

Appendix P

Comparison Group Care Recipient Survey: 12-month Follow-up

Survey of the National Family Caregiver Support Program 12-month follow-up 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. Twelve months ago, we conducted a survey to find out about how you feel and the needs of your caregiver. Today we will like to ask you a similar set of questions about how you are doing now.

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.

[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. Twelve months ago, we conducted a survey to find out about how [NAME OF CARE RECIPIENT] feels and the needs of [CARE RECIPIENT'S] caregiver. Today we will like to ask a similar set of questions to understand how {NAME OF CARE RECIPIENT} is doing now.

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: Caregiver's name and contact information was collected at baseline.]

6. 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.

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

Yes, definitely	1
Yes, probably	2
Not sure	3
No, probably not	4
No, definitely not	5
REFUSED	7
DON'T KNOW	8

7a. If no, what support do you think {he or she} needs? _____

CLOSE1. Those are all the questions I have for you today. Thank you very much for your help with this important national survey. We appreciate your time.