
Unmet Needs of Adults with Disabilities in Massachusetts – Interviews with Caregivers, 2007

Office on Health and Disability
Division of Health Promotion and Disease Prevention
Bureau of Community Health Access and Promotion
Massachusetts Department of Public Health



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Table of Contents

Introduction and Background.....	1
Findings.....	2
Description of Interviewed Caregivers	2
Care provided and unmet need	4
Caregivers' Needs.....	6
Effect of Caregiving on Caregivers.....	6
Finances of Informal Caregiving	8
Appendix A: Methodology.....	9
Appendix B: Demographics of the Caregiver.....	11
Appendix C: Survey Questions.....	12

Introduction and Background

The Massachusetts State Legislature made funding available for the Massachusetts Department of Public Health (MDPH) to support research activities to determine the need for home and community based services and an economic profile of individuals and families with neurologically and physically disabled adults.¹

MDPH contracted with the Center for Survey Research, University of Massachusetts Boston (CSR) to conduct the study. MDPH and CSR, in collaboration with the Disability Policy Consortium (DPC) and the Home and Community Based Services Committee of the DPC, designed and developed the study, which has two parts. The objective of the main study, which is described and summarized in a separate report, was to examine the unmet needs for home and community based services for adults age 18-59 with disabilities.² The objective of the caregiver study was to hear the perspective of informal caregivers on their unmet needs and the unmet needs of the people for whom they provide care.³

The MDPH and CSR agreed that using a sub-sample of a statewide random digit dial sample representative of Massachusetts households would be the most efficient and cost effective design for the main study. The Massachusetts Behavioral Risk Factor Surveillance Systems (BRFSS), the sample from which the main study was taken, is described in detail, along with a detailed description of the survey methodology, in Appendix A of the main report. The study of informal caregivers was designed as an initial attempt to hear a different perspective on unmet needs. Adults with disabilities who reported having difficulty with at least one Activity of Daily Living (ADL) or Instrumental Activity of Daily Living (IADL) and who reported receiving informal care from friends or family were asked at the end of the main interview if they would allow us to speak with their primary caregiver.

This recruiting procedure is described in detail in Appendix A of this report. Of 571 main interview respondents, 195 (34%) met the criteria for their caregiver to be included in this study. Only 94 provided sufficient information to contact the caregiver and request participation; 58 participated.

This goal of this study was to do a baseline data collection about the unmet needs of informal caregivers of adults with disabilities with the expectation that the findings would suggest areas for further study. It is important to note that the caregivers we spoke with were providing care for people who could (and did) participate in two survey interviews – the BRFSS and then the Unmet Needs Study. As we noted in the main study report, the sample of people with disabilities very likely under-represents the population of adults with disabilities in the state and, thus, understates the full set of potential needs of the group. Individuals with the most severe limitations were not included in the study, in part because the BRFSS does not include individuals living in institutions and also because the BRFSS methodology precludes anyone

¹ Following is what the 2006 state legislation made available: *“Provided further, that \$120,000 shall be expended for a study for home and community based services and an economic profile of individuals and families with neurologically and physically disabled adults under 65; and provided further, that said study shall be one-time in nature and shall not result in any annualization in fiscal year 2007.”*

² “2007 Study of the Unmet Needs of Adults with Disabilities in Massachusetts,” by Karen Bogen, Nelly Oliver, and Mary Ellen Colten, 2008.

³ Informal caregiving is provided by friends or family, either living with the recipient or not. It excludes paid caregivers, personal care attendants, agency volunteers, or any other more formal caregivers.

assisting the selected respondent in completing the interview if the selected adult had difficulty participating for any reason. People who need the most assistance are excluded.

The study is exploratory, and the sample is likely not representative of the state's caregivers of persons with disabilities. To avoid an appearance of "representativeness," the report presents the main findings from unweighted frequencies of the survey data. These results are presented to encourage additional research concerning this topic, not to imply that they are definitive of the needs of Massachusetts caregivers. Nevertheless, the findings suggest issues for caregivers that may need attention. Bearing in mind that these study respondents are providing care to persons whose disabilities require lower levels of assistance or assistance with fewer activities than the population of persons with disabilities living in Massachusetts, this study likely underestimates difficulties faced by informal caregivers in Massachusetts.

Findings

This report is based on 58 interviews with informal caregivers of adults with disabilities who participated in the main interview. The exact criteria for selection into the caregiver study are described in Appendix A. The first part of this report describes the important characteristics of informal caregivers, particularly as they relate to the care recipient, and the second part of the Findings section is more specific to the questions this survey was designed to address: the unmet needs of adults with disabilities and their informal caregivers. All of the data reported here are based on unweighted data and should be considered exploratory in nature.

Description of Interviewed Caregivers⁴

Table 1 summarizes the relationship of the care recipients to the caregiver.

Table 1. Relationship of care recipient to informal caregiver

Care recipient is...	Number (n=58)	%
Spouse	22	38
Friend/neighbor	11	19
Adult child	9	16
Parent	6	10
Partner	6	10
Sibling	3	5
Grandchild	1	2

Most of the interviewed caregivers (n=44, 76%) live with the person for whom they also provide care. Nine of the thirteen who do not live with their care recipients live within 20 minutes of the person and three caregivers live 20 minutes to an hour away. One caregiver appears to rent an apartment in a building owned and lived in by the care recipient. Informal caregivers who do not live with the care recipient vary in how frequently they provide care: five of them help more

⁴ Appendix B describes the demographic characteristics of the caregivers.

than once a week, two of them help once a week, five of them help a few times a month, and one just a few times a year.⁵

The needs of care recipients differ widely, with some needing what amounts to emotional support and others needing help with a host of ADLs and IADLs. As such, the amount of time caregivers provide help also varied widely, ranging from less than an hour a week to as high as 100 hours per week, with an average of about 16 hour per week. Table 2 shows the range of hours of help provided.

Table 2. Hours of help provided per week

	Number (n=57)	%
One hour or less	4	7
2-5 hours	17	29
6-12 hours	9	16
13-20 hours	12	21
21-30 hours	10	18
31 or more hours	5	9
Average: 16 hours		

There is also a wide spread in how long informal caregivers have provided care, ranging from less than a year to 30 years, with an average of about seven years. The distribution is shown in Table 3.

Table 3. Number of years of informal caregiving

	Number (n=57)	%
Less than one year	5	9
1-2 years	15	26
3-5 years	15	26
6-10 years	14	25
More than 10 years	8	14
Average: 7 years		

Approximately one-fourth of the interviewed caregivers (n=15, 26%) reported that they provide regular help for someone in addition to the care recipient we interviewed. Typically, they provide help to just one other person (n=9), but four respondents reported providing regular help to two other people besides the interviewed care recipient.

The interviewed caregivers are not themselves in perfect health. As shown in Table 4, one-fourth of these respondents (n=15, 26%) reported their physical health as being fair or poor and

⁵ Caregivers who live with the care recipients were not asked this question.

an almost equal number (n=14, 24%) reported their mental health as being fair or poor. Over one-third (n=21, 36%) reported that they often feel that they are stressed.

Table 4. Caregivers' self-reported health

	Number (n=58)	%
PHYSICAL HEALTH		
Excellent/very good	27	47
Good	16	28
Fair/poor	15	26
MENTAL HEALTH		
Excellent/very good	23	40
Good	21	36
Fair/poor	14	24
FEEL STRESSED		
Often	21	36
Sometimes	27	47
Rarely/never	10	17

Care Provided and Unmet Need

The informal caregivers were asked questions about the care recipients' care and their level of need. Only eight caregivers (14%) reported that the care recipient received paid professional help at home on a regular basis. Quite a few, though, reported that the recipient receives additional help from other family and friends (n=22, 39%). On average about 10 hours of additional help per week is provided from other informal caregivers.

The caregivers were asked about whether they ever provide help with three of the ADLs, bathing and showering, dressing, and using the toilet, and three IADLs, transportation, housework, and preparing meals. Table 5 summarizes how much help they provide for these activities.

In the majority of cases, the informal caregivers provide help with transportation and meal preparation. The other activities appear to require less help. After asking whether they provide help for the three ADLs and how often they help, the caregivers who provided such help were asked if they felt like they could have "used more help" with the care recipient's personal needs in the past 12 months. Only 3 of 21 caregivers answered Yes. A similar question was asked after the three IADL questions, and 20 of the 58 caregivers (35%) responded Yes, they felt like they could have used more help with transportation, meal preparation, or housework in the past 12 months. The 20 who said they needed more help were asked if they had tried to find either paid help or other friends or family to help in the past 12 months. No one has tried to get professional paid help, but half of them have tried to enlist other informal help from family or friends. Of those 11, nine of them reported finding someone to help but three of them said they could still use more help.

Table 5. Assistance provided helps

	Ever help with (n=57 except as indicated)	Help all or most of the time
ACTIVITIES OF DAILY LIVING		
Bathing or showering	n=8, 14%	n=4, 7%
Dressing	n=18, 31%	n=3, 5%
Using the toilet	n=4, 7%	n=1, 2%
INSTRUMENTAL ACTIVITIES OF DAILY LIVING		
Transportation	n=45, 78%	n=16, 28%
Housework (asked of just 14 caregivers who do not live with care recipient)	n=9, 64%	n=3, 21%
Preparing meals	n=44, 76%	n=22, 38%

To get a sense of the level of dependence on the caregiver, we asked if a substitute is needed if the interviewed caregiver were ill or unable to provide their usual help. Nine of the caregivers (16%) said that a substitute would be needed and seven of them said that it would be very difficult or somewhat difficult to find a substitute.

Caregivers' Needs

The interview asked a number of questions about the caregivers having any time off from their caregiving responsibilities. They were asked whether other family members or friends have helped out in the past 12 months so that the caregiver could take time off of caring for the recipient, and 22 (38%) said Yes. In addition, they were asked if the care recipient attended any regular programs or activities during the day, which would leave the caregiver free. About one-fourth (n=14) said Yes. Only one person said the care recipient had received in-home respite care and one reported receipt of care in a respite care facility. Most informal caregivers reported that they did not know of any organizations that provide respite care services, in or out of the home.

When informal caregivers were asked very directly if in the past 12 months they could have used more time off from their caregiving duties, 17 of them (29%) responded Yes. Likewise, when asked if they could use more help at home if an agency or organization were to provide help at no cost to them, 24 of the caregivers (41%) said Yes. The number of hours of help they could use and what they would have the helpers do varied widely, from just two hours per week to 56 hours per week, and from house chores, cleaning, and laundry to organization, transportation, financial management, and running errands. Of those who said they could use such help thought that it would reduce their work by a lot (n=10) or some (n=9). When asked why the care

recipient is unable to get all the help needed right now, 18 of the 24 reported cost and 20 of the 24 reported such help was not available.

In an effort to anticipate possible future need, caregivers were asked how likely it was that they will need more help at home taking care of the recipient in the next 12 months. As shown in Table 6, over one-third anticipate that their level of need will increase in the next 12 months, saying it was very or somewhat likely.

Table 6. How likely they will need more help at home in the next 12 months

	Number (n=58)	%
Very likely	8	14
Somewhat likely	13	22
Not very likely	15	26
Not at all likely	22	38

Effect of Caregiving on Caregivers

Two-thirds of the interviewed caregivers (n=39, 67%) reported that they are currently employed for pay, and another 11 (19%) reported that they have been employed at some time since they began providing care. The 50 caregivers who are currently or formerly employed were asked about a number of ways in which their caregiving responsibilities could have affected their work. Table 7 summarizes the caregivers' responses. All of the caregivers in this sample reported that their work life was affected by their caregiving responsibilities. As described earlier, it is likely that this study under-represents informal caregiver needs because the study of adults with disabilities excluded those with the greatest need. About half of the interviewed caregivers (48%) said that at some time they had to go in late, leave early, or take time off from work to provide care. None of the caregivers said that their caregiving led them to have to stop working entirely.

Table 7. Effect of caregiving responsibilities on work

Because of your caregiving responsibilities, do/did you ever have to....	Number Yes or Sometimes (n=50 except as indicated)	%
...go in late, leave early, or take time off from work to provide care	24	48.0
...take a leave of absence from work to provide care	8	16.0
...reduce your official working hours to provide care	11	22.0
...arrange to have more flexible work hours	12	24.0
...give up working entirely or choose early retirement to provide care (asked of just 11 caregivers who were formerly employed while providing care)	0	0

The informal caregivers were asked a number of questions about the ways in which caregiving affects their lives, interactions with other family member, and sense of self. As shown in Table 8, the perceived effects on health and well-being are strong for a substantial number of caregivers. Half of the caregivers reported feeling like they often or sometimes don't have enough time for themselves, somewhat more than any of the other possible effects on their lives. However, the other effects were also reported as occurring often or sometimes by at least one third of the caregivers.

Table 8. Effect of caregiving on lives, interactions, and sense of self

In your experiences as a caregiver, how often do you feel that ...	Often or Sometimes	Rarely or Never
...you do not have enough time for yourself	n=30, 52%	n=28, 48%
...you do not have enough time for other members of your family	n=22, 39%	n=34, 61%
...caregiving negatively affects your mental health	n=24, 41%	n=34, 59%
...caregiving negatively affects your physical health	n=20, 35%	n=38, 66%
...caregiving interferes with your social life	n=25, 43%	n=33, 57%
...caregiving interferes/d with your work (asked of 50 caregivers who are currently or formerly employed while providing care)	n=17, 34%	n=33, 66%

On the positive side, most of the informal caregivers (n=49, 84%) reported that they feel a lot or some personal satisfaction in being a caregiver. Only one caregiver said he/she felt no personal satisfaction.

The survey asked about stress in two different ways. One question was specifically about how stressful they feel it is to be a caregiver. The other question was more general and asked how

often they feel that they are stressed. For the specific question, 22 caregivers (38%) said that it is very or somewhat stressful to be a caregiver. Another 24 (41%) said it was a little stressful, and 12 (21%) said it was not at all stressful. For the general question, there seems to be a higher level of stress reported, with 48 caregivers (83%) saying that they often or sometimes feel stressed, and just 10 (17%) saying they rarely or never feel stressed. Three of the informal caregivers reported experiencing injuries from caregiving in the past 12 months.

The caregivers were asked about three possible ways that they might have been helped as caregivers: receiving information, receiving counseling or participating in a support group, and attending caregiver classes or training. The reports of receiving such help were quite low (2 to 5 caregivers said Yes they'd received such help). The caregivers who had not received such help were asked if such a service would have been helpful to them. Table 9 summarizes the caregivers' interest.

Table 9. Interest in getting assistance in being a caregiver

Do you think it would have been helpful to you as a caregiver to receive...	Number	%
...information to connect you to services or resources that you need as a caregiver	21	36%
...counseling or participating in a support group intended to help you in being a caregiver	18	31%
...caregiver training or class intended to help you make decisions or solve problems in your role as a caregiver	21	36%

Finances of Informal Caregiving

Caregivers who were related to their care recipients were asked about how difficult it has been for the family to afford the care recipient's out-of-pocket health care expenses in the past 12 months. Three out of five of the caregivers (28 of 47, 60%) said that it was very or somewhat difficult. The remainder said that it was a little difficult or not difficult at all.

Four of the interviewed caregivers reported being paid for any of the time they provided care. The caregivers who do not live with care recipients (n=14) were asked if they spend any of their own money to help the care recipient, and almost all (n=12) reported that they do. The dollar amounts they spend range widely, from about \$16 per month to \$500 per month, with an average of about \$106 per month.

Appendix A: Methodology

Survey Development and Pretesting

The Center for Survey Research, the Massachusetts Department of Public Health (MDPH), and members of the Disability Policy Consortium (DPC) worked together to develop the survey content. The first step was to review what other kinds of data have been collected about caregivers' needs and to decide which content areas to cover in the 15-minute survey. Once the general content areas were identified, we tried to use questions that had been used in previous surveys. After agreeing on a draft, CSR conducted four cognitive interviews to help understand if respondents were all interpreting the questions as intended. Respondents for the cognitive interviews were recruited through flyers posted on the UMass Boston campus, through advertisements posted on the web, from the DPC, and through word of mouth. After completing the cognitive interviews, extensive revisions to the questionnaire were proposed by CSR. Once questionnaire revisions were agreed upon by the group, CSR conducted a pretest of five telephone interviews. Respondents for the pretest were individuals who were recruited during the cognitive interviewing phase of this study. Again, after the pretest, minor revisions to the questionnaire were proposed prior to moving into production interviewing.

Sample

The caregiver names and contact information were provided by respondents to the main interview. The eligibility criteria were that the main respondent had to have reported having difficulty with at least one ADL or IADL and had to have reported being the recipient of informal in-home care. All main study respondents who fit those criteria were recruited using the following script:

That is the end of our survey questions. If you are willing, we would like to conduct a short interview with the family member, friend, or neighbor who provides you the most care or assistance so that we can learn what additional needs they might have as a caregiver. We will not share your answers with that person; we will be asking them different questions. But we need your permission to speak with them. Would that be okay with you?

If the respondent agreed, we asked for their first name (so that we could use it when we called the caregiver), the name of the caregiver, the caregiver's relationship to the main respondent, and the best way and time to contact him/her.

Of the 571 main interview respondents, approximately one third (n=195, 34%) met the eligibility criteria to be asked about caregiver participation. Of the 195, about half (n=99, 51%) agreed to provide contact information, though in the end, only 94 (48%) provided sufficient information to actually attempt to contact the caregiver. Table A1 is a disposition of the 94 sample numbers.

The data from the caregivers study is exploratory in nature. In thinking ahead to future studies that might use a similar approach to recruiting caregivers to participate, there are a number of things we would recommend. The first has to do with the recruiting script. We tried a number of ways to revise the actual words we used to persuade main interview respondents to let us contact their caregivers, but as noted above, we were successful only about half the time. So, further effort would need to be made to find the right method for getting main respondent cooperation in providing caregiver contact information. Clearly a more persuasive argument is needed for this effort, and perhaps an incentive would be useful. Also, more information needs to be gathered to find out if this is the appropriate caregiver. For example, we found out later

that some of our caregivers were children, under age 18, and we did not want to include them. Likewise, some of the caregivers were providing limited help to the person, and future studies should be more deliberate in deciding what level of care must be provided in order to be included. There is some tradeoff in this decision: caregivers who provide many hours of care are likely extremely busy and harder to get for an interview, yet those are the very caregivers who could probably use more assistance in their caregiving. Finally, at the stage of talking to caregivers, future researchers need to think carefully about use of the term caregiver. Some people adamantly refused to call themselves caregivers and, therefore, thought that they were not suitable participants in the survey. In one example, one potential respondent emphatically insisted that she was a wife, not a caregiver, even though she provided a lot of care to her husband.

Table A1. Disposition of telephone numbers in sample

	#
STARTED WITH	94
No longer caring for main respondent	7
Caregiver was under age 18	3
Could not locate the person with contact information provided	6
Caregiver was too ill to respond	1
Refused or did not reach respondent in time to complete the interview	19
Completed the interview	58
Total	94

Survey Administration

Three interviewers/supervisors were trained to work on the study. The three were selected for their high level of experience for what we anticipated might be a complex interview. The field work was conducted between December 10, 2007 and January 5, 2008. The average interview length was 15 minutes, with times ranging from 8 to 31 minutes.

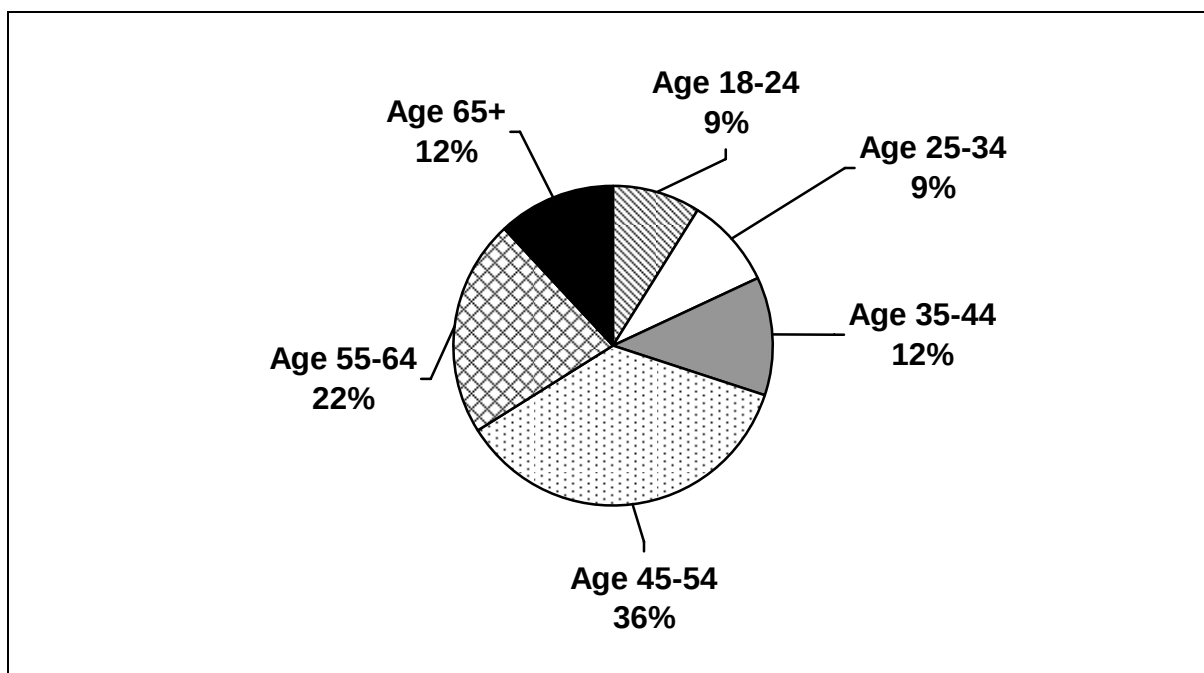
Write-in entries

Based on the cognitive interviews, we were concerned that the huge variation among the caregivers (from people who live separately from the recipient and provide intermittent care to caregivers who share the same household and provide huge amounts of daily care), that it would be impossible to anticipate all the possible answers they might provide. As such, the automated instrument with pre-coded answers also allowed a “does not fit response” answer for most questions. This would allow the interviewer to type in verbatim what the respondent said, rather than trying to make it fit the provided codes. CSR did not code these write-in entries. They are available on a separate text file for future use, with an ID for matching to the quantitative data.

Appendix B: Demographic Characteristics of the Interviewed Caregivers

We interviewed 28 male caregivers and 30 female caregivers. Over half of the interviewed caregivers (n=33, 57%) reported that they were married at the time of the survey. The caregivers ranged in age from 18 to 85 with an average age of 49 years. The following chart provides a breakdown of age ranges.

Figure 1. Age Distribution



Nearly all respondents identified themselves as non-Hispanic White (n=55, 95%), with a few reporting Hispanic ethnicity (n=3), Asian (n=1), or something else and not Hispanic (n=7, 12%). No respondents identified themselves as Black or African American. Respondents could report themselves in more than one race category.

Approximately half of the interviewed caregivers (n=31, 53%) had completed some college or higher education. Less than a third (n=17, 29%) had a high school degree and 10 (17%) had less than a high school diploma.

A little over half of respondents (n=32, 55%) lived in a household where they were the only adult and almost a quarter of respondents (n=14, 24%) had at least one child, age 17 or younger, living with them.

Twenty-four survey respondents (41%) reported a total family income of between \$30,000 and \$60,000. Fourteen of the caregivers (24%) reported a total family income of less than \$30,000 and 11 (19%) reported income of more than \$90,000 in 2006.

Appendix C: Survey Questions

Sometimes people with health problems or disabilities need help with different kinds of tasks around the home, such as personal care, house cleaning, shopping, meal preparation, or transportation where they need to go. The amount of help needed may vary, of course, depending on the health problem or disability. We are going to ask questions about your experience providing help to (NAME). The questions will ask what kinds of things you do with or for (NAME), how hard this may be, and what you see as areas where you think you might be able to use more help. Do you have any questions before we begin?

A. HELP RECEIVED – GENERAL

A1. First, what is NAME's relationship to you? For example is he/she your (mother/father), a friend, a neighbor, etc.?

IF CARE RECIPIENT IS FEMALE	IF CARE RECIPIENT IS MALE
Aunt	Uncle
Daughter	Son
Daughter-in-law	Son-in-law
Friend	Friend
Granddaughter	Grandson
Grandmother	Grandfather
Mother	Father
Mother-in-law	Father-in-law
Neighbor	Neighbor
Niece	Nephew
Other Relative	Other Relative
Paid caregiver/assistant	Paid caregiver/assistant
Partner	Partner
Sister	Brother
Wife	Husband

A2. Do you and [NAME] live together?

☐ Yes (or in attached in-law apartment) → skip to A3

☐ No

☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY] → skip to A3

☐ NA → skip to A3

A2a. How far away do you live from him/her? Do you live less than 20 minutes away, between 20 and 60 minutes away, about 1 hour away, or more than one hour away?

☐ LESS THAN 20 MINUTES AWAY

☐ BETWEEN 20 AND 60 MINUTES AWAY

☐ ABOUT 1 HOUR AWAY

☐ MORE THAN AN HOUR AWAY

☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY]

☐ NA

A2b. On average, how often do you help [NAME]? More than once a week, once a week, a few times a month, once a month, a few times a year, or less often?

- ☐ MORE THAN ONCE A WEEK
- ☐ ONCE A WEEK
- ☐ FEW TIMES A MONTH
- ☐ ONCE A MONTH
- ☐ FEW TIMES A YEAR
- ☐ LESS OFTEN
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY]
- ☐ NA

A3. In a typical week, about how many hours do you provide help to NAME because of his/her health condition or disability? [INTERVIEWER: ACCEPT BEST ESTIMATE]

_____ HOURS per DAY / WEEK / MONTH (circle one)

- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY]
- ☐ DON'T KNOW
- ☐ NA

A4. For how long have you provided any help for NAME because of his/her health condition or disability? [Do not read options; code using respondent's unit of time]

_____ DAYS
_____ WEEKS
_____ MONTHS
_____ YEARS

- ☐ ENTIRE LIFE
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY]
- ☐ DON'T KNOW
- ☐ NA

A5. Does NAME receive any professional paid help at home on a regular basis because of his/her health condition or disability? (NOTE TO IVWR: Include all paid help, regardless of who pays.)

- ☐ YES
- ☐ SOMETIMES
- ☐ NO → skip to A6
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY] → skip to A5a
- ☐ NA → skip to A6
- ☐ R SAYS HE/SHE IS PAID (PCA) → A5b.

A5b. Does NAME receive professional paid help at home on a regular basis from anyone else besides you?

- ☐ YES
- ☐ NO → skip to A6
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY] → skip to A5a
- ☐ NA → skip to A6

A5a. About how many hours of paid professional home help does he/she usually receive each week [FILL IF A5b IS YES: from others besides you]?

_____ HOURS per DAY / WEEK / MONTH (circle one)

- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY]
- ☐ DON'T KNOW
- ☐ NA

A6. Does NAME receive any help from other family and friends, besides you, on a regular basis because of his/her health condition or disability?

- ☐ YES
- ☐ SOMETIMES
- ☐ NO → skip to next section
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY] → skip to A6a
- ☐ NA → skip to B1

A6a. In a typical week, about how many hours of help does NAME usually receive from these other friends and family?

_____ HOURS per DAY / WEEK / MONTH (circle one)

- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY]
- ☐ DON'T KNOW
- ☐ NA

B. HELP RECEIVED -- SPECIFIC

The next set of questions asks about some everyday activities and whether you help [NAME] to do them.

B1. Because of NAME's health condition or disability, do you ever help him/her to bathe or shower?

- ☐ YES
- ☐ SOMETIMES
- ☐ NO → skip to 2
- ☐ DOESN'T NEED HELP → skip to B2
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY] → skip to B2
- ☐ NA → skip to B2

B1a. When NAME bathes or showers, how often do you help – is it every time he/she bathes or showers, most of the time, some of the time, or only occasionally?

- ☐ EVERY TIME
- ☐ MOST OF THE TIME
- ☐ SOME OF THE TIME
- ☐ ONLY OCCASIONALLY
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY]
- ☐ NA

B2. Because of NAME's health condition or disability, do you ever help him/her to get dressed?

- ☐ YES
- ☐ SOMETIMES
- ☐ NO → skip to B3
- ☐ DOESN'T NEED HELP → skip to B3
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY] → skip to B3
- ☐ NA → skip to B3

B2a. When NAME gets dressed, how often do you help – is it every time he/she gets dressed, most of the time, some of the time, or only occasionally?

- ☐ EVERY TIME
- ☐ MOST OF THE TIME
- ☐ SOME OF THE TIME
- ☐ ONLY OCCASIONALLY
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY]
- ☐ NA

B3. Because of NAME's health condition or disability, do you ever help him/her to use the toilet?

- ☐ YES
- ☐ SOMETIMES
- ☐ NO → skip to the skip before 4
- ☐ DOESN'T NEED HELP → skip to the skip before B4
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY] → skip to B4
- ☐ NA → skip to B4

B3a. When NAME uses the toilet, how often do you help – is it every time he/she uses the toilet, most of the time, some of the time, or only occasionally?

- ☐ EVERY TIME
- ☐ MOST OF THE TIME
- ☐ SOME OF THE TIME
- ☐ ONLY OCCASIONALLY
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY]
- ☐ NA

IF YES/SOMETIMES TO ANY OF B1, B2, or B3 (Others Skip to B5)

B4. Sometimes the people who help others with a health problem or disability feel like THEY could use more help than they are getting. At any time in the past 12 months, did you ever feel like you could have used more help with NAME's personal needs, including bathing, showering, dressing, or using the toilet?

- ☐ YES
- ☐ SOMETIMES
- ☐ NO → skip to B5
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY] → skip to B4a
- ☐ NA → skip to B5

B4a. In the past 12 months, have you or NAME [or anyone else] tried to find a paid professional to come help more with NAME's personal needs?

☐ YES

☐ NO

☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY]

☐ NA

B4b. In the past 12 months, have you or NAME [or anyone else] tried to find any other friends or relatives to help more with NAME's personal needs?

☐ YES

☐ NO

☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY]

☐ NA

IF B4a AND B4b ARE NA SKIP TO B5

ASK IF NO TO BOTH B4a AND B4b

B4c. There are many good reasons why people don't look for this kind of help. Can you please tell me why you decided not to look in the past 12 months for additional help with NAME's personal needs?

☐ TEXT[specify] → skip to B5

☐ NA → skip to B5

ASK IF YES TO EITHER B4a AND B4b

B4d. Did you find someone to help with any of NAME's personal needs?

☐ YES → B4e

B4e. Has that been working out, or do you still feel like you need more help with NAME's personal needs?

☐ WORKING OUT → skip to B5

☐ NEED MORE HELP → skip to B5

☐ DOES NOT FIT RESPONSE

CATEGORIES [specify] → skip to B5

☐ NA → skip to B5

☐ NO → B4f.

B4f. Can you please tell me what happened and why you were not able to get the help needed?

☐ TEXT [specify]

☐ NA

☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY] → skip to B5

☐ NA → skip to B5

B5. Because of NAME's health condition or disability, do you ever help him/her to get where he/she needs to go, either on public transportation or by driving him/her?

- ☐ YES
- ☐ SOMETIMES
- ☐ NO → skip to 6
- ☐ DOESN'T NEED HELP → skip to B6
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY] → skip to B6
- ☐ NA → skip to B6

B5a. When NAME needs to go out, how often do you help with transportation – is it every time he/she needs to go out, most of the time, some of the time, or only occasionally?

- ☐ EVERY TIME
- ☐ MOST OF THE TIME
- ☐ SOME OF THE TIME
- ☐ ONLY OCCASIONALLY
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY]
- ☐ NA

IF R LIVES WITH NAME, SKIP TO B7

B6. Because of NAME's health condition or disability, do you ever help with or do the housework, such as straightening up, doing dishes, or vacuuming?

- ☐ YES
- ☐ SOMETIMES
- ☐ NO → skip to 7
- ☐ DOESN'T NEED HELP → skip to B7
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY] → skip to B7
- ☐ NA → skip to B7

B6a. How often do you help with or do the housework -- all the time, most of the time, some of the time, or only occasionally?

- ☐ ALL THE TIME
- ☐ MOST OF THE TIME
- ☐ SOME OF THE TIME
- ☐ ONLY OCCASIONALLY
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY]
- ☐ NA

B7. Because of NAME's health condition or disability, do you ever help with or prepare meals for NAME?

- ☐ YES
- ☐ SOMETIMES
- ☐ NO → skip to the skip before B8
- ☐ DOESN'T NEED HELP → skip to the skip before B8
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY] → skip to the skip before

B8

- ☐ NA → → skip to the skip before B8

B7a. How often do you help with or prepare NAME's meals -- all the time, most of the time, some of the time, or only occasionally?

- ☐ ALL THE TIME
- ☐ MOST OF THE TIME
- ☐ SOME OF THE TIME
- ☐ ONLY OCCASIONALLY
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY]
- ☐ NA

ASK IF YES/SOMETIMES TO ANY OF B5, B6 or B7 (OTHERS SKIP TO SECTION C)

B8. At any time in the past 12 months, did you ever feel like you could have used more help with transportation for NAME or preparing meals for NAME [FILL if don't live together: or housework]?

- ☐ YES
- ☐ SOMETIMES
- ☐ NO → skip to next section
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY] → skip to B8a
- ☐ NA → skip to B8a

B8a. In the past 12 months, have you or NAME [or anyone else] tried to find a paid professional to help with NAME's transportation or meal preparation [FILL: or house work]?

- ☐ YES
- ☐ NO
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY]
- ☐ NA

B8b. In the past 12 months, have you or NAME [or anyone else] tried to find any other friends or relatives to help with NAME's transportation or meal preparation [FILL: or house work]?

- ☐ YES
- ☐ NO
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY]
- ☐ NA

IF B8a AND B8b ARE NA SKIP TO C1

ASK IF NO TO BOTH B8a AND B8b

B8c. There are many good reasons why people don't look for this kind of help. Can you please tell me why you decided not to look in the past 12 months for additional help for these things?

- ☐ TEXT[specify] → skip to C1
- ☐ NA → skip to C1

ASK IF YES TO EITHER B8a AND B8b

B8d. Did you find someone to help with any of NAME's transportation or meal preparation [FILL: or house work]?

☐ YES → B8e.

B8e Has that been working out, or do you still feel like you need more help with these things?

☐ WORKING OUT → skip to C1

☐ NEED MORE HELP → skip to C1

☐ DOES NOT FIT RESPONSE

CATEGORIES [specify] → skip to C1

☐ NA → skip to C1

☐ NO → B8f.

B8f. Can you please tell me what happened and why you were not able to get the help needed?

☐ TEXT [specify]

☐ NA

☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY] → Skip to C1

☐ NA → skip to C1

C. CAREGIVER'S PERCEPTION OF OWN NEEDS/RESOURCES, TIME OFF

C1. If you are ill or unable to provide your usual help to NAME, does someone else need to come in and substitute for you, or can NAME make do on his/her own until you can return?

☐ SUBSTITUTE NEEDED

☐ CAN MAKE DO → skip to C1b

☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY] → skip to C2

☐ NA → skip to C2

C1a. How difficult is it to find someone to fill in and provide help to NAME when you cannot? Would you say it is very difficult, somewhat difficult, a little difficult, or not at all difficult?

☐ VERY DIFFICULT

☐ SOMEWHAT DIFFICULT

☐ A LITTLE DIFFICULT

☐ NOT AT ALL DIFFICULT

☐ DON'T KNOW/NEVER NEEDED

☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY] → skip to C2

☐ NA → skip to C2

C1b. How long could you be ill or unable to provide your usual help before NAME would need help from someone else?

☐ TEXT [specify]

☐ NA

C2. In the past 12 months, have any family members or friends helped out so you could take time off of caring for [NAME]?

☐ YES

☐ NO

☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY]

☐ NA

C3. In the past 12 months, has NAME regularly attended any programs or regular activities during the day, such as recreation, training, or social programs designed for people with health problems or disabilities? [NOTE FOR IWR: Do not include work.]

☐ YES → **C3a. About how many hours per week does he/she spend at those programs or activities?**

_____ HOURS per DAY / WEEK / MONTH (circle one)

☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY]

☐ DON'T KNOW

☐ NA

☐ NO

☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY]

☐ NA

C4. In the past 12 months, have any organizations or agencies provided in-home respite care, that is given you time away from caring for NAME by coming into [FILL if in same hh: your; otherwise NAME's] home so that you can leave and do other things? [NOTE FOR IWR: Do not include visiting nurses.]

☐ YES → skip to C4b

☐ NO

☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY] → skip to C4a

☐ NA → skip to C4a

C4a. Do you know of any organizations or agencies that provide in-home respite care that will give you time away or relief from the responsibility of caring for [NAME]?

☐ YES → skip to C5

☐ NO → skip to C5

☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY] → skip to C5

☐ NA → skip to C5

C4b. How would you rate the quality of service provided – would you say it was excellent, very good, good, fair, or poor?

- ☐ EXCELLENT
- ☐ VERY GOOD
- ☐ GOOD
- ☐ FAIR
- ☐ POOR
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY]
- ☐ NA

C5. In the past 12 months, has NAME gone to a respite care facility where he/she would be cared for so that you can do other things?

- ☐ YES → skip to C5b
- ☐ NO
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY] → skip to C5a
- ☐ NA → skip to C5a

C5a. Do you know of any organizations or agencies that provide care outside the home so that you can have time away or relief from the responsibility of caring for [NAME]?

- ☐ YES → skip to C6
- ☐ NO → skip to C6
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY] → skip to C6
- ☐ NA → skip to C6

C5b. How would you rate the quality of service provided – would you say it was excellent, very good, good, fair, or poor?

- ☐ EXCELLENT
- ☐ VERY GOOD
- ☐ GOOD
- ☐ FAIR
- ☐ POOR
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY]
- ☐ NA

C6. Everyone needs a break from their responsibilities sometimes. In the past 12 months, have you felt like you could have used (more) time off from caring for NAME? [fill more if C2 or C3 or C4 or C5=Yes]

- ☐ YES
- ☐ NO
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY]
- ☐ NA

**D. EFFECT OF CAREGIVING ON CAREGIVER'S HEALTH,
JOB, FAMILY, FINANCES, SENSE OF SELF**

D1. Are you currently employed for pay?

- ☐ YES → skip to D2a
☐ NO
☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY]
☐ NA

D2. Have you been employed for pay at any time since you began helping (NAME)?

- ☐ YES
☐ NO → skip to D3a
☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY] → skip to D3a
☐ NA → skip to D3a

IF CURRENTLY OR FORMERLY WORKING

		YES	SOMETIMES	NO	SPECIFY	NA
D2a	Because of your caregiving responsibilities, do/did you ever have to go in late, leave early, or take time off from work to provide care?					
D2b	Did you ever have to take a leave of absence from work to provide care?					
D2c	Did you ever have to reduce your official working hours to provide care?					
D2d	[Because of your caregiving responsibilities,] did you ever have to arrange to have more flexible work hours?					
D2e	[IF FORMERLY WORKING] Did you ever have to give up working entirely or choose early retirement to provide care?					

D3a. In your experience as a caregiver, how often do you feel that you do not have enough time for yourself? Would you say often, sometimes, rarely, or never?

- ☐ OFTEN
☐ SOMETIMES
☐ RARELY
☐ NEVER
☐ NA

D3b. In your experience as a caregiver, how often do you feel that you do not have enough time for other members of your family? (Would you say often, sometimes, rarely, or never?)

- ☐ OFTEN
- ☐ SOMETIMES
- ☐ RARELY
- ☐ NEVER
- ☐ NA

D3c. How often do you feel that caregiving negatively affects your mental health? (Would you say often, sometimes, rarely, or never?)

- ☐ OFTEN
- ☐ SOMETIMES
- ☐ RARELY
- ☐ NEVER
- ☐ NA

D3d. How often do you feel that caregiving negatively affects your physical health? (Would you say often, sometimes, rarely, or never?)

- ☐ OFTEN
- ☐ SOMETIMES
- ☐ RARELY
- ☐ NEVER
- ☐ NA

D3e. How often do you feel that caregiving interferes with your social life? (Would you say often, sometimes, rarely, or never?)

- ☐ OFTEN
- ☐ SOMETIMES
- ☐ RARELY
- ☐ NEVER
- ☐ NA

IF CURRENTLY OR FORMERLY WORKING (OTHERS SKIP TO D4)

D3f. How often do/did you feel that caregiving interferes(d) with your work? Would you say often, sometimes, rarely, or never?

- ☐ OFTEN
- ☐ SOMETIMES
- ☐ RARELY
- ☐ NEVER
- ☐ NA

D4. How much personal satisfaction would you say you feel in being a caregiver for NAME? Would you say you feel a lot, some, a little, or no personal satisfaction?

- ☐ A LOT
- ☐ SOME
- ☐ A LITTLE
- ☐ NO PERSONAL SATISFACTION
- ☐ NA

D5. How stressful would you say it is to be a caregiver for NAME? Would you say it is very stressful, somewhat stressful, a little stressful, or not at all stressful?

- ☐ VERY STRESSFUL
- ☐ SOMEWHAT STRESSFUL
- ☐ A LITTLE STRESSFUL
- ☐ NOT AT ALL STRESSFUL
- ☐ NA

D6. Have you experienced any injury related to your caregiving activities in the past 12 months?

- ☐ YES
- ☐ NO → skip to E1
- ☐ NA → skip to E1

D6a. What type of injury did you have? (Probe if necessary: such as back injury, neck injury, etc.) (DO NOT READ)

- ☐ BACK
- ☐ NECK
- ☐ SHOULDER
- ☐ ANKLE
- ☐ KNEE
- ☐ OTHER (TEXT)
- ☐ NA

D6b. Did you see a doctor or other health care worker because of your injury?

- ☐ YES
- ☐ NO
- ☐ NA

D6c. Did your injury interfere with your ability to take care of [NAME]?

- ☐ YES
- ☐ NO
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY]
- ☐ NA

IF CURRENTLY/FORMERLY WORKING (OTHERS SKIP TO SECTION E)

D6d. Did you miss any work days because of your injury?

- ☐ YES
- ☐ NO → skip to next section
- ☐ WASN'T WORKING THEN → skip to next section
- ☐ NA → skip to next section

D6e. How many days of work did you miss?

NUMBER _____ per DAY / WEEK (circle one)

- ☐ DON'T KNOW
- ☐ NA

E. SUPPORT SERVICES CAREGIVER RECEIVES AND SERVICES CAREGIVER THINKS WOULD BE HELPFUL

E1. In the past 12 months, has someone such as NAME's case worker, case manager or social worker helped you or given you information to connect you to services and resources that you need as a caregiver?

- ☐ YES → skip to E1b
- ☐ NO
- ☐ NAME DOES NOT HAVE CASE WORKER/MANAGER/SOCIAL WORKER
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY] → skip to E2
- ☐ NA

E1a. Do you think that would have been helpful to you as a caregiver?

- ☐ YES → skip to E2
- ☐ NO → skip to E2
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY] → skip to E2
- ☐ NA → skip to E2

E1b. Was that information helpful to you as a caregiver?

- ☐ YES
- ☐ NO
- ☐ NA

E2. In the past 12 months, have you received counseling or participated in a support group intended to help you in being a caregiver?

- ☐ YES → skip to E2b
- ☐ NO
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY] → skip to E3
- ☐ NA

E2a. Do you think that would have been helpful to you as a caregiver?

- ☐ YES → skip to E3
- ☐ NO → skip to E3
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY] → skip to E3
- ☐ NA → skip to E3

E2b. How helpful did you find that group -- would you say it was very helpful, somewhat helpful, a little helpful, or not helpful at all?

- ☐ VERY HELPFUL
- ☐ SOMEWHAT HELPFUL
- ☐ A LITTLE HELPFUL
- ☐ NOT AT ALL HELPFUL
- ☐ NA

E3. In the past 12 months, have you attended any caregiver training or class intended to help you make decisions or solve problems in your role as a caregiver?

- ☐ YES → skip to E3b
- ☐ NO
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY] → skip to E4
- ☐ NA

E3a. Do you think that would have been helpful to you as a caregiver?

- ☐ YES → skip to E4
- ☐ NO → skip to E4
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY] → skip to E4
- ☐ NA → skip to E4

E3b. How would you rate the quality of that training -- would you say it was excellent, very good, good, fair, or poor?

- ☐ EXCELLENT
- ☐ VERY GOOD
- ☐ GOOD
- ☐ FAIR
- ☐ POOR
- ☐ NA

E4. In the past 12 months, was there any time when you wanted to get [FILL IF YES TO 1 or 2 or 3: more] information about services for people like you who provide care to another person?

- ☐ YES
- ☐ NO → skip to E5
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY] → skip to E5
- ☐ NA → skip to E5

E4a. Were you able to get that information?

- ☐ YES → skip to E5
- ☐ NO
- ☐ NA

E4b. Can you please describe what happened?

- ☐ TEXT [specify]
- ☐ NA

E5. In your opinion, if an agency or organization were able to provide help at no cost to you, could you use more help at home taking care of NAME?

- ☐ YES
- ☐ SOMETIMES
- ☐ NO → skip to E6
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY] → skip to E6
- ☐ NA → skip to E6

E5a. Again, if the help were being provided at no cost to you, how many more hours of help at home do you think you could use to take care of NAME?

_____ HOURS per DAY / WEEK / MONTH (circle one)

- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY]
- ☐ DON'T KNOW
- ☐ NA

E5b. If you were to receive those hours of help for NAME at home, what do you think are the most important things to have such a person do to help?

- ☐ TEXT [specify]
- ☐ NA

E5c. How helpful do you think such outside help would be to you – would it reduce your work by a lot, some, only a little, or none at all?

- ☐ A LOT
- ☐ SOME
- ☐ A LITTLE
- ☐ NONE AT ALL
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY]
- ☐ NA

E5d. We are interested in why NAME is not able to get all the help [he/she] needs beyond what you are able to provide. What are the main reasons why you think NAME is unable to get all the help needed right now? [MARK ALL THAT APPLY, RECORD VERBATIM RESPONSES THAT DON'T FIT CATEGORIES]

- ☐ COST OF HELP
- ☐ QUALITY OF HELP
- ☐ NOT AVAILABLE
- ☐ HAVEN'T LOOKED
- ☐ VERBATIM: _____
- ☐ NA

E6. How likely do you think it is that you will need more help at home taking care of NAME within the next 12 months -- would you say very likely, somewhat likely, not very likely, or not at all likely?

- ☐ VERY LIKELY
- ☐ SOMEWHAT LIKELY
- ☐ NOT VERY LIKELY
- ☐ NOT AT ALL LIKELY
- ☐ NOT SURE
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY]
- ☐ NA

F. FINANCES AND OTHER CAREGIVING

IF CAREGIVE AND R ARE RELATIVES (others skip to F2)

F1. An "out-of-pocket expense" is all money paid for health care, excluding the cost of buying health insurance, called premiums. Out-of-pocket expenses include the cost of deductibles at the beginning of the year, co-payments which are personal payments to receive medical care, home health care, equipment or prescriptions.

Thinking about all of [NAME's] out-of-pocket expenses, how difficult was it for NAME and your family to afford his/her out-of-pocket medical payments over the past 12 months? Would you say they were very difficult, somewhat difficult, a little difficult, or not difficult at all to afford?

- ☐ VERY DIFFICULT
- ☐ SOMEWHAT DIFFICULT
- ☐ A LITTLE DIFFICULT
- ☐ NOT DIFFICULT AT ALL
- ☐ NA

SKIP IF A5=6 (ALREADY SAID HE/SHE IS PCA)

F2. Sometimes caregivers are paid for their time, even when caring for friends or relatives. Are you paid for any of the time you provide care to (NAME)?

- ☐ YES
- ☐ NO
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY]
- ☐ NA

FOR RS WHO DO NOT LIVE TOGETHER (others skip to F4)

F3. Do you spend any of your own money to help care for [NAME]?

- ☐ YES
- ☐ SOMETIMES
- ☐ NO → skip to F4
- ☐ DOES NOT FIT RESPONSE CATEGORIES [SPECIFY] → skip to F4
- ☐ NA → skip to F4

F3a. How much of your money would you estimate you spend in a typical month in your role as a caregiver? PROBE: Your best estimate is fine.

_____AMOUNT per MONTH / YEAR (circle one)

- ☐ DON'T KNOW
- ☐ NA

F4. Do you provide regular help for anyone with a health condition or disability besides [NAME]?

- ☐ YES
- ☐ SOMETIMES
- ☐ NO → skip to intro before G1
- ☐ NA → skip to intro before G1

F4a. How many other people do you provide regular help to, not counting [NAME]?

☐ NA

G. DEMOGRAPHICS

INTRO: Now we have a few final questions about you.

G1. [RECORD SEX OF R. IF NOT OBVIOUS, ASK:] What is your gender?

- ☐ MALE
- ☐ FEMALE
- ☐ NA

G2. Overall, how would you rate your physical health? Would you say it is excellent, very good, good, fair, or poor?

- ☐ EXCELLENT
- ☐ VERY GOOD
- ☐ GOOD
- ☐ FAIR
- ☐ POOR
- ☐ NA

G3. Overall, how would you rate your mental or emotional health? Would you say it is excellent, very good, good, fair, or poor?

- ☐ EXCELLENT
- ☐ VERY GOOD
- ☐ GOOD
- ☐ FAIR
- ☐ POOR
- ☐ NA

G4. How often do you feel that you are stressed? Would you say often, sometimes, rarely, or never?)

- ☐ OFTEN
- ☐ SOMETIMES
- ☐ RARELY
- ☐ NEVER
- ☐ NA

G5. What is your age?

_____ NUMBER OF YEARS
☐ NA

G6. What is the highest grade in school you have completed?

- ☐ LESS THAN HIGH SCHOOL DIPLOMA
- ☐ HIGH SCHOOL DIPLOMA OR GED
- ☐ SOME COLLEGE, INCLUDING ASSOCIATE'S DEGREE,
- ☐ BACHELOR'S DEGREE, OR
- ☐ SOME POST-GRADUATE WORK OR ADVANCED DEGREE?
- ☐ NA

G7. Do you consider yourself to be of Hispanic or Latino origin?

- ☐ YES
- ☐ NO
- ☐ NA

G8. Please answer yes or no for each of the following racial or ethnic groups. Which of the following racial or ethnic groups describes you best? [ANSWER YES OR NO FOR EACH]

	YES	NO	NA
Black or African-American?	☐	☐	☐
Asian?	☐	☐	☐
American Indian or Alaskan Native?	☐	☐	☐
Native Hawaiian or Pacific Islander?	☐	☐	☐
White?	☐	☐	☐
Something else?	☐	☐	☐

IF CAREGIVER IS SPOUSE, SKIP TO G10a

G9. What is your current marital status? Are you married, divorced, widowed, separated, or have you never been married?

☐ MARRIED
☐ DIVORCED
☐ WIDOWED
☐ SEPARATED
☐ NEVER MARRIED
☐ NA

G10a. How many other adults (aged 18 or older) live in your household with you [IF IN THE SAME HH: and NAME]?

_____ # ADULTS → confirm: **G10b. So, that's x adults in total?**

G10c. Do you have any children aged 17 or younger who live with you?

☐ YES
☐ NO → skip to G11

G10d. How many? _____ # CHILDREN

G10e. (Starting with the oldest,) What is the age of the (oldest/next oldest) child?

CHILD 1 AGE: _____
 CHILD 2 AGE: _____
 CHILD 3 AGE: _____
 CHILD 4 AGE: _____

G11. In studies like this, families are sometimes grouped according to income. I'm going to read you some categories. Please stop me when I get to the one that best describes your total (family) income in 2006; this means income before taxes from all sources, such as salaries, interest, retirement or any other source (for all family members living in your household).

In 2006, was your total (family) income less than \$30,000, between \$30,000 and \$60,000, between \$60,000 and \$90,000, or more than \$90,000?

- ☐ LESS THAN \$30,000
- ☐ BETWEEN \$30,000 AND \$60,000 (SKIP TO G11b)
- ☐ BETWEEN \$60,000 AND \$90,000 (SKIP TO G11c)
- ☐ MORE THAN \$90,000 (SKIP TO G11d)
- ☐ DON'T KNOW → Skip to end
- ☐ REFUSED → Skip to end

G11a. Was it less than \$10,000, between \$10,000 and \$20,000, or more than \$20,000?
→ ALL SKIP TO END

G11b. Was it less than \$40,000, between \$40,000 and \$50,000, or more than \$50,000?
→ ALL SKIP TO END

G11c. Was it less than \$70,000, between \$70,000 and \$80,000, or more than \$80,000?
→ ALL SKIP TO END

G11d. Was it less than \$100,000, between \$100,000 and \$110,000, or more than \$110,000?

END