

Appendix A: Full Questionnaire

A. INTRO

Hello. My name is _____ and I am an interviewer with National Research. We are conducting a public opinion survey about important issues facing us today. We are not selling anything or raising money. The survey is completely confidential.

May I please speak to the person 18 years old or older in your household who had a birthday most recently? **[IF NECESSARY ARRANGE FOR A CALL BACK AND RECORD DATE AND TIME. REPEAT INTRO. AS NECESSARY]**

[IF NEEDED REASSURE RESPONDENT: This research company will never try to sell you anything]

[IF ASK: The survey takes about 20 minutes]

B. SCREEN

SC1a. In the last 12 months, has anyone in your household provided unpaid care to a relative or friend 18 years or older to help them take care of themselves? Unpaid care may include help with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This person need not live with you.

[IF YES: Is that you or someone else?]

[IF R. ASKS "DOES GIVING MONEY COUNT?," ASK: Aside from giving money, do you provide any other type of unpaid care to help them take care of themselves, such as help with personal needs, household chores, arranging for outside services, or other things? **[IF NOTHING OTHER THAN MONEY, CODE "NO"]**

Yes -- Person On Phone Is Caregiver 1
Yes -- Another Person In Household..... 2
No 3
(VOL) Don't know 4
(VOL) Refused 5

SC1b. In the last 12 months, has anyone in your household given unpaid care to any child under the age of 18 because of a medical, behavioral, or other condition or disability? This could include care for ongoing medical conditions or serious short-term ones, emotional or behavioral problems, or developmental problems, including mental retardation.

[IF YES: Is that you or someone else?]

[IF R. ASKS "DOES GIVING MONEY COUNT?," ASK: Aside from giving money, do you provide any other type of unpaid care to help a child who has a medical, behavioral, or other condition or disability? **[IF NOTHING OTHER THAN MONEY, CODE "NO"]**

Yes -- Person On Phone Is Caregiver 1
Yes -- Another Person In Household..... 2
No 3
(VOL) Don't know 4
(VOL) Refused 5
AUTOCODE – Not asked (2009 Oversample of 50+) 6

[TERMINATE IF BOTH SC1a&b ARE DK/REF (SC1a=4 or 5) AND (SC1b=4 or 5).]

This is an important study and to be sure we talk to a variety of people, I need to ask you some basic questions.

SC2. First, how old were you on your last birthday? **[RECORD AGE]**

_____ **[SKIP TO SC3. TERMINATE IF <18.]**

- (VOL) Don't know 998
- (VOL) Refused 999

SC2b. **[IF DON'T KNOW/REFUSED (SC2=998 or 999)]** Well are you... **[READ LIST]**

- 18 to 24..... 1
- 25 to 34..... 2
- 35 to 44..... 3
- 45 to 54..... 4
- 55 to 64..... 5
- 65 to 74, or 6
- 75 or older? 7
- (VOL) Don't know 8 **[TERMINATE]**
- (VOL) Refused 9 **[TERMINATE]**

SC3. Are you of Hispanic origin or background?

- Yes 1
- No 2
- (VOL) Don't know 3
- (VOL) Refused 4

SC4. Would you say you are White, Black or African American, Asian or Pacific Islander, or something else? **[ALLOW MULTIPLE RESPONSE]**

[IF HISPANIC, PROMPT:] I've recorded your Hispanic ethnicity. This question asks your race. **[REPEAT QUESTION]**

- White 1
- Black..... 2
- Asian..... 3
- Other **[SPECIFY _____]** 4
- (VOL) Don't know 5 **[TERMINATE]**
- (VOL) Refused 6 **[TERMINATE]**

SC5. **RECORD GENDER, DO NOT ASK**

- Male..... 1
- Female..... 2

SC6. How many people, including children, live in the household?

[INTERVIEWER NOTE: Count should include the respondent.]

_____ [RECORD NUMBER]

- Lives alone 1 [SKIP TO CHECKPOINT]
- (VOL) Don't know 98 [TERMINATE]
- (VOL) Refused 99 [TERMINATE]

SC7. Are you the person in the household who owns or rents the residence?

[WE WANT THE PERSON WHO PAYS THE MORTGAGE OR WHOSE NAME IS ON THE LEASE]

- Yes 1
- No 2 [SKIP TO SC9]
- (VOL) Don't know 3 [TERMINATE]
- (VOL) Refused 4 [TERMINATE]

SC8. [IF HOUSEHOLDER (SC7=1)] Are you related by marriage, blood, or adoption to anyone in the household?

- Yes 1 [SKIP TO CHECKPOINT]
- No 2 [SKIP TO CHECKPOINT]
- (VOL) Don't know 3 [TERMINATE]
- (VOL) Refused 4 [TERMINATE]

SC9. Thinking about the person who owns or rents the house, please tell me, is that person related to anyone in the household by marriage, blood, or adoption?

[IF MORE THAN ONE PERSON OWNS/RENDS, WE WANT THE PERSON WHO PAYS THE MORTGAGE OR WHOSE NAME IS ON THE LEASE]

- Yes 1
- No 2
- (VOL) Don't know 3 [TERMINATE]
- (VOL) Refused 4 [TERMINATE]

SC10. Thinking about the person who owns or rents the house, please tell me how old they are? [PROMPT: Your best estimate is fine]

_____ [RECORD AGE; ALLOW ANY AGE]

- 97 or older 97
- (VOL) Don't know 98 [TERMINATE]
- (VOL) Refused 99 [TERMINATE]

SC11. As far as you know, is the person of Hispanic origin or background?

- Yes 1
- No 2
- (VOL) Don't know 3
- (VOL) Refused 4

SC12. Would you say they are White, Black or African American, Asian or Pacific Islander, or something else? **[ALLOW MULTIPLE RESPONSE]**

[IF HISPANIC, PROMPT:] I've recorded their Hispanic ethnicity. This question asks their race. **[REPEAT QUESTION]**

- White 1
- Black..... 2
- Asian..... 3
- Other **[SPECIFY_____]** 4
- (VOL) Don't know 5 **[TERMINATE]**
- (VOL) Refused 6 **[TERMINATE]**

CHECKPOINT:

IF NO CAREGIVER IN SC1 (SC1a=3, 4, OR 5) AND (SC1b=3, 4, OR 5): TERMINATE AS "NO CAREGIVER".

IF HISPANIC SAMPLE AND:

IF R IS HH & NOT HISPANIC ((SC6=1 OR SC7=1) AND SC3=2,3,4) OR HH IS NOT HISP (SC11=2,3,4): TERMINATE AS "NON-HISP HH".

IF AFRICAN-AMERICAN SAMPLE AND:

IF R IS HH & NOT AA ((SC6=1 OR SC7=1) AND (SC4m1≠2 AND SC4m2≠2 AND SC4m3≠2..etc)) OR HH IS NOT AA (SC12m1≠2 AND SC12m2≠2 AND SC12m3≠2...etc): TERMINATE AS "NON-BLACK HH".

IF ASIAN SAMPLE AND:

IF R IS HH & NOT ASIAN (((SC6=1 OR SC7=1) AND (SC4m1≠3 AND SC4m2≠3 AND SC4m3≠3..etc)) OR HH IS NOT ASIAN (SC12m1≠3 AND SC12m2≠3 AND SC12m3≠3...etc): TERMINATE AS "NON-ASIAN HH".

IF INITIAL RESPONDENT CAREGIVER (SC1a=1 OR SC1b=1): GO TO TEXT BEFORE Q1.

IF INITIAL RESPONDENT NOT CAREGIVER, BUT CAREGIVER IN HH (SC1a=2 AND SC1b≠1) OR (SC1a≠1 AND SC1b=2): CONTINUE TO SC13.

SC13. May I please speak to the person in your household who is providing unpaid care to **[IF SC1a=2 and SC1b ≠ 2: a relative or friend 18 years or older? /**

IF SC1a≠ 2 and SC1b = 2: a child under the age of 18 because of a medical, behavioral, or other condition or disability? /

IF SC1a=2 AND SC1b=2: an adult or a child with a medical, behavioral, or some other condition or disability?

[IF MORE THAN ONE CAREGIVER, ASK TO SPEAK TO THE ONE WITH THE LAST BIRTHDAY]

- Yes 01
- Not available **[DO NOT GO TO SC14a; THANK & ARRANGE CALLBACK]** 09
- No/Don't know/Refused
- [DO NOT GO TO SC14a; THANK & CALL BACK TO CONVERT]** 16

CALLBACK SCREENS:

CB: When would be a good time to call back? **[RECORD DATE AND TIME]**

CONF: Your appointment is set for **[DATE]** at **[TIME]**. Is that correct? **[CONFIRM OR CHANGE DATE AND TIME IF NEEDED]**

INTRO FOR CALLBACK (WHEN CALL BACK SCHEDULED AT SC13)

Hello. My name is _____ and I am an interviewer with National Research. We called you recently and we were told that someone in your household is providing unpaid care to a relative, friend, or child. **[GO TO SC13 AND ASK FOR THE CAREGIVER. USE THE CAREGIVER'S NAME IF KNOWN.]**

[IF NEEDED]:

We are conducting a survey about caregiving. We are not selling anything or raising money. The survey is completely confidential.

This research company will never try to sell you anything.

The survey takes about 20 minutes.

CAREGIVER ON PHONE (after having been handed the phone by initial respondent):

SC14a. **[IF SC1a=2]** Hello. We are conducting a survey about caregiving. Just to confirm...

At any time in the last 12 months, including now, have you provided unpaid care to a relative or friend 18 years or older to help them take care of themselves?

Caregiving may include help with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This person does not need to live with you.

- Yes 1
- No 2
- (VOL) Don't know** 3
- (VOL) Refused** 4

SC14b. **[IF SC1b = 2] [SHOW IF SC14a=SKIP:** Hello. We are conducting a survey about caregiving. Just to confirm...]

At any time in the last 12 months, including now, have you provided unpaid care to any child under the age of 18 because of a medical, behavioral, or other condition or disability?

This could include care for ongoing medical conditions or serious short-term ones; emotional or behavioral problems; or developmental problems, including mental retardation. (sentence removed)

- Yes 1
- No 2
- (VOL) Don't know** 3
- (VOL) Refused** 4
- AUTOCODE – Not asked (2009 Oversample of 50+)** 5

**IF SC14a=1 or SC14b=1, SKIP TO SC15.
ELSE, ASK SC14c.**

SC14c. Is there someone else in your household who is a caregiver?

- Yes 1 **[SKIP BACK TO SC13]**
- No 2 **[TERMINATE]**
- (VOL) Don't know** 3 **[TERMINATE]**
- (VOL) Refused** 4 **[TERMINATE]**

SC15. Just to be sure I speak to people of all ages, how old were you on your last birthday?

_____ **[RECORD AGE; SKIP TO SC17. TERMINATE IF <18 YEARS OLD.]**

- (VOL) Don't know 998
- (VOL) Refused 999

SC16. **[IF DON'T KNOW/REFUSED (SC15=98 or 99)]** Well are you... **[READ LIST]**

- 18 to 24..... 1
- 25 to 34..... 2
- 35 to 44..... 3
- 45 to 54..... 4
- 55 to 64..... 5
- 65 to 74, or 6
- 75 or older? 7
- (VOL) Don't know 8 **[TERMINATE]**
- (VOL) Refused 9 **[TERMINATE]**

SC17. Are you of Hispanic origin or background?

- Yes 1
- No 2
- (VOL) Don't know 3
- (VOL) Refused 4

SC18. Would you say you are White, Black or African American, Asian or Pacific Islander, or something else? **[ALLOW MULTIPLE RESPONSE]**

[IF HISPANIC, PROMPT:] I've recorded your Hispanic ethnicity. This question asks your race. **[REPEAT QUESTION]**

- White 1
- Black..... 2
- Asian..... 3
- Other **[SPECIFY_____]** 4
- (VOL) Don't know 5 **[TERMINATE]**
- (VOL) Refused 6 **[TERMINATE]**

SC19. **RECORD GENDER; DO NOT ASK**

- Male..... 1
- Female..... 2

ALL CAREGIVERS:

C. CHARACTERISTICS OF THE RELATIONSHIP

This survey is part of an important national study conducted by the National Alliance for Caregiving and A-A-R-P. We really appreciate your participation.

[IF HELPFUL, INTERVIEWER MAY TELL RESPONDENT] This is a national survey, and although individual answers are confidential, the results from the overall survey will be published.

1. Are you currently providing unpaid help to a relative, friend, or child, or, was this something you did in the past 12 months but are no longer doing?

[IF BOTH CURRENT AND PAST, CODE “CURRENTLY” AND SAY:] Let’s talk about whomever you are currently providing care for.

- Currently..... 1
- Past 12 months2
- (VOL) Don't know.....3
- (VOL) Refused.....4

WORDING NOTE 1:

IF CURRENTLY (Q1=1): USE PRESENT TENSE, first verb in {BRACKETS}
IF PAST 12 MONTHS (Q2=2, 3, or 4): USE PAST TENSE, second verb in {BRACKETS}

2. How many people, including adults and children {do you provide this care for? / did you provide this care for in the past 12 months?} **[RECORD NUMBER]**

_____ **[ALLOW 0-97; TERMINATE IF 0]**

- (VOL) Don't know.....98 **[TERMINATE]**
- (VOL) Refused.....99 **[TERMINATE]**

FOR THE FEW RESPONDENTS WHO SAY THEY ARE CAREGIVERS TO 5+ PEOPLE, WE WILL DOUBLE CHECK THAT THEY ARE TRULY CAREGIVERS – THEY CAN'T BE IN AN INSTITUTIONAL SETTING AND THEY MUST BE CARING FOR RECIPIENTS WHO DO HAVE SPECIAL NEEDS.

3. **[IF Q2 >= 5]** {Are/were} all of these people together in an institutional or group setting like nursing care or day care or a school where you work or volunteer?

- Yes **[TERMINATE]**..... 1
- No.....2
- (VOL) Don't know **[TERMINATE]**3

4. **[IF Q2 >= 5]** I need to understand whether this {is/was} care for some kind of special needs, or whether this {is/was} normal care one would expect for average, healthy people. How many of the people you help care for {have/had} some sort of special need that {is/was} the reason for their care? All of them, some of them, or none of them?

- All **[SKIP TO TEXT AFTER Q2B]** 1
- Some **[GO TO Q2B]**2
- None **[TERMINATE]**3
- (VOL) Don't know **[TERMINATE]**4

2b. How many people, including adults and children {do you provide this care for? / did you provide this care for in the past 12 months?} **[RECORD NUMBER]**

_____ **[ALLOW 0-97; TERMINATE IF 0]**

(VOL) Don't know.....98 **[TERMINATE]**

(VOL) Refused.....99 **[TERMINATE]**

[IF ONE PERSON (Q2=1): Now, I'd like to ask you some questions about the person for whom you {provide/provided} care.]

[IF MORE THAN ONE (Q2=2 thru 97): Let's focus on the person for whom you {provide/provided} the most assistance.]

5. How old {is/was} that person? **[PROMPT: Your best estimate is fine]**

_____ **[RECORD AGE IN YEARS, SKIP TO C1.]**

Less than 1 year old.....000 **[SKIP TO C1]**

(VOL) Don't know998

(VOL) Refused999

6. **[IF DK/REF (Q5=998 or 999), ASK]:** Well, {is/was} that person 18 years or older?

Yes1

No2

(VOL) Don't know.....3 **TERMINATE**

(VOL) Refused4 **TERMINATE**

C1. **AUTOCODE: TYPE OF CAREGIVER**

Adult Care Recipient **[IF Q5>17 OR Q6=1]**.....1

Child Care Recipient **[IF Q5<18 OR Q5=997 OR Q6=2]**2

7. What {is/was} this person's relationship to you? **[PRE-CODED OPEN END. DO NOT READ LIST]**

[AS NEEDED: She/He is your _____?]

RELATIVE:

Aunt.....1

Brother2

Brother-In-Law3

Companion/Partner4

Daughter5

Father.....6

Father-In-Law.....7

Granddaughter8

Grandfather9

Grandmother10

Grandparent-In-Law11

Grandson12

Mother13

Mother-In-Law14

Nephew15

Niece16

Sister17

Sister-In-Law18

Son..... 19
 Spouse 20
 Uncle 21
 Other Relative [SPECIFY _____] 22 [Use "Relative"]

NON-RELATIVE:

Foster child..... 23
 Friend 24
 Guardianee 25
 Neighbor..... 26
 Other non-relative 27 [Use "care recipient"]
 (VOL) Don't know..... 28 [Use "care recipient"]
 (VOL) Refused..... 29 [Use "care recipient"]

[IF Q7 = 1, 2, 3, 5, 6, 7, 8, 9, 10, 12, 13, 14, 15, 16, 17, 18, 19, 22 → SKIP TO NOTE BEFORE Q10]

[IF Q7 = 4, 22, 23, 24, 25, 26, 27, 28, or 29 → SKIP TO Q9]

[IF Q7 = 11 or 20 → CONTINUE TO Q8]

8. [IF Q7 = 11 or 20]: RECORD GENDER OF THE RESPONDENT'S [Q7 CODE]. DO NOT ASK UNLESS NEEDED.

Male 1
 Female 2
 (VOL) Don't know..... 3

9. [IF Q7 = 4, 22, 23, 24, 25, 26, 27, 28, OR 29] Would you mind telling me if your [Q7 CODE] {is/was} male or female? RECORD GENDER OF THE RESPONDENT'S [Q7 CODE]. DO NOT ASK UNLESS NEEDED.

Male 1
 Female 2
 (VOL) Refused..... 3

[IF CHILD RECIPIENT (C1=2), SKIP TO Q11.] [IF CARE FOR SPOUSE (Q7=20), AUTOCODE Q10=2 AND SKIP TO Q11.]

10. {Is your [Q7 CODE] currently/Was your [Q7 CODE]} widowed, married, living with a partner, separated, divorced, or single – that is never been married?

Widowed 1
 Married 2
 Living with a partner 3
 Separated 4
 Divorced 5
 Single 6
 (VOL) Don't know 7
 (VOL) Refused 8

11. {Does/Did} your [Q7 CODE] live.... [READ LIST]

In your household..... 1 [SKIP TO Q16]
 Within twenty minutes of your home 2
 Between twenty minutes and an hour from your home 3
 A one to two hour drive from your home, or 4
 More than two hours away? 5
 (VOL) Don't know..... 6 [SKIP TO Q14]
 (VOL) Refused..... 7 [SKIP TO Q14]

12. **[IF NOT IN HOUSEHOLD (Q11=2 thru 5)]** On average, how often {do/did} you visit your **[Q7 CODE]**.....more than once a week, once a week, few times a month, once a month, few times a year, or less often?
- More than once a week..... 1
 Once a week 2
 Few times a month 3
 Once a month 4
 Few times a year 5
 Less often 6
(VOL) Don't know 7
(VOL) Refused 8
13. **[IF NOT IN HOUSEHOLD (Q11=2 thru 5)]** {Does/Did} your **[Q7 CODE]** live in...**[READ ENTIRE LIST]**
- His or her own home 1
 Someone else's home..... 2
[SHOW IF ADULT RECIPIENT (C1=1)] An independent living or retirement community..... 3
[SHOW IF ADULT RECIPIENT (C1=1)] In an assisted living facility where some care may be provided 4
 A nursing care or long-term care facility..... 5 **[SKIP TO Q15]**
[SHOW IF CHILD RECIPIENT (C1=2)] A group home 6 **[SKIP TO Q15]**
[SHOW IF CHILD RECIPIENT (C1=2)] Foster care..... 7 **[SKIP TO Q15]**
 Or somewhere else? **[SPECIFY _____]** 8
(VOL) Don't know..... 9
(VOL) Refused..... 10
14. **[IF ADULT RECIPIENT (C1=1), ASK:]** {Does/Did} your **[Q7 CODE]** live... **[READ ENTIRE LIST UNLESS "LIVES ALONE"]** **[MULTIPLE PUNCH]**
- Alone 1
 With her/his spouse..... 2
 With her/his grown children 3
 With other family members 4
 With friends 5
 With an aide, housekeeper, or other staff 6
 Or with someone else? **[SPECIFY _____]** 7
(VOL) Don't know..... 8
(VOL) Refused..... 9
- 14b. **[IF CHILD RECIPIENT (C1=2), ASK:]** {Does/Did} your **[Q7 CODE]** live... **[READ LIST]** **[MULTIPLE PUNCH]**
- With his/her parents 1
 With other family members 2
 With friends 3
 With an aide, housekeeper, or other staff 4
 Or with someone else? **[SPECIFY _____]** 5
(VOL) Don't know..... 6
(VOL) Refused..... 7

15. {Does/Did} your [Q7 CODE] live in an urban, suburban, or rural area?

- Urban1
- Suburban.....2
- Rural area3
- (VOL) Don't know.....4
- (VOL) Refused.....5

16. And do you live in an urban, suburban, or rural area?

- Urban1
- Suburban2
- Rural area3
- (VOL) Don't know4
- (VOL) Refused5

D. CHARACTERISTICS OF RECIPIENT

17. Would you say that your [Q7 CODE] {needs/needed} care because of any...[READ ITEMS A-F IN ORDER]

		Yes	No	(VOL) DK	(VOL) RF
a.	Short-term physical conditions?	1	2	3	4
b.	Long-term physical conditions?	1	2	3	4
c.	Emotional or mental health problems?	1	2	3	4
d.	Mental retardation or developmental delay?	1	2	3	4
e.	Learning disability or educational issue?	1	2	3	4
f.	Behavioral issues?	1	2	3	4

18. What would you say {is/was} the main problem or illness your [Q7 CODE] {has/had}, for which he/she {needs/needed} your care? [PRECODED OPEN END: ACCEPT ONE ANSWER.]

[IF “DISABLED”, PROBE: “What kind of disability would that be?”]

- ADD, ADHD, Attention deficit disorder1
- AIDS (also includes HIV).....2
- Alzheimer’s, confusion, dementia, forgetfulness.....3
- Amputee4
- Arthritis5
- Asthma, breathing problems6
- Autism7
- Back problems (also includes spine, neck)8
- Birth defect.....9
- Blindness, vision loss, can’t see well10
- Blood pressure, hypertension11
- Brain damage or injury12
- Broken bones13
- Cancer14
- Deafness, hearing loss15
- Diabetes16
- Epilepsy, seizures17
- Feeble, unsteady, falling (also includes balance, weak)18
- Heart disease19
- Lung disease, emphysema20

Mental retardation, developmental delay, Down syndrome	21
Mental illness, emotional illness, depression	22
Mobility, can't get around	23
Old age, just old, Aging	24
Osteoporosis	25
Paraplegia	26
Parkinson's	27
Pregnancy	28
Speaking, can't speak	29
Stroke	30
Substance/drug/alcohol abuse	31
Surgery, wounds	32
Other [SPECIFY _____]	33
(VOL) Don't know	34
(VOL) Refused	35
Added post interviewing:	
Cerebral palsy	36
Behavioral/social issue	37
Learning disability	38

[IF ADULT RECIPIENT (C1=1), SKIP TO Q20.]

19. **[IF CHILD RECIPIENT (C1=2), ASK]:** As a result of your [Q7 CODE]'s condition {is/was} your [Q7 CODE] limited in any way in his/her ability to do the things that most children of the same age do? **[PROMPT YES OR NO IF NEEDED.]**
- | | |
|------------------------|---|
| Yes | 1 |
| No | 2 |
| (VOL) Don't know | 3 |
| (VOL) Refused | 4 |
20. **[IF ADULT (C1=1) AND ALZHEIMER'S NOT MENTIONED (Q18#3)]** {Does/Did} your [Q7 CODE] suffer from Alzheimer's or other mental confusion?
- | | |
|------------------------|---|
| Yes—Alzheimer's | 1 |
| Yes--Other | 2 |
| No | 3 |
| (VOL) Don't know | 4 |
| (VOL) Refused | 5 |
21. For how long {have you been providing/did you provide} care to your [Q7 CODE] **[IF CHILD RECIPIENT: for his/her condition]? [RECORD YEARS] [PROMPT: Your best estimate is fine]**
- [INTERVIEWER NOTE IF CHILD RECIPIENT (C1=2): IF PARENT HAS BEEN CAREGIVER FOR CHILD'S ENTIRE LIFE, CLARIFY: Has this care always been for the child's condition, over and above normal parenting?]**
- [IF MORE THAN ONE CONDITION, PROMPT:]** Think about your caregiving for the main problem or illness you mentioned earlier.
- _____ **[ALLOW 1-93 or PRE-CODED OPEN END]**
- | | |
|--------------------------------|----|
| (VOL) All their life | 94 |
| Six months to one year | 95 |
| Less than six months | 96 |
| Occasionally, on and off | 97 |
| (VOL) Don't know | 98 |
| (VOL) Refused | 99 |

22. **[IF ADULT RECIPIENT (C1=1)]:** I'm going to read a list of kinds of help, which might be provided to a person, if the person cannot do this by him or herself. For each, just tell me if you {provide/provided} this kind of help.

{Do/Did} you help your **[Q7 CODE]**...**[RANDOMIZE & READ LIST]**

[IF CHILD RECIPIENT (C1=2)]: I'm going to read a list of kinds of help, which might be provided to a child, if the child cannot do this by him or herself. For each, just tell me if it {is/was} necessary for you to provide this kind of help to your **[Q7 CODE]**, because he/she {is/was} less able to do this task than children of the same age without his/her condition.

{Do/Did} you help your **[Q7 CODE]**... **[RANDOMIZE & READ LIST]** because he/she {is/was} less able to do this task than children of the same age without his/her condition?

		Yes	No	(VOL) DK	(VOL) RF
a.	[SHOW IF 3+ YRS OLD (Q5>=3)]: Get in and out of beds and chairs	1	2	3	4
b.	[SHOW IF 4+ YRS OLD (Q5>=4)]: Get dressed	1	2	3	4
c.	[SHOW IF 4+ YRS OLD (Q5>=4)]: Get to and from the toilet	1	2	3	4
d.	[SHOW IF 6+ YRS OLD (Q5>=6)]: Bathe or shower	1	2	3	4
e.	[SHOW IF 4+ YRS OLD (Q5>=4)]: By dealing with incontinence or diapers	1	2	3	4
f.	[SHOW IF 3+ YRS OLD (Q5>=3)]: By feeding him or her	1	2	3	4
g.	By giving medicines, pills, or injections for his/her condition <small>[NOTE: THIS IS AN IADL]</small>	1	2	3	4

[CONTINUE IF ADULT RECIPIENT (C1=1). IF CHILD RECIPIENT (C1=2), SKIP TO Q24.]

23. {Do/Did} you provide help to your **[Q7 CODE]** ...**[RANDOMIZE ITEMS A-F, KEEP G-H LAST]**

		Yes	No	(VOL) DK	(VOL) RF
a.	With managing finances, such as paying bills, or filling out insurance claims	1	2	3	4
b.	With grocery shopping	1	2	3	4
c.	With housework, such as doing dishes, laundry, or straightening up	1	2	3	4
d.	With preparing meals	1	2	3	4
e.	With transportation, either by driving him/her, or helping your [Q7 CODE] get transportation	1	2	3	4
f.	With arranging or supervising services from an agency, such as nurses or aides	1	2	3	4
g.	By advocating for him/her with care providers, government agencies, or schools	1	2	3	4
h.	By doing physical or medical therapies or treatments on him/her	1	2	3	4

[IF ADULT RECIPIENT (C1=1) AND NO/DK/REF TO (Q22a thru g AND Q23a thru f = 2, 3, or 4), THEN TERMINATE – TREAT AS NON CAREGIVER HOUSEHOLD.]

[CONTINUE IF CHILD RECIPIENT (C1=2). IF ADULT RECIPIENT (C1=1), SKIP TO Q25.]

24. As a result of your [Q7 CODE]'s condition, {do/did} you help by... **[RANDOMIZE AND READ LIST]**

		Yes	No	(VOL) DK	(VOL) RF
a.	Dealing with financial issues, such as paying bills related to their care or filling out insurance claims	1	2	3	4
f.	Arranging or supervising services from an agency, such as nurses, aides, or therapists	1	2	3	4
g.	Advocating for him/her with schools, government agencies, or care providers	1	2	3	4
h.	Monitoring the severity of his/her condition so that you can adjust care accordingly	1	2	3	4
i.	Preparing a special diet for him/her	1	2	3	4
j.	Making sure that people who {interact/interacted} with him/her {know/knew} how to deal with him/her	1	2	3	4
k.	Doing physical or medical therapies or treatments on him/her	1	2	3	4
l.	Doing or participating in learning, behavioral, or emotional therapies or treatments	1	2	3	4

25. Thinking now of all the kinds of help you {provide/provided} for your [Q7 CODE], about how many hours {do/did} you spend in an average week, doing these things? **[RECORD HOURS PER WEEK]**

_____ **[ALLOW 1-168]**

Less than 1 hour per week 169

(VOL) Constant care 170

(VOL) Don't know 171

(VOL) Refused 172

E. MEDICATIONS

26. {Does/Did} your [Q7 CODE] take any prescription medicine?

Yes 1

No 2 **[SKIP TO Q28]**

(VOL) Don't know 3 **[SKIP TO Q28]**

(VOL) Refused 4 **[SKIP TO Q28]**

27. **[IF 8+ YRS OLD (Q5>=8), ASK]:** Would you say your [Q7 CODE] {needs/needed} someone to oversee giving him/her medicine in the right amount and on time, or that he/she {manages/managed} this well on his/her own?

Needs help 1

Manages on own 2

(VOL) Don't know 3

(VOL) Refused 4

F. OTHER CAREGIVER SUPPORT

28. Has anyone else provided unpaid help to your [Q7 CODE] during the last 12 months?
- Yes 1
 No..... 2 [SKIP TO Q30]
 (VOL) Don't know..... 3 [SKIP TO Q30]
 (VOL) Refused..... 4 [SKIP TO Q30]

29. Who would you consider to be the person who {provides/provided} most of the unpaid care for your [Q7 CODE] – you yourself, or someone else?
- Self 1
 Someone else 2
 (VOL) We split it evenly 3
 (VOL) Don't know..... 4
 (VOL) Refused..... 5

30. During the last 12 months, did your [Q7 CODE] receive paid help from any aides, housekeepers, or other people who were paid to help him/her?
- Yes 1
 No..... 2 [SKIP TO Q32]
 (VOL) Don't know..... 3 [SKIP TO Q32]
 (VOL) Refused..... 4 [SKIP TO Q32]

31. **[IF YES (Q30=1), ASK]:** Who would you say {provides/provided} more of your [Q7 CODE]'s care – you, other UNPAID helpers, or PAID helpers?
- You [THE RESPONDENT]..... 1
 Other unpaid helpers..... 2
 Paid helpers 3
 (VOL) Don't know..... 4
 (VOL) Refused..... 5

G. STRESS ON WORKING CAREGIVERS

32. Now I have a few questions about you. Are you currently...**[READ LIST]**
- Working full-time **[SKIP TO Q34 IF CURRENT CG (Q1 = 1)]**..... 1
 Working part-time **[SKIP TO Q34 IF CURRENT CG (Q1 = 1)]** 2
 A student 3
 Disabled 4
 Retired..... 5
 A homemaker..... 6
 Unemployed and looking for work, or..... 7
 Something else **[SPECIFY _____]** 8
 (VOL) Don't know..... 9
 (VOL) Refused..... 10

33. {Have you been employed at any time since you began helping your [Q7 CODE]? / Were you employed at any time while you were helping your [Q7 CODE]}?

- Yes 1
- No 2 [SKIP TO Q35]
- (VOL) Don't know 3 [SKIP TO Q35]
- (VOL) Refused 4 [SKIP TO Q35]

34. In your experience as both a worker and a caregiver, did you ever...[READ LIST]

		Yes	No	DK	RF
a.	Have to go in late, leave early, or take time off during the day to provide care	1	2	3	4
b.	Have to take a leave of absence	1	2	3	4
c.	Have to go from working full-time to part-time, or taken a less demanding job	1	2	3	4
d.	Have to turn down a promotion	1	2	3	4
e.	Lose any of your job benefits?	1	2	3	4
f.	Have to give up working entirely	1	2	3	4
g.	Choose early retirement	1	2	3	4

H. PHYSICAL, EMOTIONAL AND FINANCIAL STRESS OF CAREGIVING

35. Think of a scale from 1 to 5, where 1 is not a strain at all and 5 is very much a strain. How much of a physical strain would you say that caring for your [Q7 CODE] {is/was} for you?

- 1 – Not a strain at all 1
- 2 2
- 3 3
- 4 4
- 5 – Very much a strain 5
- (VOL) Don't know 6
- (VOL) Refused 7

36. Using the same scale from 1 to 5, where 1 is not at all stressful and 5 is very stressful, how emotionally stressful would you say that caring for your [Q7 CODE] {is/was} for you?

- 1 – Not at all stressful 1
- 2 2
- 3 3
- 4 4
- 5 – Very stressful 5
- (VOL) Don't know 6
- (VOL) Refused 7

37. Using the same scale from 1 to 5, where 1 is no hardship at all and 5 is a great deal of hardship, how much of a financial hardship would you say that caring for your [Q7 CODE] {is/was} for you?
- 1 – No hardship at all 1
 2 2
 3 3
 4 4
 5 – Great deal of hardship..... 5
 (VOL) Don't know..... 6
 (VOL) Refused 7
38. Please think about all of the health care professionals or service providers who {give/gave} care or treatment to your [Q7 CODE]. How easy or difficult {is/was} it for you to coordinate care between these providers? Would you say...[READ LIST]? [ROTATE 1-4/4-1]
- Very easy 1
 Somewhat easy..... 2
 Somewhat difficult 3
 Very difficult..... 4
 (VOL) Don't know..... 5
 (VOL) Refused 6
39. We have been talking about the help you {provide/provided} for your [Q7 CODE]. Do you feel you had a choice in taking on this responsibility for caring for your [Q7 CODE]?
- Yes 1
 No 2
 (VOL) Don't know 3
 (VOL) Refused 4
40. As a caregiver, {do/did} you have less time for friends or other family members than before?
- Yes 1
 No 2
 (VOL) Don't know 3
 (VOL) Refused..... 4

I. USE OF INTERNET AND OTHER TECHNOLOGIES

41. If you were looking for information about some aspect of helping take care of your [Q7 CODE], where would you turn? [DO NOT READ CODES, MULTIPLE PUNCH IF THEY VOLUNTEER MORE THAN ONE]
- Doctor 1
 Nurse, other Health Professionals 2
 Internet 3
 Books, Magazines, Library 4
 Employer 5
 Senior Citizen's Center, Aging Organization 6
 Parent Groups 7
 School 8

- Disease-specific group or organization9
- Other [SPECIFY _____]10
- (VOL) Don't know11
- (VOL) Refused.....12

42. How often, if at all, have you gone to internet websites in the past year to find information in any way related to being a caregiver for your [Q7 CODE]? [READ LIST] [ROTATE 1-4/4-1]

- Often4
- Sometimes3
- Rarely.....2
- Never.....1 [SKIP TO Q44]
- (VOL) Don't know5 [SKIP TO Q44]
- (VOL) Refused.....6 [SKIP TO Q44]

43. Did you look online for...?

		Yes	No	(VOL) DK	(VOL) RF
a.	Information about your [Q7 CODE]'s condition or treatment?	1	2	3	4
b.	Information about services available for people like your [Q7 CODE]?	1	2	3	4
c.	Support for you personally as a caregiver?	1	2	3	4
d.	Information about how to do specific caregiving tasks?	1	2	3	4
e.	Doctors or other health professionals?	1	2	3	4
f.	Information about care facilities?	1	2	3	4

44. In caring for your [Q7 CODE], was [READ ITEM] ever used? [REPEAT STEM EVERY 3 ITEMS OR AS NEEDED.]

		Yes	No	(VOL) DK	(VOL) RF
a.	An electronic organizer or calendar?	1	2	3	4
b.	Any device that electronically sends information to a doctor or care manager to help manage his/her health care, like a device that transmits blood sugar or blood pressure readings?	1	2	3	4
c.	A text reader for individuals with low vision?	1	2	3	4
d.	An emergency response system, such as Lifeline?	1	2	3	4
e.	A website or computer software to keep track of his/her personal health records?	1	2	3	4
f.	An electronic sensor that can detect safety problems in the home and take steps to help, like when someone falls, wanders away, or leaves the stove on?	1	2	3	4
g.	Any other technology? [SPECIFY: What technology was that? _____]	1	2	3	4

J. INFORMATION/SERVICES/POLICY

45. In your experience as a caregiver, have you ever.... **[READ LIST; PROGRAM SO THAT ITEMS A AND B COME LAST IN THE SERIES]**

		Yes	No	(VOL) DK	(VOL) RF
a.	Requested information about how to get financial help for your [Q7 CODE] ?	1	2	3	4
b.	Used a respite [RESS – PIT] service or a sitter to take care of your [Q7 CODE] to free up your time?	1	2	3	4
c.	Had an outside service provide transportation for your [Q7 CODE] instead of you providing the transportation?	1	2	3	4

46. Have you done or obtained any of these types of things to make it easier to care for your **[Q7 CODE]**?

Have you...**[READ LIST]**?

		Yes	No	(VOL) DK	(VOL) RF
a.	Had modifications made in the house or apartment where your [Q7 CODE] {lives/lived} to make things easier for him/her?	1	2	3	4
b.	Obtained formal training of some sort about how to care for a person with your [Q7 CODE] 's needs?	1	2	3	4

47a. I am going to read you a list of things that policymakers are proposing to help caregivers like yourself. Please tell me which one you would {find/have found} most helpful, regardless of whether or not you used it already. **[ROTATE ITEMS; READ LIST]** Which one you would {find/have found} most helpful?

47b. Which one would you {find/have found} the next most helpful, regardless of whether or not you used it already? **[ROTATE ITEMS; READ LIST IF NEEDED, EXCLUDING IF SELECTED IN Q47a]**

	Q47a: MOST	Q47b: NEXT
An assessment of your caregiving capabilities and needs to connect you with needed services	1	1
A caregiver tax credit of three thousand dollars	2	2
[IF EVER EMPLOYED (Q33=1) OR CURR EMP (Q32<3 AND Q1=1)] A partially paid leave of absence from your work for 6 weeks	3	3
A voucher program where your [Q7 CODE] could pay you minimum wage for at least some of the hours you spend caregiving	4	4
Respite [RESS – PIT] services, where someone would take care of your [Q7 CODE] to give you a break	5	5
An outside service to provide transportation for your [Q7 CODE]	6	6
(VOL) Don't know → SKIP TO Q48	7	7
(VOL) Refused → SKIP TO Q48	8	8

48. As a caregiver, on which of the following do you feel you [need/needed] more help or information? **[RANDOMIZE AND READ LIST]**

[REPEAT EVERY 4-5 ITEMS: Do you feel you {need/needed} more help or information on...]

		Yes	No	(VOL) DK	(VOL) RF
a.	Keeping the person you care for safe at home	1	2	3	4
b.	Managing challenging behaviors, such as wandering	1	2	3	4
c.	Easy activities you can do with the person you care for	1	2	3	4
d.	Managing incontinence or toileting problems	1	2	3	4
e.	Moving or lifting the person you care for	1	2	3	4
f.	Balancing your work and family responsibilities	1	2	3	4
g.	Finding time for yourself	1	2	3	4
h.	Choosing an assisted living facility	1	2	3	4
i.	Choosing a nursing home	1	2	3	4
j.	Choosing a home care agency	1	2	3	4
k.	How to talk with doctors and other healthcare professionals	1	2	3	4
l.	Managing your emotional and physical stress	1	2	3	4
m.	Making end-of-life decisions	1	2	3	4
n.	Finding non-English language educational materials	1	2	3	4

K. DEMOGRAPHICS

And finally, just a few questions for classification purposes only....

D1. How would you describe your own health? Is it excellent, very good, good, fair, or poor?

- Excellent5
- Very good4
- Good3
- Fair2
- Poor1
- (VOL) Don't know6
- (VOL) Refused7

D2. How would you say taking care of your [Q7 CODE] has affected your health? Has it made it better, not affected it, or made it worse?

- Made it better1
- Not affected it2
- Made it worse3
- (VOL) Don't know4
- (VOL) Refused5

D3. Are you currently... **[READ LIST]**

- Married 1
- Living with a partner 2
- Widowed 3
- Separated..... 4
- Divorced 5
- Single, never married 6
- (VOL)** Don't know..... 7
- (VOL)** Refused..... 8

D4. Did you ever serve on active duty in the US Armed Forces? **[PROBE: Army, Navy, Air Force, Marines, Coast Guard or Women's Armed Forces]**

- Yes 1
- No..... 2
- (VOL)** Don't know..... 3
- (VOL)** Refused..... 4

D5. **[IF ADULT RECIPIENT (C1=1), ASK]:** Did your **[Q7 CODE]** serve in the US Armed Forces?

- Yes 1
- No..... 2
- (VOL)** Don't know..... 3
- (VOL)** Refused..... 4

[IF CHILD RECIPIENT (C1=2), CURRENT (Q1=1), AND LIVES IN HH (Q11=1), AUTOCODE D6=1 AND SKIP TO D7].

D6. Are there any children or grandchildren currently living in your household under 18 years of age?

- Yes 1
- No..... 2
- (VOL)** Don't know..... 3
- (VOL)** Refused..... 4

D7. What is the last grade of school you completed? **[IF NEEDED, READ LIST]**

- Less than high school 1
- High school grad/GED 2
- Some college 3
- Technical school 4
- College grad 5
- Graduate school/Grad work 6
- (VOL)** Don't know..... 7
- (VOL)** Refused..... 8

D8a. Last year, was your total annual household income from all sources, before taxes over or under \$50,000?

- Over 1 [GO TO d]
- Under 2 [GO TO b]
- (VOL) Don't know 3 [SKIP TO D10]
- (VOL) Refused 4 [SKIP TO D10]

b. [IF UNDER \$50,000:] Over or under \$30,000?

- Over 1 [SKIP TO D10]
- Under 2 [GO TO c]
- (VOL) Don't know 3 [SKIP TO D10]
- (VOL) Refused 4 [SKIP TO D10]

c. [IF UNDER \$30,000:] Over or under \$15,000?

- Over 1 [SKIP TO D10]
- Under 2 [SKIP TO D10]
- (VOL) Don't know 3 [SKIP TO D10]
- (VOL) Refused 4 [SKIP TO D10]

d. [IF OVER 50,000:] Over or under \$100,000?

- Over 1 [SKIP TO D10]
- Under 2 [GO TO e]
- (VOL) Don't know 3 [SKIP TO D10]
- (VOL) Refused 4 [SKIP TO D10]

e. [IF UNDER 100,000:] Over or under \$75,000?

- Over 1 [SKIP TO D10]
- Under 2 [SKIP TO D10]
- (VOL) Don't know 3 [SKIP TO D10]
- (VOL) Refused 4 [SKIP TO D10]

D10. If the situation arose, would you be interested in participating in future research on caregivers?

- Yes 1
- No 2

D11. Also, the results of this survey are totally confidential. However if a reporter writing a story about the results of the overall survey wanted to ask you more questions or get a quote from you for a news story, would you like to get a call back or not? It is completely optional.

- Yes 1
- No [SKIP TO THANK YOU] 2
- (VOL) Don't know [SKIP TO THANK YOU] 3
- (VOL) Refused [SKIP TO THANK YOU] 4

[IF D10=1 OR D11=1, ASK:] What is the best number call you on [IF D10=1: for future research]?

- [] 98
- The number we called 98
- (VOL) Refused 99

[ALL]: Finally, for verification purposes only, what is your name?

(VOL) Refused.....99

D12. LANGUAGE OF THE INTERVIEW

ENTIRELY SPANISH.....	1
Mainly Spanish.....	2
HALF AND HALF.....	3
Mainly English.....	4
ENTIRELY ENGLISH.....	5

[THANK YOU]: Thank you very much for your time. Your responses have been very helpful to this research.