

Appendix O

**Comparison Group Care Recipient
Survey:
Baseline**

Survey of the National Family Caregiver Support Program Baseline Comparison Group Care Recipient Survey

[Interviewing CARE RECIPIENT]. My name is {INTERVIEWER'S NAME} and I am calling on behalf of the U.S. Department of Health and Human Services' Administration for Community Living. We are conducting a survey to find out how we can help meet the needs of persons like you and your caregiver. Your experiences will help us to know more about caregiving around the country.

This survey will take about 10 minutes to complete. Your participation is voluntary and very important to the success of this study. Responses to this data collection will be used only for purposes of this research. The reports prepared for this study will summarize findings from all survey participants as a group. We will not report responses from a specific individual. In addition, we will not provide information that identifies individuals to anyone outside the study team, except as required by law. Your caregiver's eligibility for services will not be affected by your decision to participate or by any answers you give.

[Note to INTERVIEWER: For this survey of the care recipient of the comparison group, we need to collect the caregiver name and contact information. If the CR declines interview or is unable to answer the 7 items in this survey, please attempt to get the information asked in Question #6 about the caregiver.]

[Interviewing with PROXY or INTERPRETER]. My name is {INTERVIEWER'S NAME} and I am calling on behalf of the U.S. Department of Health and Human Services' Administration for Community Living, We are conducting a survey to find out how we can help meet the needs of persons like {NAME OF CARE RECIPIENT} who are being assisted by family members or friends who provide care. We would like to know more about caregiving around the country and the support that would be helpful.

We would like {NAME OF CARE RECIPIENT} to answer the questions as independently as possible. We want to be sure that, wherever possible, we are getting {NAME OF CARE RECIPIENT}'s actual opinions and responses.

This survey will take about 10 minutes to complete. {NAME OF CARE RECIPIENT}'s participation is voluntary and very important to the success of this study. Responses to this data collection will be used only for purposes of this research. The reports prepared for this study will summarize findings from all survey participants as a group. We will not report responses from a specific individual. In addition, we will not provide information that identifies individuals to anyone outside the study team, except as required by law. {NAME OF CARE RECIPIENT}'s eligibility for services will not be affected by {NAME OF CARE RECIPIENT}'s decision to participate or by any answers {s/he} gives.

IF NEEDED: We were given your name as the {PROXY or INTERPRETER} for {NAME OF CARE RECIPIENT}

Let's begin.

Thank you very much for agreeing to participate in this study. The first few questions are about how you feel and how things have been for you.

As I read each statement, please give me the one answer that comes closest to the way you feel.

1. In general, would you say your quality of life is . . . [READ RESPONSE OPTIONS].

| | |
|-----------------|----|
| Excellent..... | 5 |
| Very Good..... | 4 |
| Good..... | 3 |
| Fair..... | 2 |
| Poor..... | 1 |
| REFUSED..... | -7 |
| DON'T KNOW..... | -8 |

2. In general how would you rate your mental health, including your mood and your ability to think?

[READ RESPONSE OPTIONS]

| | |
|-----------------|----|
| Excellent..... | 5 |
| Very Good..... | 4 |
| Good..... | 3 |
| Fair..... | 2 |
| Poor..... | 1 |
| REFUSED..... | -7 |
| DON'T KNOW..... | -8 |

3. In general, how would you rate your satisfaction with your social activities and relationships?

[READ RESPONSE OPTIONS]

| | |
|-----------------|----|
| Excellent..... | 5 |
| Very Good..... | 4 |
| Good..... | 3 |
| Fair..... | 2 |
| Poor..... | 1 |
| REFUSED..... | -7 |
| DON'T KNOW..... | -8 |

4. In the past 7 days, how often have you been bothered by emotional problems such as feeling anxious, depressed, or irritable ? [READ RESPONSE ALOUD]

- Always..... 5
- Often..... 4
- Sometimes..... 3
- Rarely..... 2
- Never..... 1
- REFUSED..... -7
- DON'T KNOW..... -8

5. To what extent does having a caregiver help you to remain at home? [READ RESPONSE OPTIONS]

- Not at all helpful..... 1
- A little helpful..... 2
- Somewhat helpful..... 3
- Mostly helpful..... 4
- Very helpful..... 5
- REFUSED..... -7
- DON'T KNOW..... -8

[Note to INTERVIEWER: Most likely, you will not already know the caregiver's name and contact information. If so, please ask item #6. This item will only be asked of the comparison group care recipients. If PROXY or INTERPRETER, ask if they are the caregiver.]

6. We are also interested in speaking with the person who helps {you/NAME OF CARE RECIPIENT} and learning about their needs as a caregiver.. Can I have the name, address, and telephone number of the person who helps you/RECIPIENT?

FIRST NAME: _____ LAST NAME: _____
& STREET: _____
APT. # _____
CITY: _____ STATE: _____ ZIP CODE: _____
HOME TELEPHONE NUMBER (with area code): _____ - _____ - _____
OTHER PHONE NUMBER (with area code) _____ - _____ - _____

REFUSED
DON'T KNOW

Note: This module asks OAA services recipients, who have stated they have a family caregiver, for their caregiver's contact information so we can contact and interview these caregivers. These caregivers will constitute the NFCSP evaluation's comparison group.

7. How much do you enjoy being with [CAREGIVER NAME]?
[READ RESPONSE OPTIONS]

- A lot 1
- Some 2
- A little 3
- Not at all 4
- DON'T KNOW..... -7
- REFUSED -8

{READ:} Sometimes caregivers get support from family, friends, or an organization.

8. Do you think [CAREGIVER NAME] is receiving all the help that [he or she] needs to take care of you?

- Yes, definitely1
- Yes, probably2
- Not sure3
- No, probably not4
- No, definitely not5
- REFUSED7
- DON'T KNOW8

8a. If no, what support do you think {he or she} needs? _____

CLOSE1. Those are all the questions I have for you today. We would like to call you back in 12 months to ask if there are any changes in your answers to these questions at that time. Thank you very much for your help with this important national survey. We appreciate your time.