank you for your willingness to participate in the caregiver survey.

[CONTRACTOR NAME] is working on a research project with the Office of the Assistant Secretary for Planning and Evaluation (ASPE) to implement a survey about the characteristics and support activities of informal (not paid) caregivers for people with disabilities. This survey will address the following questions: (1) the key characteristics of the caregiving provided to individuals with disabilities or chronic health conditions under the age of 65; (2) caregiver and care recipient demographic characteristics; (3) informal caregiving strategies and challenges; and (4) the assistance caregivers need to facilitate short and long-term.

Here are a few points about your participation in the survey:

- This on-line survey will take approximately 15-20 minutes to complete.
- Your participation is entirely voluntary.
- You can refuse to take part in the survey and/or you can decline to respond to any survey item(s).
- Your responses and feedback will be confidential and your name will not be linked to your survey responses.
- Although your responses will be summarized with others in a report to ASPE, your name, any identifying information, and any responses specific to the person for whom you provide care will not appear in the report.
- There is a small risk of the loss of confidentiality as a result of participating in this survey.
- It is estimated that 1,276 individuals will participate in the caregiver survey.
- [Name of contractor] will receive and analyze the data which will be reported in the aggregate in a final report to ASPE.

I have read the foregoing information, and by filling out the survey and submitting my responses, I am consenting voluntarily to be a participant in this study.

If you have any questions regarding this survey, please contact [INSERT NAME AND NUMBER OF ASPE PROJECT OFFICER] or [INSERT NAME AND NUMBER OF CONTRACTOR PROJECT DIRECTOR AND/OR THE CONTRACTOR'S IRB].

DOMAIN 1: CAREGIVING RESPONSIBILITIES

Thank you for your time in responding to this survey. This first section asks about any assistance you might provide to another person, under 65 years old, because of a health condition or disability s/he has. This could include a physical, mental, emotional, cognitive, behavioral, or developmental disability, a chronic health condition or psychiatric condition, or blindness or deafness. It also asks for some information about the person who receives assistance.

1. Do you provide unpaid assistance or care to a family member or friend because of a health condition or disability? This could include a physical, mental, emotional, cognitive, behavioral or developmental disability; a chronic health condition or psychiatric condition, or blindness or deafness. Assistance can include medical care or help with everyday activities (including supervision or reminders).
 - a. Yes [GO TO Q3]
 - b. No [GO TO Q2]
 - c. Don't know [GO TO DOMAIN 6]
 - d. Refused [GO TO DOMAIN 6]

2. Does someone else in your home provide unpaid assistance to a family member or friend because of his or her disability or other health condition?
 - a. Yes [INSERT DIRECTION BASED ON MODE]
 - b. No [GO TO DOMAIN 6]
 - c. Don't know [GO TO DOMAIN 6]
 - d. Refused [GO TO DOMAIN 6]

3. Do you provide assistance to more than one person with a disability or chronic health condition?
 - a. Yes How many _____ [GO TO Q4]
 - b. No [GO TO Q4B]
 - c. Don't know [GO TO Q4B]
 - d. Refused [GO TO Q4B]

4. Beginning with the oldest person, how old is the oldest person to whom you provide assistance?

Age in years _____

4A. How old is the second oldest person to whom you provide assistance?

Age in years _____ [REPEAT UNTIL ALL CR AGES ARE DOCUMENTED]

[IF ALL Q4 \geq 65, GO TO DOMAIN 6. ELSE GO TO Q5]

4B. How old is the person to whom you provide assistance?

Age in years _____ [IF Q4B <65, GO TO Q6, IF Q4B \geq 65, GO TO DOMAIN 6]

4C. Can you provide the person's name, nickname, initials or pseudonym to use for the rest of the survey?

[USE IN PLACE OF CR]

5. This study is about assisting people under age 65. Please answer the rest of the questions thinking about the person to whom you provide the most assistance who is under age 65. What is the age of this person?

- a. <18
- b. 18-64

5A. Please provide the name, nickname, initials or pseudonym of this person.

[USE IN PLACE OF CR]

6. When thinking about the amount of care that [CR] receives, would you say:

- a. You are the primary caregiver?
- b. Someone else is the primary caregiver?
- c. You share caregiving responsibilities about equally with someone else?
- d. Don't know
- e. Refused

[IF CR<18, GO TO Q9, ELSE GO TO Q7]

7. Do you provide assistance, supervision or reminders to [CR], because of his/her condition or disability, with any of the following activities? [CHECK ALL THAT APPLY]
- a. Bathing or showering
 - b. Dressing
 - c. Eating
 - d. Getting in or out of bed or chairs
 - e. Using the toilet, including getting to and from the toilet
 - f. Refused
8. Do you provide assistance, supervision or reminders to [CR], because of his/her condition or disability, with any of the following activities? [CHECK ALL THAT APPLY]
- a. Preparing meals
 - b. Shopping
 - c. Managing money, such as keeping track of expenses or paying bills
 - d. Using the telephone, including texting
 - e. Provide support so that [CR] can participate in social events
 - f. Doing heavy work around the house like scrubbing floors, washing windows, and doing heavy yard work
 - g. Doing light work around the house like doing dishes, straightening up, light cleaning, or taking out the trash
 - h. Managing medications
 - i. Communicating with others
 - j. No
 - k. Refused

[GO TO Q12]

9. Does [CR] need or use more medical care, mental health, or educational services than is usual for most children of the same age?
- a. Yes
 - b. No
 - c. Don't know
 - d. Refused
10. Has [CR's] need for medical care, mental health, or educational services lasted or is expected to last 12 months or longer?
- a. Yes
 - b. No
 - c. Don't know
 - d. Refused

11. Is [CR] limited in any way in doing the things most children of the same age can do?
- Yes
 - No
 - Don't know
 - Refused
12. What are the reasons that [CR] needs assistance? [CHECK ALL THAT APPLY]
- A physical disability
 - An emotional or behavioral disability or psychiatric condition
 - A cognitive or intellectual disability
 - A developmental disability
 - Deafness or blindness
 - A chronic health condition
 - Other
 - Don't know
 - Refused
13. How long have you been providing assistance for [CR]; would you say
- Since [CR's] birth
 - 6 months or less
 - More than 6 months but less than 1 year
 - At least 1 year but less than 2 years
 - 2 years but less than 5 years
 - 5-10 years
 - More than 10 years
 - Refused
14. What kind of health insurance or health care coverage does [CR] have? [CHECK ALL THAT APPLY]
- Private health insurance
 - Medicare or Medi-Gap
 - Any state health insurance: Medicaid, CHIP
 - Any military health care: TRICARE/VA/CHAMP-VA
 - Indian Health Service
 - [CR] does not have health insurance
 - Refused
 - Don't know

15. Is anyone paid to provide paid assistance at home to [CR] because of his/her disability or condition?

- a. Yes
- b. No [GO TO Q18]
- c. Don't know [GO TO Q18]
- d. Refused [GO TO Q18]

16. Who pays for this assistance? [CHECK ALL THAT APPLY]

- a. I do
- b. [CR]
- c. Another family member or friend
- d. Private health insurance
- e. Church or other religious organization
- f. Government program, including state health programs
- g. Scholarships/grants
- h. Don't know
- i. Refused [GO TO Q18 UNLESS "f" IS CHECKED]

17. On average, how many hours a week of government-paid assistance does [CR] receive at home?

_____ Number of hours [IF Q17 >7 GO TO DOMAIN 6]

18. Where does [CR] live most days and nights of the week?

- a. At my home
- b. With relatives (not including me)
- c. With friends (not including me)
- d. In his/her own residence
- e. In a place that provides medical care and/or staff assistance with everyday activities [GO TO DOMAIN 6]
- f. In a therapeutic or foster care setting, supervised apartment or group home or in a private residential school [GO TO DOMAIN 6]
- g. Pediatric or adult residential or psychiatric treatment facility [GO TO DOMAIN 6]
- h. In a jail or prison [GO TO DOMAIN 6]
- i. Other (Please specify _____)
- j. Don't know
- k. Refused

19. What is your relationship to [CR]?

- a. [CR's] Parent
- b. [CR's] Husband or wife
- c. [CR's] Partner
- d. [CR's] Grandchild
- e. [CR's] Grandparent
- f. [CR's] Child
- g. [CR's] Brother or sister
- h. [CR's] Friend/ Family friend
- i. [CR's] Other relative
- j. Other (Please specify _____)
- k. Refused

20. Are you the legal guardian for [CR]

- a. Yes
- b. No
- c. Not applicable, [CR] under 18 and parent is respondent
- d. Refused

21. Does [CR] currently go to a day treatment, vocational rehabilitation or activity center for persons with disabilities or chronic health conditions during the normal working hours? Do not consider preschool, elementary, middle or high school or summer programs such as camp or school.

- a. Yes
- b. No [GO TO Q23]
- c. Don't know [GO TO Q23]
- d. Refused [GO TO Q23]

22. On average, how many hours a week does [CR] attend this program? If [CR] attends more than one program, please report the total number of hours across all programs.

_____ Number of hours [IF Q22 > 7 GO TO DOMAIN 6]

23. In the past month, how many days per week did you provide care and assistance to [CR] with daily activities?

_____ Days

24. On average, how many hours per day do you spend providing care and assistance to [CR]?
- a. 0-<1 hour
 - b. 1-2 hours
 - c. 3-4 hours
 - d. 5 hours or more
 - e. None
 - f. Refused

DOMAIN 2: NEEDS OF CARE RECIPIENT AND CAREGIVERS

The next set of questions address strategies and resources you use in helping [CR] and the additional support and resources you might need to continue providing help.

1. Which of the following resources have you used in your role as a caregiver for [CR]? [CHECK ALL THAT APPLY]
 - a. Friends/family
 - b. Volunteers
 - c. On-line communities or forums
 - d. Community resources such as libraries, local recreation programs
 - e. Community programs, such as legal aid, social services, and food pantries
 - f. Local respite or other services for people with disabilities
 - g. School-based services
 - h. Faith community/church
 - i. Advocacy groups
 - j. Support groups
 - k. Emergency services
 - l. Other (Please specify _____)
 - m. None
 - n. Refused

2. If you personally were unable to provide the assistance [CR] needs, is there someone else who would do the things you do?
 - a. Yes
 - b. No
 - c. Don't know
 - d. Refused

3. Thinking about the assistance that you provide to [CR], what parts have been challenging for you? [CHECK ALL THAT APPLY]
- a. Assisting [CR] with personal care such as eating, bathing, toileting, and dressing
 - b. Coordinating and managing medications, medical equipment and other medical care, including care coordination
 - c. Managing difficult behaviors
 - d. Managing and meeting [CR's] social needs
 - e. Managing and meeting [CR's] emotional needs
 - f. Helping [CR] to communicate with others
 - g. Understanding and managing [CR's] legal, financial and/or insurance issues or benefits
 - h. Coordinating or providing transportation
 - i. Finding paid help such as personal care attendants or respite workers
 - j. Finding activities that [CR] could participate in and qualify for
 - k. Other
 - l. None of the above [GO TO Q5]
 - m. Refused [GO TO Q5]
4. Which of these has been the most challenging?
- a. Assisting [CR] with personal care such as eating, bathing, toileting, and dressing
 - b. Coordinating and managing medications, medical equipment and other medical care, including care coordination
 - c. Managing difficult behaviors
 - d. Managing and meeting [CR's] social needs
 - e. Managing and meeting [CR's] emotional needs
 - f. Helping [CR] to communicate with others
 - g. Understanding and managing [CR's] legal, financial and/or insurance issues or benefits
 - h. Coordinating or providing transportation
 - i. Finding paid help such as personal care attendants or respite workers
 - j. Other (Please specify _____)
 - k. None of the above
 - l. Refused

5. What aspects of caregiving have been challenging to you personally? [CHECK ALL THAT APPLY]
- a. Meeting the financial burden of caregiving
 - b. Educating others, including school and health care personnel, about [CR's] disability or condition
 - c. Getting time with other family members, or meeting other family members' needs
 - d. Getting a short break of from caregiving
 - e. Managing the emotional or mental distress of caregiving
 - f. Finding a temporary substitute to provide occasional care for [CR]
 - g. Taking care of myself
 - h. Providing physical assistance, including lifting and carrying
 - i. Other (Please specify _____)
 - j. None of the above [GO TO Q7]
 - k. Refused [GO TO Q7]
6. Which of these has been the most challenging? [CHECK ALL THAT APPLY]
- a. Meeting the financial costs of caregiving
 - b. Educating others, including school and health care personnel, about [CR's] disability or condition
 - c. Getting time with other family members, or meeting other family members' needs
 - d. Getting a short break from caregiving
 - e. Managing the emotional or mental distress of caregiving
 - f. Finding a temporary substitute to provide occasional care for [CR]
 - g. Taking care of myself
 - h. Providing physical assistance, including lifting and carrying
 - i. Other (Please specify _____)
 - j. None of the above
 - k. Refused
7. In addition to what you currently have or use now, what additional medical-related support would help you as a caregiver? [CHECK ALL THAT APPLY]
- a. Mental health services, supports or therapy for me
 - b. Medical equipment and supplies such as nebulizers, hospital beds and wheelchairs for [CR]
 - c. Home medication and adaptive equipment such as hand rails, ramp and bath chairs for [CR]
 - d. Nutritional supplements such as Ensure, Boost, etc. for [CR]
 - e. Stress relief exercise such as yoga for me
 - f. I don't need any other medical help
 - g. Don't know
 - h. Refused

8. In addition to what you currently have or use now, what additional caregiving-related services would help you as a caregiver? [CHECK ALL THAT APPLY]
- a. Caregiver education or training; including medication management
 - b. Caregiver support group or advocacy group
 - c. In-home respite care or a temporary break from providing [CR's] care
 - d. Other in-home services, such as home health aide, personal care assistant, housekeeper, companion, etc.
 - e. Temporary out-of-home respite care
 - f. Child care
 - g. Other (Please specify _____)
 - h. I don't need any other help
 - i. Don't know
 - j. Refused
9. In addition to what you currently have or use now, what additional programs or services would help you as a caregiver? [CHECK ALL THAT APPLY]
- a. Legal assistance
 - b. Transportation
 - c. Financial planning and assistance
 - d. Programs or services geared to [CR's] social and emotional needs
 - e. Transition services
 - f. Other (Please specify _____)
 - g. I don't need any other help
 - h. Don't know
 - i. Refused
10. Have you received help or therapy from a social worker, psychologist, counselor, therapist, or physician because of your caregiving responsibilities?
- a. Yes
 - b. No [GO TO Q12]
 - c. Refused [GO to Q12]
11. Would you say this professional was helpful to you in dealing with your caregiving responsibilities? Would you say s/he was:
- a. Very helpful
 - b. Somewhat helpful
 - c. Neither helpful nor unhelpful
 - d. Somewhat unhelpful
 - e. Very unhelpful
 - f. Don't know
 - g. Refused

12. People sometimes have difficulties in meeting their essential household expenses for things such as mortgage, rent, utility bills, medical care, food or groceries. During the past 12 months, has there been a time when you or your household did not meet all of your essential expenses?
- a. Yes
 - b. No
 - c. Don't know
 - d. Refused
13. Do your caregiving responsibilities make it difficult to meet your essential household expenses?
- a. Yes
 - b. No
 - c. Don't know
 - d. Refused

DOMAIN 3: EXPERIENCE WITH THE FORMAL SERVICES SYSTEM

This section asks about your experience using or trying to use formal services and public programs to help care for [CR].

TABLE 1. List of Program and Services
Monthly cash payment for a disability from Social Security (SSDI or SSI), Worker's Compensation or VA
Mental health services (inpatient and outpatient) including substance abuse treatment
State-funded health insurance
Temporary care (more than 8 hours per week)
Occupational, speech and/or physical therapy
Specialized educational services, including Head Start, Early Intervention or an IEP
Behavioral modification services, such as ABA
Home health

1. Does [CR] currently receive [PROGRAM FILL FROM TABLE 1]?
 - a. Yes [GO TO Q2]
 - b. No [GO TO Q4]
 - c. Don't know [GO TO NEXT PROGRAM]
 - d. Refused [GO TO NEXT PROGRAM]

2. If [CR] did not receive [PROGRAM FILL FROM TABLE 1], could [CR] continue to function at the same level, where s/he currently lives?
 - a. Yes
 - b. No
 - c. Don't know
 - d. Refused

3. How important is it that [CR] receives [PROGRAM FILL FROM TABLE 1], for you to continue in your role as a caregiver? Would you say
 - a. Very important
 - b. Somewhat important
 - c. A little important
 - d. Not at all important
 - e. Don't know
 - f. Refused

[ALL GO TO NEXT PROGRAM]

4. Have you or someone else ever helped [CR] try to access [PROGRAM FILL FROM TABLE 1]?
 - a. Yes [GO TO Q5]
 - b. No [GO TO Q6]
 - c. Don't know [GO TO NEXT PROGRAM]
 - d. Refused [GO TO NEXT PROGRAM]

5. Which best describes what happened when [CR] tried to access [PROGRAM FILL FROM TABLE 1]? [CHECK ALL THAT APPLY]
 - a. [CR] did not qualify for [PROGRAM FILL FROM TABLE 1] because of [CR's] diagnosis, condition type, or related program eligibility rules
 - b. [CR] did not qualify for [PROGRAM FILL FROM TABLE 1] because of the program's income guidelines or financial rules
 - c. [CR] received [PROGRAM FILL FROM TABLE 1] in the past but stopped because she/he no longer wanted it
 - d. [CR] received [PROGRAM FILL FROM TABLE 1] in the past but stopped because it was not helpful
 - e. [CR] received [PROGRAM FILL FROM TABLE 1] in the past but no longer needs it
 - f. [CR] was put on a waiting list
 - g. [CR's] application was denied because not all forms or documents were included or forms were lost by agency
 - h. Did not complete because process was too difficult
 - i. Could not afford additional costs
 - j. Don't know
 - k. Refused

[ALL GO TO NEXT PROGRAM]

6. Why didn't you help [CR] try to access [PROGRAM FILL FROM TABLE 1]?
[CHECK ALL THAT APPLY]

- a. [CR] does not need this program
- b. It is too difficult to access
- c. [CR] does not have the necessary forms and documents
- d. It is not worth the hassle
- e. I don't think [CR] is eligible for [PROGRAM FILL FROM TABLE 1]
- f. I don't like or trust government programs
- g. I have never heard of [PROGRAM FILL FROM TABLE 1] before
- h. The program does not meet CR's need
- i. The program is not flexible enough for me or CR's needs
- j. [PROGRAM FILL FROM TABLE 1] is not available where we live
- k. Don't know
- l. Refused

[ALL GO TO NEXT PROGRAM]

7. Have you changed where you live so you could get services for [CR]?

- a. Yes
- b. No
- c. Refused

DOMAIN 4: COMPENSATION STRATEGIES

This next set of questions asks about ways that you make sure [CR] gets the help s/he needs.

1. People manage their caregiving responsibilities in different ways. Which of these describes your approach? [CHECK ALL THAT APPLY]
 - a. Shared responsibilities with spouse or other family member
 - b. Asked a family member for help
 - c. Asked a friend for help
 - d. Stopped working
 - e. Worked less but did not stop working
 - f. Hired help
 - g. Applied for government assistance
 - h. Sought other resources
 - i. Prayed
 - j. None of the above
 - k. Refused

2. Do you share the responsibilities of handling the finances related to [CR's] condition and/or health needs?
 - a. Yes
 - b. No
 - c. Refused

3. In an average month, about how much do you and your family pay for [CR's] medicine, medical care, durable equipment, diets or specialized foods, and other types of assistance that is not covered by insurance/benefits? Please include copays for doctor visits, tests, procedures, prescription drugs and medical supplies, but do not include health insurance premiums or any amount paid by [CR's] insurance.
 - a. \$1,000 or more
 - b. \$500-\$999
 - c. \$250-\$499
 - d. \$101-\$250
 - e. \$1-100
 - f. Nothing or \$0
 - g. Don't know
 - h. Refused

4. What is your current work status?
- a. Working full-time (35 or more hours per week) for pay at a job or business [GO TO Q7]
 - b. Working part-time (fewer than 35 hours per week) for pay at a job or business [GO TO Q5]
 - c. Self-employed [GO TO Q5]
 - d. Looking for work [GO TO DOMAIN 5]
 - e. Not working at a job or business and not looking for work [GO TO Q5]
 - f. Not working due to my own health or a disability [GO TO DOMAIN 5]
 - g. Retired
 - h. Refused [GO TO DOMAIN 5]

5. Is this your current work situation because your caregiving responsibilities prevent you from working full-time or some other reason?
- a. Caregiving responsibilities prevent me from working full-time
 - b. No, some other reason
 - c. Refused

[IF Q4 = "e" GO TO DOMAIN 5, ELSE GO TO Q6]

6. How many hours per week do you typically work for pay?
- a. _____ hours per week
 - b. Don't know
 - c. Refused
7. How often do you have the flexibility you need at work to manage your caregiving responsibilities. Would you say...
- a. Never
 - b. Sometimes
 - c. Usually
 - d. Always
 - e. Refused

8. [ASK ONLY IF RESPONDENTS REPORTED SHARING CAREGIVING RESPONSIBILITIES] How often does the family member you share caregiving with have the flexibility she/he needs at work to manage his/her caregiving responsibilities. Would you say...
- Never
 - Sometimes
 - Usually
 - Always
 - Not applicable (no shared caregiving or other caregiver does not work)
 - Refused
9. How often have you had too little time for work because of your caregiving responsibilities? Would you say...
- Never
 - Sometimes
 - Usually
 - Always
 - Refused
10. To manage your caregiving responsibilities, have you... [CHECK ALL THAT APPLY]
- Taken time off from work to take [CR] to health care or other appointments?
 - Permanently reduced the number of hours you work?
 - Taken paid leave from work so that you could care for [CR]?
 - Taken unpaid leave from work so that you could care for [CR]?
 - Changed your work schedule to coordinate with other family members' work schedules?
 - Worked a flexible schedule so that you could care for [CR]?
 - Shared your job with another person so that you could care for [CR]?
 - Changed a job because of the schedule or flexibility it offered?
 - Missed career development opportunities such as promotions?
 - None of these

11. To manage your caregiving responsibilities, has someone else in your family...
[CHECK ALL THAT APPLY]

- a. Taken time off from work to take [CR] to health care or other appointments?
- b. Permanently reduced the number of hours he/she works?
- c. Taken paid leave from work so that he/she could care for [CR]?
- d. Taken unpaid leave from work so that he/she could care for [CR]?
- e. Changed his/her work schedule to coordinate with other family members' work schedules?
- f. Worked a flexible schedule so that he/she could care for [CR]?
- g. Shared your job with another person so that he/she could care for [CR]?
- h. Changed a job because of the flexibility it offered?
- i. Missed career development opportunities such as promotions?
- j. None of these

DOMAIN 5: EXPECTATION AND PLANNING TOWARDS THE FUTURE

These next questions ask about your future expectations for [CR] and what you have done and will need to meet those expectations.

1. What kind of activities is [CR] involved in at this time? [CHECK ALL THAT APPLY]
 - a. Working at a paid job in the community
 - b. Unpaid or volunteer work
 - c. Going to school
 - d. Attending church or religious services
 - e. Attending family events
 - f. Participating in sports, recreation, or social events
 - g. Self-advocacy
 - h. Other (Please specify _____)
 - i. Don't know
 - j. Refused

2. What kinds of activities do you hope that [CR] becomes involved in one year from now? [CHECK ALL THAT APPLY]
 - a. Working at a paid job in the community
 - b. Unpaid or volunteer work
 - c. Going to school
 - d. Attending community events with support
 - e. Attending community events without support
 - f. Self-advocacy
 - g. Don't know
 - h. Refused

3. What do you think is needed to make these things happen? (Please explain _____)

4. Based on everything you know about [CR] and his/her care needs, where do you think it is most likely that [CR] will be living 5 years from now?
- a. At my home
 - b. With relatives (not including me)
 - c. With friends (not including me)
 - d. In his/her own residence
 - e. At college/in a dorm
 - f. In a therapeutic foster care setting, supervised apartment or group home or in a private residential school or facility
 - g. In a pediatric or adult residential treatment or psychiatric treatment facility
 - h. Other (Please specify _____)
 - i. Don't know
 - j. Refused
5. Ideally, where do you hope [CR] will be living 5 years from now? [CHECK ALL THAT APPLY]
- a. At my home
 - b. With relatives (not including me)
 - c. With friends (not including me)
 - d. In his/her own residence
 - e. At college/in a dorm
 - f. In a therapeutic foster care setting, supervised apartment or group home or in a private residential school or facility
 - g. In a pediatric or adult residential treatment or psychiatric treatment facility
 - h. Other (Please specify _____)
 - i. Don't know
 - j. Refused

6. What steps, if any, have you taken to make this happen? [CHECK ALL THAT APPLY]
- a. Looked into medical and/or health care supports
 - b. Looked into income supports or cash assistance program
 - c. Looked into housing supports
 - d. Looked into education, independent living training or employment supports
 - e. Looked into transportation services
 - f. Looked into legal advocacy or legal services
 - g. Looked into family support services
 - h. Looked into getting help to find out about choices
 - i. Researched for available seminars
 - j. Saved money
 - k. Asked for assistance from family/friends
 - l. Applied for benefits
 - m. Prayed
 - n. Other
 - o. None
 - p. Refused

DOMAIN 6: DEMOGRAPHICS

To help us understand more about caregivers, these last few questions are about you and your household.

1. What is your age?
 - a. 18-34
 - b. 35-44
 - c. 45-59
 - d. 60-64
 - e. 65-74
 - f. 75 or older
 - g. Refused
2. Are you male or female?
 - a. Male
 - b. Female
3. Which of the following best represents how you think of yourself?
 - a. Lesbian or gay
 - b. Straight, that is not lesbian or gay
 - c. Bisexual
 - d. Something else
 - e. Refused
 - f. Don't know
4. What is your race? [CHECK ALL THAT APPLY]
 - a. White
 - b. Black/African American
 - c. American Indian/Alaskan Native
 - d. Asian
 - e. Native Hawaiian/Other Pacific Islander
 - f. Other
5. Are you of Hispanic or Latino/a Origin?
 - a. Yes
 - b. No, not of Hispanic, Latino/a, or Spanish origin

6. What is your marital status?
 - a. Married
 - b. Widowed
 - c. Divorced
 - d. Separated
 - e. Never married
 - f. Refused

7. What is the highest grade or year of school you have completed?
 - a. 8th grade or less
 - b. Some high school, but did not graduate
 - c. High school graduate or GED completed
 - d. Some college or 2-year degree
 - e. 4-year college graduate
 - f. More than 4-year college degree
 - g. Don't know
 - h. Refused

8. In general, how would you rate your overall health?
 - a. Excellent
 - b. Very good
 - c. Good
 - d. Fair
 - e. Poor
 - f. Refused

9. In general, how would you rate your overall mental or emotional health?
 - a. Excellent
 - b. Very good
 - c. Good
 - d. Fair
 - e. Poor
 - f. Refused

10. We do not need to know exactly, but just roughly, could you tell me if your annual household income from all sources before taxes is... [READ]
- a. Less than \$24,250
 - b. \$24,250-\$48,500
 - c. \$48,501-\$72,750
 - d. \$72,751-\$97,000
 - e. \$97,001-\$150,000
 - f. More than \$150,000
 - g. Don't know
 - h. Refused

Survey Closing

Is there anything that we have not asked you that you think is important for us to know?
If yes, please specify: _____

Thank you very much for your time. Your participation is invaluable.

To obtain a printed copy of this report, send the full report title and your mailing information to:

U.S. Department of Health and Human Services
Office of Disability, Aging and Long-Term Care Policy
Room 424E, H.H. Humphrey Building
200 Independence Avenue, S.W.
Washington, D.C. 20201
FAX: 202-401-7733
Email: webmaster.DALTCP@hhs.gov

NOTE: All requests must be in writing.

RETURN TO:

Office of Disability, Aging and Long-Term Care Policy (DALTCP) Home
<http://aspe.hhs.gov/office-disability-aging-and-long-term-care-policy-daltcp>

Assistant Secretary for Planning and Evaluation (ASPE) Home
<http://aspe.hhs.gov>

U.S. Department of Health and Human Services (HHS) Home
<http://www.hhs.gov>