

## 18th ACL National Survey of Older Americans Act Participants Caregiver Questionnaire

This is the U.S. Department of Health and Human Services' Administration for Community Living (ACL) National Survey of Older Americans Act Participants (NSOAAP) for people receiving services from the National Family Caregiver Support Program (NFCSP).

It is very important that the questions in this booklet be answered by the person addressed in the letter. That person may receive assistance filling out the questionnaire, if needed, but the questions should be answered from his or her point of view.

You may skip any question that you do not want to answer, but we would really appreciate your answering all the questions you can.

**MAILING INSTRUCTIONS:** Please return your completed questionnaire in the pre-addressed postage paid envelope. If you have any questions about the questionnaire, please feel free to call us at 1-855-519-7052.

According to the Paperwork Reduction Act of 1995 5 CFR § 1320.8(b)(3), no persons are required to respond to a collection of information unless such collection displays a valid OMB control number (OMB 0985-0023). Public reporting burden for this collection of information is estimated to average 30 minutes per response, including time for gathering, maintaining the data needed, completing, and reviewing the collection of information. The obligation to respond to this collection is voluntary under the GPRA Modernization Act of 2010 (GPRAMA), and the Older Americans Act (OAA) Section 202(f). This collection of information gathers data through an annual cross-sectional survey of OAA participants. ACL uses collected data to assess among OAA program participants the following issues associated with aging in place: importance of staying safely in the home; available assistance and informal support; the use of home features or modifications; and the need for and consideration of home features or modifications. Data will be kept private to the extent allowed by law. The survey instrument and collection of data, takes the following precautions: All project staff, including recruitment specialists, telephone interviewers, research analysts, and systems analysts, receive training in the disclosure requirements of the survey and are required to sign statements affirming their obligation to maintain privacy. Only staff who are authorized to work on the National Survey have access to client contact information, completed survey instruments, and data files. Data files that are delivered contain no personal identifiers for program participants. Analysis and publication of survey findings are in terms of aggregated statistics only. Send comments regarding the burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to Center for Policy and Evaluation, Administration for Community Living, U.S. Department of Health and Human Services, 330 C Street, SW, Washington, DC 20201 or Email [evaluation@acl.hhs.gov](mailto:evaluation@acl.hhs.gov).

## A. Caregiver Support Services

A1. Are you taking care of another adult person aged 60 years or older?

- a. Yes
- b. Unsure
- c. No

**If you marked No:**

THANK YOU. The focus of this survey is on informal caregivers who are currently providing care to a family member or loved one. If you are not currently a caregiver for another adult person aged 60 years or older, please stop here and go to mailing information on page 21. Thank you for your interest in participating.

In this survey, we refer to the person who is being cared for as the “Care Receiver” and the person providing care as the “Caregiver”.

A2. Do you help your care receiver with...?

	Yes	No
a. Activities like dressing, eating, bathing, or getting to the bathroom	<input type="checkbox"/>	<input type="checkbox"/>
b. Medical needs such as taking medicine or changing bandages	<input type="checkbox"/>	<input type="checkbox"/>
c. Keeping track of bills, checks, or other financial matters	<input type="checkbox"/>	<input type="checkbox"/>
d. Preparing meals, doing laundry, or cleaning the house	<input type="checkbox"/>	<input type="checkbox"/>
e. Local trips, such as going shopping or to the doctor’s office	<input type="checkbox"/>	<input type="checkbox"/>
f. Arranging for care or services provided by others	<input type="checkbox"/>	<input type="checkbox"/>

A3. Did you mark "Yes" to any of the activities above (items a-f)?

- a. Yes (go to A4)
- b. No

**If you marked No:**

THANK YOU. The focus of this survey is on informal caregivers who are currently providing care to a family member or loved one. If you are not currently a caregiver for another adult person aged 60 years or older, please stop here and go to mailing information on page 21. Thank you for your interest in participating.

A4. What prompted you to contact the Area Agency for Aging?

- a. Medical or health issue or hospitalization
- b. Spouse, son/daughter, sibling, friend no longer able to help
- c. Paid caregiver quit
- d. Recently moved to the area
- e. Needed transportation
- f. Just wanted information
- g. Waiting list
- h. Needed assistance locating or accessing services
- i. Don’t remember

A5. How long have you been receiving caregiver support services?

- a. 6 months or less
- b. More than 6 months, but less than 1 year
- c. At least 1 year, but less than 2 years
- d. 2 to 5 years
- e. 5 to 10 years
- f. 11 to 20 years
- g. More than 20 years
- h. Never received caregiver support services

**If you marked “Never received caregiver support services”:**

THANK YOU. The focus of this survey is on informal caregivers who are currently providing care to a family member or loved one and receiving services from the National Family Caregiver Support Program provided through an Area Agency on Aging. If you have not received any caregiver support from this program, please stop here and go to mailing information on page 21. Thank you for your interest in participating.

A6. We’re interested in understanding your relationship with the person you take care of (your care receiver). For example, if the care receiver is your husband, mark “Wife”.

You are your care receiver's...

- a. Husband
- b. Wife
- c. Partner
- d. Son or Step-son
- e. Son-in-law
- f. Daughter or Step-daughter
- g. Daughter-in-law
- h. Father
- i. Mother
- j. Mother-in-law or father-in-law
- k. Brother
- l. Sister
- m. Sister-in-law or brother-in-law
- n. Granddaughter
- o. Grandson
- p. Niece
- q. Nephew
- r. Cousin
- s. Other relative
- t. A friend or a neighbor or another person

The next few questions are about caregiving experiences.

A7. If your care receiver needed a greater amount of care, would you be able to increase your caregiving responsibilities?

- a. Yes
- b. No

A8. Do you know where to go to ask for respite care? *Respite care allows you a brief period of rest or relief while temporary care is provided to your care receiver in your home or your care receiver's home or someplace else.*

- a. Yes
- b. No

A9. Have you attended caregiver education or training such as classroom or on-line courses?

- a. Yes (go to A11)
- b. No

A10. Do you have a need for caregiver education or training, such as classroom or on-line courses?

- a. Yes
- b. No

A11. Have you attended counseling to assist with your specific caregiving situation?

- a. Yes (go to A13)
- b. No

A12. Do you have a need for counseling to assist with your specific caregiving situation?

- a. Yes
- b. No

A13. Have you attended caregiver support groups?

- a. Yes (go to A15)
- b. No

A14. Do you have a need for attending caregiver support groups?

- a. Yes
- b. No

A15. In the last year, have you needed assistance with applying or accessing other programs or services for your care receiver or yourself?

- a. Yes
- b. No

A16. Have the family caregiver services provided supplemental services such as...?

	Yes	No
a. Home modifications, such as a ramp or grab bar	<input type="checkbox"/>	<input type="checkbox"/>
b. Liquid nutritional supplements, such as Ensure, Boost, or Glucerna	<input type="checkbox"/>	<input type="checkbox"/>
c. Walkers, canes, crutches, Hoyer Lift, microwaves	<input type="checkbox"/>	<input type="checkbox"/>
d. Emergency response systems, CPAP or apnea machines, hospital bed, a device to monitor wandering	<input type="checkbox"/>	<input type="checkbox"/>
e. Consumable supplies such as wound care, catheter, or incontinence supplies ( <i>Consumable supplies are things that you use once and throw away.</i> )	<input type="checkbox"/>	<input type="checkbox"/>
f. Money or stipend	<input type="checkbox"/>	<input type="checkbox"/>

A17. As a result of the caregiver services you have received, do you...?

	Yes	No
a. Have more time for personal activities	<input type="checkbox"/>	<input type="checkbox"/>
b. Feel less stress	<input type="checkbox"/>	<input type="checkbox"/>
c. Find it easier to care for your care receiver	<input type="checkbox"/>	<input type="checkbox"/>
d. Have a clearer understanding of how to get the services you and your care receiver need	<input type="checkbox"/>	<input type="checkbox"/>
e. Know more about your care receiver's condition or illness	<input type="checkbox"/>	<input type="checkbox"/>

A18. Have these caregiver services helped you to be a better caregiver?

- a. Yes
- b. No

A19. Have these caregiver services enabled you to provide care for your care receiver for a longer time than would have been possible without these services?

- a. Yes
- b. No

A20. Overall, how would you rate the caregiver support services you received?

- a. Excellent
- b. Very good
- c. Good
- d. Fair
- e. Poor

A21. Has it been difficult for you to get services from agencies for your care receiver?

- a. Yes
- b. No

## **B. Caregiving and Employment/Expenses**

The next few questions are about your employment.

B1. Are you currently employed?

- a. Yes
- b. No (go to B5)

B2. Has providing care for your care receiver interfered with your job?

- a. Yes
- b. No (go to B5)

B3. Because of providing care for your care receiver, did you...?

	Yes	No
a. Take a less demanding job	<input type="checkbox"/>	<input type="checkbox"/>
b. Change from full-time to part-time work or reduce your official working hours	<input type="checkbox"/>	<input type="checkbox"/>
c. Lose some of your employment fringe benefits	<input type="checkbox"/>	<input type="checkbox"/>
d. Have time conflicts between working and caregiving	<input type="checkbox"/>	<input type="checkbox"/>
e. Use your vacation time to provide care	<input type="checkbox"/>	<input type="checkbox"/>
f. Take a leave of absence to provide care	<input type="checkbox"/>	<input type="checkbox"/>
g. Lose a promotion	<input type="checkbox"/>	<input type="checkbox"/>
h. Work less than your normal number of hours last month	<input type="checkbox"/>	<input type="checkbox"/>

B4. Did the caregiver support services help you deal with these work difficulties?

- a. Yes
- b. No

B5. Due to caregiving-related changes in your employment or expenses, have you had to...?

	Yes	No
a. Dip into your savings	<input type="checkbox"/>	<input type="checkbox"/>
b. Cut back on your own spending for vacations or travel, entertainment, going out, or other leisure activities	<input type="checkbox"/>	<input type="checkbox"/>
c. Cut down on your own spending for groceries or meals	<input type="checkbox"/>	<input type="checkbox"/>
d. Cut back on your own spending on health care, dental care, or prescription medicine	<input type="checkbox"/>	<input type="checkbox"/>
e. Cut back on your own spending for household expenses and maintenance	<input type="checkbox"/>	<input type="checkbox"/>
f. Quit your job	<input type="checkbox"/>	<input type="checkbox"/>

The following questions are about your situation as a caregiver.

B6. How much satisfaction do you gain from performing your care tasks?

- a. No satisfaction
- b. Some satisfaction
- c. A lot of satisfaction

B7. In the last year, have you used your own money to pay for your care receiver's...?

	Yes	No
a. Medications or medical care	<input type="checkbox"/>	<input type="checkbox"/>
b. Insurance premiums or copayments	<input type="checkbox"/>	<input type="checkbox"/>
c. Mobility devices, such as walkers, canes, or wheelchairs	<input type="checkbox"/>	<input type="checkbox"/>
d. Features that have made your care receiver's home safer, such as a railing or ramp, grab bars in the bathroom, a seat for the shower or tub or an emergency response system	<input type="checkbox"/>	<input type="checkbox"/>
e. Any other assistive devices that make it easier or safer to do activities or allow your care receiver to do them on their own	<input type="checkbox"/>	<input type="checkbox"/>

## C. Well-Being and Health

C1. The following questions are about how **you** feel these days.

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. How much of the time during the past four weeks have you felt calm and peaceful?	<input type="checkbox"/>				
b. How much of the time during the past four weeks have you had a lot of energy?	<input type="checkbox"/>				
c. How much of the time during the past four weeks have you felt downhearted or depressed?	<input type="checkbox"/>				

C2. Regarding your present social activities, do you feel that you are doing...

- About enough
- Too much
- Would like to be doing more

C3. Have your social opportunities increased since you became involved with your Area Agency on Aging services?

- Yes
- No

C4. How often does.....?

	Always	Usually	Sometimes	Rarely	Never
a. Caregiving prevent you from having enough time for yourself	<input type="checkbox"/>				
b. Caregiving prevent you from having enough time for your family	<input type="checkbox"/>				
c. Caregiving conflict with your social life	<input type="checkbox"/>				
d. Being a caregiver for your care receiver give you the joy of spending time with someone you care about	<input type="checkbox"/>				
e. Being a caregiver provide you with a sense of accomplishment	<input type="checkbox"/>				

C5. How often do you feel that your care receiver appreciates the care that you are providing?

- Always
- Usually
- Sometimes
- Rarely
- Never

C6. As a caregiver, how often do you feel you are fulfilling your duty by caring for your care receiver?

- a. Always
- b. Usually
- c. Sometimes
- d. Rarely
- e. Never

C7. For the next set of questions, please respond to how true the statement is for you.

	Not at all true	Hardly true	Moderately true	Exactly true
a. You are confident that you could deal efficiently with unexpected events.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. You can remain calm when facing difficulties because you can rely on your coping abilities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. You can usually handle whatever comes your way.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C8. Compared to one year ago, how would you rate your health in general now? Would you say...

- a. Much better
- b. Somewhat better
- c. About the same
- d. Somewhat worse
- e. Much worse

C9. In the past month, have you been bothered by pain?

- a. Yes
- b. No (go to C11)

C10. In the last month, how often has pain limited your activities?

- a. Every day
- b. Most days
- c. Some days
- d. Rarely
- e. Never

C11. In the past 12 months, have you been to see a doctor or gone to an urgent care center? *Do not include going to the hospital emergency department. Doctor includes Physician Assistant or Nurse Practitioner.*

- a. Yes
- b. No

C12. In the past 12 months, have you ever missed or delayed routine doctor visits because of your caregiving situation?

- a. Yes
- b. No

C13. In the past 12 months, did you go to a hospital emergency department for a health problem of your own?

- a. Yes
- b. No (go to C15)

C14. In the past 12 months, how many times did you go to a hospital emergency department?

\_\_\_\_\_ Number of times at hospital emergency department

C15. In the past 12 months, did you have to stay overnight in a hospital?

- a. Yes
- b. No (go to D1)

C16. In the past 12 months, how many times were you hospitalized for one night or longer?

\_\_\_\_\_ Number of times hospitalized overnight

## D. Caregiving Situation

D1. Thinking about all the family members or friends who provide help, care, or supervision for your care receiver, what proportion of the care do **you** provide during a typical week?

- a. Less than one-quarter
- b. About one-quarter
- c. About one-half
- d. About three-quarters
- e. All or almost all of the care

The next set of questions ask about any thoughts you have had about alternative types of care.

D2. In the past 6 months, have you ever considered a nursing home, boarding home, or assisted living for your care receiver?

- a. Yes
- b. No

D3. In the past 6 months, have you felt that your care receiver would be better off in a nursing home, boarding home, or assisted living facility?

- a. Yes
- b. No (go to D6)

D4. In the past 6 months, have you discussed that possibility with your care receiver?

- a. Yes
- b. No (go to D6)

D5. In the past 6 months, have you taken any steps toward placement?

- a. Yes
- b. No

D6. Are you responsible for providing help or supervision to your care receiver on a 24-hour basis?

- a. Yes
- b. No (go to D8)

D7. On a scale from 1 to 5 where 1 is not very intense and 5 is very intense, how intense is the care you provide? \_\_\_\_\_

D8. Would you recommend the caregiving support services to a friend?

- a. Yes
- b. No

D9. Do you have any recommendations to improve the caregiver support services?

- a. Yes
- b. No (go to D11)

D10. Choose **one** type of caregiver support service you have received that you think needs the most improvement?

- a. Information about available services
- b. Assistance gaining access to services
- c. Caregiver education/training, individual counseling, and support groups
- d. Respite care
- e. Other supplemental services
- f. Something else

D11. Overall, do you feel like you have enough support?

- a. Yes
- b. No

## E. Nutrition

E1. In the past 12 months, have you tried to get meals, food, or groceries through your Area Agency on Aging (AAA)?

- a. Yes
- b. No (go to E2)

E1a. Were you unable to get food?

- a. Yes
- b. No (go to E2)

E1b. Were you unable to get meals, food, or groceries from your Area Agency on Aging for any of the following reasons? *Mark all that apply.*

- a. No response from AAA
- b. I was put on a waiting list
- c. I was told that I could not have more meals or food
- d. I was told there was no more food available
- e. I was told there was not enough staff
- f. I was unable to pick up the meals or get to the meal pick-up place

E2. Have you recently lost weight without trying? If you are unsure, some things that might indicate weight loss are clothes or rings fitting looser, or using a different belt notch.

- a. Yes
- b. No (go to E3)

E2a. How much weight have you lost?

- a. 2-13 lbs
- b. 14-23 lbs
- c. 24-33 lbs
- d. 34 lbs or more
- e. Unsure

E3. Have you been eating poorly because of a decreased appetite? For example, eating less than 75% of your usual intake. Most often this is due to poor appetite, but there may be other reasons sometimes such as chewing or swallowing difficulties.

- a. Yes
- b. No

E4. Have you recently gained weight without trying?

- a. Yes (go to E4a)
- b. No
- c. Unsure

E4a. How much weight have you gained?

\_\_\_\_\_ Number of pounds

Below are several statements that people have made about their food situation. They use the terms "we" and "your household". A household includes everyone who lives with you. If you live alone, then you are a household of one.

E5. "The food that we bought just didn't last, and we didn't have money to get more." Was that often, sometimes, or never true for your household in the last 12 months?

- a. Often true
- b. Sometimes true
- c. Never true

E6. "We couldn't afford to eat balanced meals." Was that often, sometimes, or never true for your household in the last 12 months?

- a. Often true
- b. Sometimes true
- c. Never true

E7. In the last 12 months, did you or other adults in your household ever cut the size of your meals or skip meals because there wasn't enough money for food?

- a. Yes
- b. No (go to E8)

E7a. How often did this happen?

- a. Almost every month
- b. Some months but not every month
- c. Only 1 or 2 months

E8. In the last 12 months, did you ever eat less than you felt you should because there wasn't enough money for food?

- a. Yes
- b. No

E9. In the last 12 months, were you ever hungry but didn't eat because there wasn't enough money for food?

- a. Yes
- b. No

## F. Care Receiver Additional Services

F1. These next questions ask about additional help your care receiver (CR) may have received from your Area Agency on Aging (AAA).

	Yes	No
a. In the past year, has your CR attended a meals program at a senior center or other group setting?	<input type="checkbox"/>	<input type="checkbox"/>
b. In the past year, has your CR received meals or other food from the meals program?	<input type="checkbox"/>	<input type="checkbox"/>
c. In the past year, has your CR received Homemaker or Housekeeping services? <i>(These are services that may include help with doing light housework, laundry, preparing meals, shopping, or delivery of groceries or prescriptions.)</i>	<input type="checkbox"/>	<input type="checkbox"/>
d. In the past year, has your CR received case management services? <i>(When someone receives case management, they have a case manager who may set up in-home services, such as homemaker or personal care services for them. The case manager may also call to check on how they are doing, or how they like the services.)</i>	<input type="checkbox"/>	<input type="checkbox"/>
e. In the past year, has your CR received transportation services?	<input type="checkbox"/>	<input type="checkbox"/>
f. In the past year, has your CR received adult daycare services? <i>(Adult Day Care or adult health is when people go to a place to spend the day.)</i>	<input type="checkbox"/>	<input type="checkbox"/>
g. In the past year, has your CR received personal care services? <i>(Personal care services are help with care like dressing or bathing.)</i>	<input type="checkbox"/>	<input type="checkbox"/>
h. In the past year, has your CR received heavy chore services, such as washing windows, yardwork, or shoveling snow? <i>(Chore Services help with heavier housecleaning and yard work.)</i>	<input type="checkbox"/>	<input type="checkbox"/>
i. In the past year, has your CR received legal assistance? <i>(Legal Assistance may help with making a will or understanding a bill and other legal matter.)</i>	<input type="checkbox"/>	<input type="checkbox"/>
j. In the past year, has your CR received information and assistance services? <i>(Information and Assistance helps people find out about services that are available to them.)</i>	<input type="checkbox"/>	<input type="checkbox"/>
k. Has your CR received flu shots, pneumonia shots, COVID vaccinations, or other immunizations from your AAA?	<input type="checkbox"/>	<input type="checkbox"/>

F2. Did you mark "Yes" to any of the additional services in the table above (items a-l)?

- a. Yes
- b. No (go to F4)

- F3. Overall, how would you rate the **group** of services the person you care for receives?
- Excellent
  - Very good
  - Good
  - Fair
  - Poor

F4. Is the person you care for receiving any other types of assistance, such as...

	Yes	No
a. Food stamps	<input type="checkbox"/>	<input type="checkbox"/>
b. Energy Assistance	<input type="checkbox"/>	<input type="checkbox"/>
c. Medicaid	<input type="checkbox"/>	<input type="checkbox"/>
d. Housing Assistance	<input type="checkbox"/>	<input type="checkbox"/>

- F5. Does your care receiver's family or friends help arrange for the services your care receiver receives?
- Yes
  - No

## G. Preference and Needs Related to Community Living

Most older adults want to remain living in their homes and communities as they age. These next questions are about your care receiver's desire to remain living in their home and the types of home modifications and community supports that can help make this possible.

- G1. How important is it for your care receiver to be able to stay in their current home for as long as possible?
- Very important
  - Somewhat important
  - Not important

G2. Is the following statement often, sometimes, or never true?

*"My care receiver worries about being able to afford living where they currently live for another year."*

- Often true
- Sometimes true
- Never true

G3. Is there a place or organization in your care receiver's community that feels welcoming for people their age to socialize, exercise, and/or participate in activities?

- Yes (Go to G3a.)
- No (Go to G4)
- Don't know (Go to G4)

G3a. If Yes, does your care receiver go there?

- a. Yes
- b. No

G4. Does your care receiver have any of the following in their home?

	Yes	No	If No, would this be helpful for your care receiver?
a. Grab bars in the bathroom	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know
b. Shower bench/chair	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know
c. Ramp into home/no stairs for entry	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know
d. Door frames wide enough for a wheelchair (i.e., 36 inches)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know
e. Roll in shower (i.e., no step or barrier when using a wheelchair or walker)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know
f. Raised toilet seat height (i.e., chair height)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know
g. Lever door handles (i.e., can be opened with a simple pull-down motion)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know
h. Main floor bathroom	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know
i. Main floor bedroom	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know
j. Stair lift	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know

G5. How much consideration has your care receiver given to what modifications may be necessary for their home for them to be able to stay there as they age?

- a. A lot
- b. Some
- c. Little
- d. None

## **H. Falls**

The next few questions are about falling down (any fall, slip, or trip in which you lose your balance and land on the floor or ground or at a lower level.)

H1. In the last month, have you fallen down?

- a. Yes
- b. No

H2. In the last month, did you worry about falling down?

- a. Yes
- b. No (go to section I)

H3. In the last month, did this worry ever limit your activities?

- a. Yes
- b. No

## **I. Social Integration**

The next few questions are about your contact with other people.

I1. How often do you feel that you lack companionship?

- a. Hardly ever
- b. Some of the time
- c. Often

I2. How often do you feel left out?

- a. Hardly ever
- b. Some of the time
- c. Often

I3. How often do you feel isolated from others?

- a. Hardly ever
- b. Some of the time
- c. Often

I4. How often do you feel alone?

- a. Never
- b. Hardly ever
- c. Some of the time
- d. Often

## **J. Care Receiver Health Status and Medical Conditions**

J1. In your judgment, if the services that you and your care receiver have received had not been available, would your care receiver be able to continue to live in the same residence?

- a. Yes (go to J3)
- b. No

- J2. Where would your care receiver be living? *Mark only one.*
- a. In caregiver's home
  - b. In the home of another family member or friend
  - c. In an assisted living facility
  - d. In a nursing home
  - e. Care receiver would have died
  - f. Other

The next few questions are about the health of your care receiver.

- J3. In general, how is your care receiver's health?
- a. Excellent
  - b. Very good
  - c. Good
  - d. Fair
  - e. Poor

J4. Has a doctor ever said that your care receiver has....?

	Yes	No
a. Arthritis or rheumatism	<input type="checkbox"/>	<input type="checkbox"/>
b. High blood pressure or hypertension	<input type="checkbox"/>	<input type="checkbox"/>
c. A heart attack, coronary heart disease, angina, congestive heart failure, or other heart conditions	<input type="checkbox"/>	<input type="checkbox"/>
d. High cholesterol	<input type="checkbox"/>	<input type="checkbox"/>
e. Diabetes or high blood sugar	<input type="checkbox"/>	<input type="checkbox"/>
f. Allergies/asthma/emphysema/chronic bronchitis/other breathing or lung conditions	<input type="checkbox"/>	<input type="checkbox"/>
g. Cancer or a malignant tumor, excluding minor skin cancer	<input type="checkbox"/>	<input type="checkbox"/>
h. Stroke	<input type="checkbox"/>	<input type="checkbox"/>
i. Anemia ( <i>such as iron-deficiency</i> )	<input type="checkbox"/>	<input type="checkbox"/>
j. Osteoporosis	<input type="checkbox"/>	<input type="checkbox"/>
k. Kidney disease	<input type="checkbox"/>	<input type="checkbox"/>
l. Eye or vision conditions such as glaucoma, cataracts, macular degeneration or other medical conditions ( <i>This does not include needing to wear glasses or contact lenses.</i> )	<input type="checkbox"/>	<input type="checkbox"/>
m. Hearing loss or other hearing conditions	<input type="checkbox"/>	<input type="checkbox"/>
n. An emotional or mental health condition	<input type="checkbox"/>	<input type="checkbox"/>
o. Memory related disease such as Alzheimer's or dementia	<input type="checkbox"/>	<input type="checkbox"/>
p. Seizures or epilepsy	<input type="checkbox"/>	<input type="checkbox"/>
q. Parkinson's disease	<input type="checkbox"/>	<input type="checkbox"/>
r. Multiple Sclerosis	<input type="checkbox"/>	<input type="checkbox"/>
s. Serious bladder or bowel incontinence	<input type="checkbox"/>	<input type="checkbox"/>
t. Thyroid disease	<input type="checkbox"/>	<input type="checkbox"/>
u. A digestive or colon-related condition	<input type="checkbox"/>	<input type="checkbox"/>

- J5. Does your care receiver have access to public transportation such as a bus or rail?
- a. Yes
  - b. No

Now we would like to ask about oral or dental health, that is, the health of your care receiver's teeth and gums.

J6. About how long has it been since your care receiver last visited a dentist? Include dental hygienists, orthodontists, oral surgeons, and other dental-related specialists.

- a. 6 months or less
- b. More than 6 months, but not more than 1 year ago
- c. More than 1 year, but not more than 2 years ago
- d. More than 2 years, but not more than 3 years ago
- e. More than 3 years, but not more than 5 years ago
- f. More than 5 years ago
- g. Never has been to a dentist
- h. I don't remember

J7. During the past 12 months, was there a time when your care receiver needed dental care but could not get it at that time?

- a. Yes
- b. No

J8. Overall, how would you rate the health of your care receiver's teeth and gums?

- a. Excellent
- b. Very good
- c. Good
- d. Fair
- e. Poor

## **K. Care Receiver's Activities and Instrumental Activities of Daily Living (ADL/IADLs)**

The next set of questions ask about your care receiver's ability to perform some common activities of everyday life and whether your care receiver needs assistance performing these activities. We are only interested in long-term conditions, not temporary conditions.

K1. Does your care receiver have difficulty.....?

	Yes	No
a. getting in or out of bed or a chair	<input type="checkbox"/>	<input type="checkbox"/>
b. when taking a bath or shower	<input type="checkbox"/>	<input type="checkbox"/>
c. when dressing	<input type="checkbox"/>	<input type="checkbox"/>
d. when walking or getting around inside the home	<input type="checkbox"/>	<input type="checkbox"/>
e. eating	<input type="checkbox"/>	<input type="checkbox"/>
f. using the toilet	<input type="checkbox"/>	<input type="checkbox"/>
g. going outside the home, for example to shop or visit a doctor's office	<input type="checkbox"/>	<input type="checkbox"/>
h. keeping track of money or bills	<input type="checkbox"/>	<input type="checkbox"/>
i. preparing meals	<input type="checkbox"/>	<input type="checkbox"/>
j. doing light housework, such as washing dishes or sweeping a floor	<input type="checkbox"/>	<input type="checkbox"/>
k. doing heavy housework, such as scrubbing floors or washing windows	<input type="checkbox"/>	<input type="checkbox"/>
l. taking the right amount of prescribed medicine at the right time	<input type="checkbox"/>	<input type="checkbox"/>
m. using the phone	<input type="checkbox"/>	<input type="checkbox"/>

K2. Is there a car or personal motor vehicle in working condition in your care receiver's household?

- a. Yes
- b. No

K3. Does your care receiver have difficulty driving a car or other personal motor vehicle?

- a. Yes
- b. No
- c. Not applicable (because CR does not want or need to drive)
- d. Not applicable (because household does not have a working vehicle)

K4. Does your care receiver have difficulty using public transportation such as a bus or rail?

- a. Yes
- b. No
- c. Never uses public transportation

K5. What is your care receiver's current age?

\_\_\_\_\_ Age

## L. Caregiving for Others

L1. How many persons total are you caring for not counting this care receiver?

[If none, enter 0].

\_\_\_\_\_ Number of people

If you answered 0, go to section M.

L2. Not counting your care receiver, how are the other people you care for related to you? *Mark all that apply.*

- a. Husband, wife, or partner
- b. Son(s) or daughter(s )
- c. Father
- d. Mother
- e. Brother(s) or sister(s)
- f. Grandson(s) or granddaughter(s)
- g. Cousin or other relative(s)
- h. Friend(s) or neighbor(s)
- i. Brother-in-law or sister-in-law
- j. Other persons not mentioned above

## M. Demographics

The purpose of the following questions is to help ACL and its network of AAAs better understand the level of satisfaction and needs of all clients based on several types of demographic information. The goal is to provide equitable community-based programs and support services to all clients. Only ACL's contracted research team will have access to this information. Your responses will be kept confidential and secure. Any reports and studies resulting from this survey will summarize information and not identify any individuals. The information will not be used for any discriminatory purpose.

M1. What is your age? \_\_\_\_\_

M2. What is your highest level of education?

- a. Less than high school diploma
- b. High school diploma or GED
- c. Some college, including Associate's degree (includes business school and vocational or technical school)
- d. Bachelor's degree
- e. Some post-graduate work or advanced degree

M3. Are you Hispanic or Latino?

- a. Yes
- b. No

M4. Which one or more of the following best describes your race? *Mark all that apply.*

- a. White
- b. Black or African American
- c. Asian
- d. American Indian or Alaska Native
- e. Native Hawaiian or other Pacific
- f. Islander
- g. Some other race (specify) \_\_\_\_\_

M5. Have you ever served on active duty in the U.S. Armed Forces, military Reserves or National Guard? Active duty does not include training for the Reserves or National Guard.

- a. Yes
- b. No

M6. Is your home located in...

- a. The city
- b. The suburbs
- c. A rural area
- d. Don't know

M7. What is your current marital status?

- a. Married
- b. Living with a partner
- c. Widowed
- d. Divorced
- e. Separated
- f. Never Married

M8. We'd like to ask about the persons who live in your household. Does anyone else live with you?

- a. Yes
- b. No (go to M9)

M8a. If yes...

(Only complete the table below if someone else lives with you.)

	Yes	No
1. Do you live with your spouse or unmarried partner?	<input type="checkbox"/>	<input type="checkbox"/>
2. Do you live in the home of one of your children?	<input type="checkbox"/>	<input type="checkbox"/>
3. Do one or more of your children live in your home	<input type="checkbox"/>	<input type="checkbox"/>
4. Do you live with other relatives?	<input type="checkbox"/>	<input type="checkbox"/>
5. Do you live with non-relatives?	<input type="checkbox"/>	<input type="checkbox"/>

M8b. Including yourself, how many people live in your household?

\_\_\_\_\_ Number of household members

M9. What is your sex?

- a. Female
- b. Male

M10. Thinking about the total combined income from all sources for all persons in your household, including income from jobs, Social Security, retirement income, public assistance, and all other sources, which category best describes your total household annual income during the year 2023?

- a. \$5,000 or less (\$417 or less per month)
- b. \$5,001 - \$10,000 (\$418 to \$833 per month)
- c. \$10,001 - \$15,000 (\$834 to \$1,250 per month)
- d. \$15,001 - \$20,000 (\$1,251 to \$1,666 per month)
- e. \$20,001 - \$25,000 (\$1,667 to \$2,083 per month)
- f. \$25,001 - \$30,000 (\$2,084 to \$2,500 per month)
- g. \$30,001 - \$35,000 (\$2,501 to \$2,917 per month)
- h. \$35,001 - \$40,000 (\$2,918 to \$3,333 per month)
- i. \$40,001 - \$50,000 (\$3,334 to \$4,167 per month)
- j. Over \$50,000 (\$4,168 or more per month)
- k. Prefer not to answer

M11. Did someone else complete this survey for the person addressed in the letter?

- a. Yes
- b. No

THANK YOU!

Your answers will help us better evaluate the services funded by the Older Americans Act.

Please return your completed questionnaire in the pre-addressed postage paid envelope to:

Westat  
1600 Research Blvd., Room # RCB16  
Rockville, MD 20850