

Contract No.: Q146901
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**EVALUATION OF THE CASH AND
COUNSELING DEMONSTRATION**

**9 MONTH
INSTRUMENT**

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Submitted to:

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**Evaluation of the Cash and Counseling Demonstration (Project 8349)
Nine-Month Follow-Up Instrument (Task 250)
Revised 3/06/02**

FOR FRONT END, SET UP 35 SPIGOTS.

- 1=PAID WORKER--CONTROL--NJ
- 2=INFORMAL CAREGIVER-TREATMENT-AR--STRATUM 1
- 3=INFORMAL CAREGIVER-TREATMENT-AR--STRATUM 2
- 4=INFORMAL CAREGIVER-TREATMENT-AR--STRATUM 3
- 5=INFORMAL CAREGIVER-TREATMENT-AR--STRATUM 4
- 6=INFORMAL CAREGIVER--CONTROL--AR--STRATUM 1
- 7=INFORMAL CAREGIVER--CONTROL--AR--STRATUM 2
- 8=INFORMAL CAREGIVER--CONTROL--AR--STRATUM 3
- 9=INFORMAL CAREGIVER--CONTROL--AR--STRATUM 4
- 10=INFORMAL CAREGIVER--TREATMENT--NJ--STRATUM 1
- 11=INFORMAL CAREGIVER--TREATMENT--NJ--STRATUM 2
- 12=INFORMAL CAREGIVER--TREATMENT--NJ--STRATUM 3
- 13=INFORMAL CAREGIVER--TREATMENT--NJ--STRATUM 4
- 14=INFORMAL CAREGIVER--CONTROL--NJ--STRATUM 1
- 15=INFORMAL CAREGIVER--CONTROL--NJ--STRATUM 2
- 16=INFORMAL CAREGIVER--CONTROL--NJ--STRATUM 3
- 17=INFORMAL CAREGIVER--CONTROL--NJ--STRATUM 4
- 18=INFORMAL CAREGIVER--TREATMENT--FL--STRATUM 1
- 19=INFORMAL CAREGIVER--TREATMENT--FL--STRATUM 2
- 20=INFORMAL CAREGIVER--TREATMENT--FL--STRATUM 3
- 21=INFORMAL CAREGIVER--TREATMENT--FL--STRATUM 4
- 22=INFORMAL CAREGIVER--TREATMENT--FL--STRATUM 5
- 23=INFORMAL CAREGIVER--TREATMENT--FL--STRATUM 6
- 24=INFORMAL CAREGIVER--CONTROL--FL--STRATUM 1
- 25=INFORMAL CAREGIVER--CONTROL--FL--STRATUM 2
- 26=INFORMAL CAREGIVER--CONTROL--FL--STRATUM 3
- 27=INFORMAL CAREGIVER--CONTROL--FL--STRATUM 4
- 28=INFORMAL CAREGIVER--CONTROL--FL--STRATUM 5
- 29=INFORMAL CAREGIVER--CONTROL--FL--STRATUM 6
- 30=FNS TREATMENT--AR
- 31=FNS TREATMENT--NJ
- 32=FNS TREATMENT--FL
- 33=SSI--TREATMENT--AR
- 34=SSI--TREATMENT--NJ
- 35=SSI==TREATMENT--FL

I. INTRODUCTION

IF CLIENT<18 THEN SET PROXY=P (MAY CHANGE LATER)

>ti1a< CATI CHECK: WAS CLIENT DECEASED AT 4 MONTH?

<1> YES [goto i1b]

<0> NO

>i1< Hello, my name is INTERVIEWER'S FULL NAME from Mathematica Policy Research in Princeton, New Jersey. May I please speak to [AGE<18:a parent or guardian of][CLIENT]?

[IF AGE<18:]

(INTERVIEWER: ATTEMPT TO SPEAK TO SAME PARENT/GUARDIAN WHO COMPLETED THE BASELINE OR 4 MONTH INTERVIEW. REFER TO CONTACT SHEETS FOR NAME.)

<1> SPEAKING TO [AGE<18: PARENT] [OW:CLIENT] [goto i4]

<2> WANTS MORE INFORMATION [goto i2]

<3> [AGE<18: PARENT] [OW:CLIENT] UNAVAILABLE (UNDER 7 DAYS) [goto

cb]

<14>[AGE<18: PARENT][OW:CLIENT] UNAVAILABLE (7 DAYS OR MORE)
[goto ti14b]

<4> [AGE<18: PARENT] [OW:CLIENT] COMES TO THE PHONE [goto i3]

<5> [AGE<18: PARENT][OW:CLIENT] PHYSICALLY OR MENTALLY
UNABLE TO RESPOND ON THE TELEPHONE [goto i7]

<6> CLIENT AT HOME IN A COMA (VOLUNTEERED)[goto i10]

<7> CLIENT DECEASED [goto i11]

<8> [AGE<18: PARENT] [OW: CLIENT] IN HOSPITAL [goto i12]

<9> [AGE<18: PARENT] [OW:CLIENT] IN NURSING HOME OR ICF/MR [goto

i14]

<10> [AGE<18: PARENT] [OW:CLIENT] MOVED (NOT IN NURSING
HOME)[goto i20]

<11> WRONG NUMBER [goto bdph]

<12> PROBLEMS [goto prob]

<r> REFUSAL [goto ref]

INTERVIEWER: ICF/MR IS AN INTERMEDIATE CARE FACILITY FOR THE
MENTALLY RETARDED OR DEVELOPMENTALLY DISABLED.

==>

>i1b< [AGE \geq 18:]
Hello, my name is INTERVIEWER'S FULL NAME from Mathematica Policy Research in Princeton, New Jersey. A family member of [CLIENT] should have received a letter about a study in which [CLIENT] was participating before [YOU] passed away.

PRESS ENTER TO CONTINUE [goto i14e]

[AGE<18:]
Hello, my name is INTERVIEWER'S FULL NAME from Mathematica Policy Research in Princeton, New Jersey. A parent or guardian of [CLIENT] should have received a letter about a study in which [CLIENT] was participating before [YOU] passed away. May I please speak to a parent or guardian of [CLIENT]?

[AGE<18:](INTERVIEWER: ATTEMPT TO SPEAK TO SAME PARENT/GUARDIAN WHO COMPLETED THE BASELINE OR 4 MONTH INTERVIEW. REFER TO CONTACT SHEETS FOR NAME.)

PRESS ENTER TO CONTINUE

PROGRAMMER: NOTE THAT RESPONSE CHOICES <6> AND <7> HAVE BEEN REMOVED.

>i1c< <1> SPEAKING TO PARENT [goto i4b]
<2> WANTS MORE INFORMATION [goto i2]
<3> PARENT UNAVAILABLE (UNDER 7 DAYS) [goto cb]
<14> PARENT UNAVAILABLE (7 DAYS OR MORE) [goto ti14b]
<4> PARENT COMES TO THE PHONE [goto i3]
<5> PARENT PHYSICALLY OR MENTALLY
UNABLE TO RESPOND ON THE TELEPHONE [goto i7]
<8> PARENT IN HOSPITAL [goto i12]
<9> PARENT IN NURSING HOME OR ICF/MR [goto i14]
<10> PARENT MOVED (NOT IN NURSING HOME)[goto i20]
<11> WRONG NUMBER [goto bdph]
<12> PROBLEMS [goto prob]

<r> REFUSAL [goto ref]

INTERVIEWER: ICF/MR IS AN INTERMEDIATE CARE FACILITY FOR THE MENTALLY RETARDED OR DEVELOPMENTALLY DISABLED.

==>

>i2<

[AGE<18:]

A parent or guardian of [YOUc] should have received a letter about a study in which [YOU] [AREd] participating, on help for people of all ages with disabilities. We are calling to interview people over the telephone. I'd like to begin the interview at this time.

INTERVIEWER: ATTEMPT TO SPEAK TO SAME PARENT/GUARDIAN WHO COMPLETED THE BASELINE OR FOUR-MONTH INTERVIEW. REFER TO CONTACT SHEET(S) FOR NAME.

AGE ≥ 18:

[YOUc] should have received a letter about a study in which [YOU] [ARE] participating, on[AGE>64: the care of older people] [AGE18-64:help for people with disabilities] We are calling to interview people over the telephone. I'd like to begin the interview at this time.

PROBE IF RESPONDENT IS RELUCTANT:

[AGE<18: A parent or guardian of] [YOUc] [PROXY=R,X in baseline: or a relative or friend knowledgeable about his/her services] already completed the first telephone interview about nine months ago.

PROBE: The study is for the state of [STAT] and the United States Department of Health and Human Services and the Robert Wood Johnson Foundation.

>i2a<

<1> SPEAKING TO [AGE<18: PARENT] [OW:CLIENT] [goto i4b]

<2> WANTS MORE INFORMATION [goto i2]

<3> [AGE<18: PARENT] [OW:CLIENT] UNAVAILABLE (UNDER 7 DAYS) [goto cb]

<14>[AGE<18: PARENT][OW:CLIENT] UNAVAILABLE (7 DAYS OR MORE) [goto ti14b]

<4> [AGE<18: PARENT] [OW:CLIENT] COMES TO THE PHONE [goto i3]

<5> [AGE<18: PARENT][OW:CLIENT] PHYSICALLY OR MENTALLY UNABLE TO RESPOND ON THE TELEPHONE [goto i8]

<6> CLIENT AT HOME IN A COMA (VOLUNTEERED)[goto ti14b]

<7> CLIENT DECEASED [goto i11a]

<8> [AGE<18: PARENT] [OW: CLIENT] IN HOSPITAL [goto i12a]

<9> [AGE<18: PARENT] [OW:CLIENT] IN NURSING HOME OR ICF/MR [goto

i14a]

<10> [AGE<18: PARENT] [OW:CLIENT] MOVED (NOT IN NURSING HOME)[goto i20a]

<11> WRONG NUMBER [goto bdph]

<12> PROBLEMS [goto prob]

<13> CODE FINAL STATUS (SPVSR ONLY) [goto fds]

<r> REFUSAL [goto ref]

INTERVIEWER: ICF/MR IS AN INTERMEDIATE CARE FACILITY FOR THE MENTALLY RETARDED OR DEVELOPMENTALLY DISABLED.

==>

>i3< Hello, my name is INTERVIEWER'S FULL NAME from Mathematica Policy Research in Princeton, New Jersey.

PRESS ENTER TO CONTINUE

==>

>i4< You should have received a letter about a study in which [YOUc] [AREd] participating on [AGE>65: the care of older people] [AGE<18: help for people of all ages with disabilities] [AGE 18-64: help for people with disabilities]. We are calling people to interview them over the telephone. The questions we are asking are about the services [YOUc] [RECEIVED], satisfaction with those services, and [YOURc] health.

PROBE IF CLIENT IS RELUCTANT:

As you may remember, you (or a relative or friend knowledgeable about your services: {PROXY=R,X in baseline}) already completed the first telephone interview about nine months ago. However, your participation is voluntary.

IF NECESSARY: All of the answers will be held in strict confidence, and reported only as averages for groups of people.

PROBE: The study is for the state of [fill STAT] and the United States Department of Health and Human Services and the Robert Wood Johnson Foundation.

PRESS ENTER TO CONTINUE

==>

>i4b< I would like to begin the interview now.

<1> BEGIN INTERVIEW [goto ti14b] ***If age ge 18 store C in PROXY***

<2> NOT A GOOD TIME--SKIP TO CALLBACK [goto cb]

<3> DID NOT RECEIVE OR DOES NOT RECALL THE LETTER [goto i5]

<12> PROBLEMS--LANGUAGE, SUPERVISOR REVIEW [goto ti60]

<f> [AGE<18: PARENT] [OW:CLIENT] REFUSAL [goto ref]

==>

>i5< The letter explained that we would be calling to interview you because [YOUc] agreed about nine months ago to participate in the [fill STAT] [fill PROG] evaluation

I would like to begin the interview now.

INTERVIEWER: OFFER TO READ LETTER, IF NECESSARY.

<1> BEGIN INTERVIEW [goto ti14b] ***If age ge 18 store C in PROXY***

<2> NOT A GOOD TIME--SKIP TO CALLBACK [goto cb]

<3> WANTS ANOTHER LETTER [goto i6a]

<t> [AGE<18: PARENT] [OW:CLIENT] REFUSAL [goto ref]

==>

>i6a< (I would like to verify that the address information I have is correct.)

CURRENT ADDRESS IS:

[AGE<18: Parent or Guardian of] [CLIENT]

[fill ADDR]

[fill CITY] [fill ST] [fill ZIP:0]

INTERVIEWER: IF DIFFERENT, RECORD [AGE<18: PARENT] [OW:CLIENT]
ADDRESS ON CONTACT SHEET. FILE CONTACT SHEET IN
THE SLOT LABELED "NEEDS LETTER."

==> [goto cb]

>i7< [AGE<18:A parent or guardian of] [YOUc] should have received a letter about a study in which [YOU] [AREd] participating, on [AGE≥ 65: the care of older people][AGE<18: help for people of all ages with disabilities] [AGE 18-64: help for people with disabilities]. We are calling to interview people over the telephone. The questions we are asking are about the services [YOUc] [RECEIVED], satisfaction with those services, and [YOURc] health.

PROBE IF RESPONDENT IS RELUCTANT:

[AGE<18:A parent or guardian of] [YOUc] [PROXY=R,X in baseline: or a relative or friend knowledgeable about [YOUR] services] already completed the first telephone interview about nine months ago.

PROBE: The study is for the state of [fill STAT] and the United States Department of Health and Human Services and the Robert Wood Johnson Foundation.

PRESS ENTER TO CONTINUE

==>

>i8< Do you think [AGE<18:A parent or guardian of] [YOUc] will be able to talk on the telephone if I call back next week?

<1> YES/ MAYBE

<0> NO [goto ti14b]

<d> DON'T KNOW [goto ti14b]

==>

>i9< When would be a good time to call to see if he/she [<=if client<18, do not fill] is up to it?

INTERVIEWER: RECORD DAY AND TIME ON CONTACT SHEET.

PRESS ENTER TO CONTINUE

==> [goto cb]

>i10< I am very sorry to hear that [YOU] [ARE] so ill. [AGE<18:A parent or guardian of] [YOUc] should have received a letter about a study in which [YOU] [ARE] participating on [AGE≥ 65: the care of older people][AGE<18: help for people of all ages with disabilities] [AGE 18-64: help for people with disabilities]. We are calling to interview people over the telephone. The questions we are asking are about the services [YOUc] [RECEIVED], satisfaction with those services, and [YOURc] health.

PROBE IF RESPONDENT IS RELUCTANT:

[AGE<18:A parent or guardian of] [YOUc] [PROXY=R,X in baseline: or a relative or friend knowledgeable about [YOUR] services] already completed the first telephone interview about nine months ago.

PROBE: The study is for the state of [fill STAT] and the United States Department of Health and Human Services and the Robert Wood Johnson Foundation.

==> [goto ti14b]

>i11< I am very sorry to hear that [YOU] passed away. I am calling about a study we are conducting in which [YOU] [WERE] participating, on [AGE≥ 65: the care of older people][AGE<18: help for people of all ages with disabilities] [AGE 18-64: help for people with disabilities]. We sent a letter to [AGE<18:A parent or guardian of] [YOUc] saying that we would be calling.

Could you tell me when [YOU] passed away?

INTERVIEWER: IF RECENT DEATH, YOU CAN SKIP TO CALLBACK AND RESCHEDULE INTERVIEW.

Month: <1-12> <d> DON'T KNOW OR REFUSED
Day: <1-31> <d> DON'T KNOW OR REFUSED
Year: <1998-2001> <d> DON'T KNOW OR REFUSED

==>[goto ti11a]

>i11a< I am very sorry to hear that. Could you tell me when [YOU] passed away?

INTERVIEWER: IF RECENT DEATH, YOU CAN SKIP TO CALLBACK AND RESCHEDULE INTERVIEW.

Month: <1-12> <d> DON'T KNOW OR REFUSED
Day: <1-31> <d> DON'T KNOW OR REFUSED (dk insert 15th)
Year: <1998-2001> <d> DON'T KNOW OR REFUSED

>ti11a< CATI CHECK: DID CLIENT DIE ONE MONTH OR LESS AFTER DATE OF ENROLLMENT?

<1> YES [goto thnx]

<0> NO [goto ti14b]

====>

>i12< [AGE<18:A parent or guardian of] [YOUc] should have received a letter about a study in which [YOU] [ARE] participating, on [AGE≥ 65: the care of older people][AGE<18: help for people of all ages with disabilities] [AGE 18-64: help for people with disabilities]. Do you expect [AGE<18:A parent or guardian of] [YOUc] to come home from the hospital within the next week?

PROBE: The study is for the state of [fill STAT] and the United States Department of Health and Human Services and the Robert Wood Johnson Foundation.

<1> YES [goto i13]

<0> NO

<d> DON'T KNOW

====> [goto ti14b]

>i12a< Do you expect [AGE<18:A parent or guardian of] [YOUc] to come home from the hospital within the next week?

<1> YES

<0> NO [goto ti14b]

<d> DON'T KNOW [goto ti14b]

====>

>i13< Would [AGE<18:A parent or guardian of] [YOUc] be able to talk on the telephone about the services [YOU] [RECEIVED], satisfaction with those services, and [YOUR] health if I called back next week?

<1> YES [goto cb]

<0> NO

<d> DON'T KNOW

====> [goto ti14b]

>i14< I am calling about a study we are conducting in which [YOUc] [ARE] participating, on [AGE≥ 65: the care of older people][AGE<18: help for people of all ages with disabilities] [AGE 18-64: help for people with disabilities]. [AGE<18:A parent or guardian of] [YOUc] should have received a letter letting [YOUm] [<= if client<18, fill him/her] know to expect our call.

Would [AGE<18:A parent or guardian of] [YOUc] be able to talk on the telephone about the services [YOU] [RECEIVED], satisfaction with those services, and [YOUR] health, if I called [YOUm] at the nursing home?

PROBE: The study is for the state of [fill STAT] and the United States Department of Health and Human Services and the Robert Wood Johnson Foundation.

<1> YES [goto i23a]

<0> NO

<d> DON'T KNOW

==> [goto ti14b]

>i14a< Would [AGE<18:A parent or guardian of] [YOUc] be able to talk on the telephone about the services [YOU] [RECEIVED], satisfaction with those services, and [YOUR] health, if I called [YOUm] [<= if client<18, fill him/her] at the nursing home?

<1> YES [goto i23a]

<0> NO

<d> DON'T KNOW

==>

>ti14b< CATI CHECK: IS CLIENT LESS THAN 18 YEARS OF AGE?

<1> YES

<0> NO [goto ti14d]

==>

>ti14x< CATI CHECK: ARE WE SPEAKING TO A PARENT WHO AGREED TO BEGIN THE INTERVIEW (i4b=1 or i5=1)?

<1> YES [goto ti27]

<0> NO

==>

>ti14c< CATI CHECK: IS CLIENT IN A COMA OR DID CLIENT DIE (i1= [6 or 7] or i2a=[6 or 7])?

<1> YES [goto i14e]

<0> NO [goto i15]

==>

>ti14d< CATI CHECK: IS CLIENT DECEASED (i1=7 or i2a=7)?

<1> YES [goto i14e]

<0> NO

==>

>ti14j< CATI CHECK: ARE WE SPEAKING WITH CLIENT?

<1> SPEAKING TO CLIENT [goto ti27]

<2> NOT CLIENT [goto i14e]

==>

>i14e< (I am very sorry to hear that [YOU] [ARE] so ill.: {i1 or i2a=6} [i1 or i2a=14,5,6,8,9: Because [YOUc] [ARE] unable to respond for [YOURSELF],) I would like to speak to[AGE<18:a parent or guardian of] [someone who is knowledgeable about the services [YOUc] [RECEIVED] (before [YOU] passed away: {i1=7 or i2a=7 or ti1a=1}). We have questions about things like satisfaction with those services, and [YOURc] health. Is he/she [<= do not fill]/that person) available at this time?

[AGE<18: INTERVIEWER: ATTEMPT TO SPEAK TO SAME PARENT/GUARDIAN WHO COMPLETED THE BASELINE OR FOUR-MONTH INTERVIEWS. REFER TO CONTACT SHEETS FOR NAME.]

IF NECESSARY: We sent a letter to [AGE<18:A parent or guardian of] [YOUc] about a study in which [YOU] [AREd] participating, on [AGE≥ 65: the care of older people][AGE<18: help for people of all ages with disabilities] [AGE 18-64: help for people with disabilities]. We are calling to interview people over the telephone. I would like to begin the interview now.

PROBE IF RESPONDENT IS RELUCTANT:

[AGE<18:A parent or guardian of] [YOUc] [PROXY=R,X in baseline: or a relative or friend knowledgeable about [YOUR] services] already completed the first telephone interview about nine months ago.

- <1> SPEAKING TO [AGE<18: PARENT] [OW:MOST KNOWLEDGEABLE PERSON] [goto ti14f]
- <2> [AGE<18: PARENT] [OW:MOST KNOWLEDGEABLE PERSON] UNAVAILABLE AT THIS TIME (BUT UNDER 7 DAYS) [goto ti14f]
- <3> [AGE<18: PARENT] [OW:MOST KNOWLEDGEABLE PERSON] UNAVAILABLE FOR 7 DAYS OR MORE [goto i15]
- <4> [AGE<18: PARENT] [OW:MOST KNOWLEDGEABLE PERSON] COMES TO THE PHONE [goto ti14f]

<r> REFUSED [goto ref]

==>

>ti14f< CATI CHECK: IS CLIENT LESS THAN 18 YEARS OF AGE?

<1> CLIENT < 18 [goto ti14ff]

<2> CLIENT ≥ 18 [goto i16aa]

==>

>ti14ff<: CATI CHECK:
IF i14e=1 AND ti14f=1, GOTO ti27
ELSE IF i14e=2 AND ti14f=1, GOTO CB

>i15< Perhaps you could answer the questions on behalf of [CLIENT]. Are you knowledgeable about the services [YOU] [RECEIVED] [before [YOU] passed away]?

PROBE: Things like satisfaction with services and [YOUR] health.

<1> YES [goto i16a]

<0> NO

<d> DON'T KNOW

<r> REFUSED

==>

>i15a< Is there another family member for friend who could answer questions on behalf of [CLIENT]?

PROBE: Is there a family member or friend who is knowledgeable about the services [YOUc] [RECEIVED], satisfaction with those services, and [YOUR] health?

<1> YES

<0> NO [goto i26]

<d> DON'T KNOW [goto i26]

<r> REFUSED [goto ref]

==>

>i15b< Is he/she [=< do not fill] available now?

<1> YES, PROXY COMES TO PHONE

<2> NO, PROXY IS UNAVAILABLE [goto i16aa]

<3> NO, PROXY DOES NOT LIVE HERE [goto i16aa]

<d> DON'T KNOW [goto cb]

<r> REFUSED [goto ref]

==>

>i16< Hello, my name is INTERVIEWER'S FULL NAME from Mathematica Policy Research in Princeton, New Jersey.

[AGE<18:A parent or guardian of][DECEASED: A family member of] [YOUc] should have received a letter about a study in which [YOU] [AREd] participating, on [AGE≥ 65: the care of older people][AGE<18: help for people of all ages with disabilities] [AGE 18-64: help for people with disabilities]. We are calling to interview people over the telephone.

(I am sorry to hear that [YOU] [DECEASED: passed away][COMA:[ARE] ill].) You were suggested as the person most knowledgeable about the services [YOUc] [RECEIVED]. Would you mind doing the interview?

PROBE IF RESPONDENT IS RELUCTANT:

[AGE<18:A parent or guardian of] [YOUc] [PROXY=R,X in baseline: or a relative or friend knowledgeable about [YOUR] services] already completed the first telephone interview about nine months ago.

<1> BEGIN INTERVIEW [goto i16aa]

<2> NOT A GOOD TIME [goto i16aa]

<r> REFUSED [goto ref]

==>

>i16a< I'd like to begin the interview now.

<1> BEGIN INTERVIEW

<2> NOT A GOOD TIME

<r> CLIENT/PARENT REFUSAL [goto REF]

==>

>i16aa< [i14e=2 or i15b=2 or i16=2 or i16a=2:In that case, I would like to record [i14e=1,4 or i15=1 or i15b=1:your] [i14e=2 or i15b=2,3:his/her [<= do not fill]] name and address so I know who to ask for when I call back.] [i14e=1,4 or i15b=3 or i16=1 or i16a=1:May I please have [your name] [the name of this person]?

INTERVIEWER: RECORD FIRST AND LAST NAME

<y> ENTER NAME < >

<d> DON'T KNOW

<r> REFUSED [goto ref]

==>

>i16ab< May I please have [i14e=1,4 or i15=1 or i15b=1:your] [i14e=2 or i15b=2,3:his/her [<= do not fill]] telephone number?

<0> SAME AS CLIENT'S [goto i16d]

<y> ENTER TELEPHONE NUMBER < >-< >

<d> DON'T KNOW [goto LOC]

<r> REFUSED [goto ref]

==>

>i16ac< And what is (your:{i14e=1,4 or i15=1 or i15b=1} / his/her [<= do not fill]:{i14e =2 or i15b=2,3} address?

INTERVIEWER: RECORD PROXY'S ADDRESS BELOW.

<y>ENTER ADDRESS < >
ENTER CITY, STATE < >
ENTER ZIP < >

<d> DON'T KNOW

<r> REFUSED [goto cb]

==>

>i16d< How (are you: {i14e=1,4 or i15=1 or i15b=1} / is [fill i16aa]: {i14e=2 or i15b=2,3 & i16aa=<y>} / is this person: {i14e=2 or i15b=2,3 & i16aa=<d,r>}) related to [CLIENT]?

- <1> SPOUSE
- <2> MOTHER
- <3> FATHER
- <4> DAUGHTER
- <5> DAUGHTER-IN-LAW
- <6> SON
- <7> SON-IN-LAW
- <8> SISTER/SISTER-IN-LAW
- <9> BROTHER/BROTHER-IN-LAW
- <10> GRANDPARENT
- <11> GRANDCHILD
- <12> OTHER RELATIVE
- <13> NON RELATIVE

- <d> DON'T KNOW
- <r> REFUSED

==>

>vi16d< So (you are: {i14e=1,4 or i15=1 or i15b=1} / he/she [<= do not fill] is: {i14e=2 or i15b=2,3}) [YOURc] [fill i16d]?

- <1> YES
- <0> NO [goto i16d]

==>

>ti17< CATI CHECK: WHO ARE WE (WILL WE BE) CONDUCTING THE INTERVIEW WITH, AND ARE WE CONTINUING WITH THE INTERVIEW NOW?

- <2> CONTINUING INTERVIEW WITH PROXY OF: a) ADULT OR b) CHILD WITHOUT PARENT AVAILABLE [goto ti27]
[i14e = 1 or 4] or [(i16a = 1 or i16 = 1)
- <3> CALLING BACK FOR PROXY [goto cb]
[i14e =2] or [i16 = 2 or i16a =2 or i15b =2,3]

==>

>i20< We sent a letter to [AGE<18:A parent or guardian of] [YOUc] about a study in which [YOU] [ARE] participating, on [AGE≥ 65: the care of older people][AGE<18: help for people of all ages with disabilities] [AGE 18-64: help for people with disabilities].

Do you know how we can reach [AGE<18:A parent or guardian of] [YOUm]?

PROBE: The study is for the state of [fill STAT] and the United States Department of Health and Human Services and the Robert Wood Johnson Foundation.

<1> YES [goto i21a]

<0> NO, SPECIAL SEARCH NEEDED

<d> DON'T KNOW

<r> REFUSED [goto ref]

==> [goto LOC]

>i20a< Do you know how we can reach [AGE<18:A parent or guardian of] [CLIENT]?

<1> YES [goto i21a]

<0> NO, SPECIAL SEARCH NEEDED

<d> DON'T KNOW

<r> REFUSED [goto ref]

==> [goto LOC]

>i21a< May I please have [YOUR] [<= if client<18, do not fill] telephone number and address?

PROBE: For [AGE<18:A parent or guardian of] [CLIENT].

<y> RECORD PHONE NUMBER < >

<d> DON'T KNOW

<r> REFUSED

==>

>i21b< <y> RECORD ADDRESS < >

<d> DON'T KNOW

<r> REFUSED

==>

>i21c< INTERVIEWER: DID THE CLIENT MOVE OUT OF STATE?

STATE YOU JUST ENTERED ON MOVE SCREEN IS: _____
STATE IN SAMPLE WAS: _____

<1> YES, MOVED OUT OF STATE [need this info later for cb interview]
<0> NO, STILL IN SAME STATE

==>

>i22< CATI CHECK: WAS PHONE NUMBER RECORDED IN i21a?

<1> YES [goto i26]
<0> NO

==> [goto LOC]

>i23a< What is the name of the nursing home?

<y> RECORD NURSING HOME < >

<d> DON'T KNOW

<r> REFUSED [goto ref]

==>

>i23b< At what telephone number and address can [AGE<18:A parent or guardian of] [YOUc] be reached?

<y> RECORD PHONE NUMBER < >

<d> DON'T KNOW

<r> REFUSED [goto ref]

==>

>i23c< <y> RECORD ADDRESS < >

<d> DON'T KNOW

<r> REFUSED

==>

>i25< CATI CHECK: WAS PHONE NUMBER OF NURSING HOME RECORDED IN
i23b?

<1> YES

<0> NO [goto LOC]

==>

>i26< Thank you very much for your time.

TYPE <g> TO CONTINUE

==> [goto cb]

>ti27< CATI CHECK: IS CLIENT IN TREATMENT GROUP AND WHAT IS REPRESENTATIVE STATUS?

- <1> TREATMENT GROUP AND SAME REP AT 4 MO. {i14g=1 or check baseline if no 4 mo.}[goto i28a]
- <2> TREATMENT GROUP AND NEW REP AT 4 MO {i14h=1} [goto i28b]
- <3> ALL OTHERS [goto i30]

==>

>i28a< Is [RNAME] still managing the [MONTHLY] from [PROG] as a representative for [CLIENT]?

PROBE: A representative is a family member or friend of [YOURc]'s who helps decide how the [MONTHLY] will be spent, and may help with the hiring and supervision of workers.

- <1> YES [goto ti29]
- <0> NO
- <2> NOT IN PROGRAM NOW
- <d> DON'T KNOW/REFUSED

==>[goto i30]

>i28b< When we last spoke, we were told that [YOUc] had changed representatives, the family member or friend who agreed to manage the [MONTHLY] from PROG for [YOUm]. Is this person still doing this for [YOUm]?

PROBE: A representative is a family member or friend of [YOURc]'s who helps decide how the [MONTHLY] will be spent, and may help with the hiring and supervision of workers.

PROBE: Do not include a [COUNS] or [FISCAL] from [PROG].

PROBE: When we last spoke to you on [4-MONTH INTERVIEW DATE].

- <1> YES [goto ti29]
- <0> NO
- <2> NOT IN PROGRAM NOW
- <d> DON'T KNOW/REFUSED

==> [goto i30]

>ti29< CATI CHECK: IS THIS A PROXY RESPONDENT (IS PROXY=X)?

<1> YES [goto i29a]

<0> NO [goto i30]

==>

>i29a< Are you that person?

PROBE: The person who manages the [MONTHLY] from PROG for [CLIENT].

INTERVIEWER: CODE IF KNOWN.

<1> YES

<0> NO

<d> DON'T KNOW/REFUSED

==>

>i30< I want to assure you that all of your answers will be held in confidence to the full extent provided by federal law. The study reports will only include averages for groups of people. (If, at any time during the interview, you become tired or uncomfortable, please let me know and we'll stop and call back to finish when you're more rested.)

PRESS ENTER TO CONTINUE

==> [goto A1]

>cb< (We'll call back in a few days to make sure you've received the letter.:{i5=3})

When would be the best time to reach [AGE<18:A parent or guardian of] [YOUc] [fill PROXY NAME]:X / [fill RNAME]:R)?

INTERVIEWER: RECORD DAY AND TIME ON CONTACT SHEET. IF INFORMATION REQUESTED, PLACE IN "NEEDS MATERIALS" FOLDER.

TYPE <g> TO CONTINUE

==>

>thnx< (There is no need for us to disturb you further.:{ti11a=1}) Thank you very much for your time.

==>[goto end]

>ref< INTERVIEWER: PLEASE SEND REFUSAL LETTER TO CLIENT ADDRESS BELOW (IF CLIENT REFUSED OR IF UNIDENTIFIED INFORMANT REFUSED). IF PROXY REFUSAL, SEND LETTER TO PROXY ADDRESS BELOW.
CLIENT'S ADDRESS:

PROXY'S ADDRESS:

>proxy< INTERVIEWER: IS THE RESPONDENT THE CLIENT, PARENT, OR PROXY?

- <1> CLIENT
- <2> PARENT/GUARDIAN
- <4> PROXY

A. HEALTH AND FUNCTIONAL IMPAIRMENT

>tA1< CATI CHECK: RANDOM/VITAL STATUS

- <1> CONTROL GROUP [goto tA2]
- <2> TREATMENT GROUP, DIED BEFORE 4 MO. INTERVIEW [goto tB1]
- <3> TREATMENT GROUP, DIED SINCE 4 MO. INTERVIEW [goto tA1b]
- <4> TREATMENT GROUP, ALIVE

>A1a< [ARE] [YOUc] currently participating in the [PROG] program?

PROBE IF NO: Did someone tell the [PROG] program that [YOU] did not want to participate in the program (any longer)? (IF YES, CODE <0>.)

PROBE: [PROG] is a special program that lets you decide who will provide personal assistance services and how the [[MONTHLY]] will be spent.

PROBE: Or other services and equipment to help [YOUm] be more independent.

IF DISENROLLED AT 4-MONTH INTERVIEW: [HAVE] [YOUc] re-enrolled in [PROG] since we last spoke to you?

- <1> YES, PARTICIPATING
- <0> NO, DROPPED OUT OF PROGRAM

- <r> DON'T KNOW/REFUSED

>tA1b< CATI CHECK: DID CLIENT REPORT RECEIPT OF CASH AT 4 MONTH?

- <1> YES [goto A1c]
- <0> NO

>A1b< [IF A1a=0 OR DECEASED: Had][OTHERWISE: Has] the [MONTHLY] started going into [YOUR] [PROG] account?

PROBE: For example, [had/has] anyone been paid to help [YOU] or [had/has] anything been bought using the [PROG] [MONTHLY]?

PROBE: Either [YOURc] own account or one being handled by a [FISCAL].

PROBE: [YOUc] [WERE] first enrolled in the [PROG] program on [EDATE]. Most people start getting the [MONTHLY] within three or four months of that date.

PROBE: The [MONTHLY] or allotment from [PROG].

<1> YES

<0> NO [goto tA2]

<d> DON'T KNOW [goto tA2]

<r> REFUSED [goto tA2]

==>

>A1c< What was the most recent month in which the [MONTHLY] was received or deposited?

PROBE: For example, [had/has] anyone been paid to help [YOU] or [had/has] anything been bought using the [PROG] [MONTHLY]?

PROBE: Did [YOUc] receive the [MONTHLY] this month?

PROBE: [DO] [YOU] have any reason to believe the [MONTHLY] has stopped going into [YOUR] account? IF NO, CODE CURRENT MONTH.

PROBE: The [MONTHLY] or allotment from [PROG]

<1> JANUARY

<2> FEBRUARY

<3> MARCH

<4> APRIL

<5> MAY

<6> JUNE

<7> JULY

<8> AUGUST

<9> SEPTEMBER

<10> OCTOBER

<11> NOVEMBER

<12> DECEMBER

<r> DON'T KNOW/REFUSED [goto A1d]

==>[goto tA2]

>A1d< Did [YOUc] receive the [MONTHLY] since we last spoke to you on [4-MONTH INTERVIEW DATE, OR BASELINE INTERVIEW DATE IF DID NOT COMPLETE 4-MONTH]?

PROBE: Was the [MONTHLY] received or deposited into [YOUR] [PROG] account since then?

<1> YES

<2> NO [goto tA2]

<d> DON'T KNOW

<r> REFUSED [goto tA2]

>A1e< Did [YOUc] receive the [MONTHLY] in [PREVIOUS CALENDAR MONTH]?

PROBE: Was the [MONTHLY] received or deposited into [YOUR] [PROG] account last month?

<1> YES

<0> NO

<r> DON'T KNOW/REFUSED

>tA2< CATI CHECK: IS CLIENT IN A COMA OR DECEASED?

<1> DIED 2 OR MORE MONTHS AGO [goto tB1]

<2> DIED WITHIN LAST 2 MONTHS, OR IN COMA [goto A4]

<3> ALIVE, NOT IN COMA

>A2< First, I have some questions about [YOURc] health.

Relative to other people [YOUR] age, how would you rate [YOURc] health now?
Would you say it's. . .

<1> Excellent

<2> Good

<3> Fair, or

<4> Poor

<r> DON'T KNOW/REFUSED

PROBE: Considering everything.

==>

>A4< [IF DIED SINCE 4 MO. SURVEY: I'm sorry to hear that [CLIENT] passed away recently.] During the last two months [WERE] [YOUc] *admitted to a hospital or nursing home* for an overnight stay?

PROBE: That's since [DATE TWO MONTHS AGO].

PROBE: Please do not count admissions that do not involve an overnight stay, such as admissions to an outpatient surgery center.

PROBE: Please count any time [YOU] [WERE] admitted to a hospital following an emergency room visit.

PROBE: Or [WERE] [YOUc] admitted prior to [DATE 2 MOS AGO] and still there during that time?

<1> YES

<0> NO

<r> DON'T KNOW/REFUSED

==>

>tA5< CATI CHECK: IS CLIENT DECEASED?

<1> YES [goto tB1]

<0> NO

==>

>A5< The next questions are about specific health problems.

During the past month, [HAVE] [YOUc] had a urinary tract infection?

PROBE: [WERE] [YOU] still taking medicine for it during the past month?

PROBE: That's since [DATE ONE MONTH AGO].

<1> YES

<0> NO

<r> DON'T KNOW/REFUSED

⇒

>A6< During the past month, [HAVE] [YOUc] had a respiratory infection?

PROBE: For example, a cold, pneumonia, or bronchitis.

PROBE: [WERE] [YOU] still taking medicine for it during the past month?

PROBE: That's since [DATE ONE MONTH AGO].

<1> YES

<0> NO

<r> DON'T KNOW/REFUSED

⇒

>A7< During the past month, [HAVE] [YOUc] *developed* bed sores or pressure sores, or have existing sores gotten worse?

PROBE: These sores are also called decubitus ulcers.

PROBE: That's since [DATE ONE MONTH AGO].

<1> YES, NEW OR GOTTEN WORSE

<0> NO

<r> DON'T KNOW/REFUSED

⇒

>A8< REPEAT PERIOD IF NECESSARY: [HAVE] [YOUc] *developed* contractures--muscles that won't straighten out--or, have existing contractures gotten worse?

PROBE: Did [YOUR] doctor or other health care provider tell [YOU] that [YOU] had contractures?

PROBE: That's since [DATE ONE MONTH AGO].

<1> YES, NEW OR GOTTEN WORSE

<0> NO

<r> DON'T KNOW/REFUSED

==>
>A9< REPEAT PERIOD IF NECESSARY: [HAVE] [YOUc] *developed* shortness of breath or has an existing problem with that gotten worse?

PROBE: That's since [DATE ONE MONTH AGO].

<1> YES, NEW OR GOTTEN WORSE

<0> NO

<r> DON'T KNOW/REFUSED

==>

>A10< During the past month, [WERE] [YOUc] injured when someone who was *paid* was trying to help [YOUm]?

PROBE: That's since [DATE ONE MONTH AGO].

PROBE: Include paid help at home.

INTERVIEWER: CODE YES EVEN IF RESPONDENT SAYS IT WAS INTENTIONAL.

<1> YES

<0> NO

<7> NO PAID HELP

<d> DON'T KNOW

<r> REFUSED

==>

>A11< During the past month, [HAVE] [YOUc] fallen?

PROBE: That's since [DATE ONE MONTH AGO].

[IF A10=1: PROBE: Even if you already told me about it.]

<1> YES

<0> NO [goto A13]

<r> DON'T KNOW/REFUSED [goto A13]

==>

>A12< [WERE] [YOUc] injured seriously enough in the fall to see a doctor?

PROBE: In any fall during the last month.

PROBE: Either in a hospital, doctor's office, or clinic or in [YOURc] home.

PROBE: That's since [DATE ONE MONTH AGO].

<1> YES

<0> NO

<r> DON'T KNOW/REFUSED

==>

>A13< During the past month, [HAVE] [YOU] seen a doctor for a cut, burn, or scald?

PROBE: Either in a hospital, doctor's office, or clinic or in [YOURc] home.

PROBE: That's since [DATE ONE MONTH AGO].

[IF A10=1: PROBE: Even if you already told me about it.]

<1> YES

<0> NO

<r> DON'T KNOW/REFUSED

==>

>A14< [IF CHILD OR COMA: Is [CLIENT] given] [OTHERWISE: [DO] [YOUc] take] medicines *regularly*?

PROBE: Medicines that a doctor or other health care provider prescribed or recommended.

PROBE: Including over-the-counter medicines or nutritional supplements, if they were prescribed or recommended.

<1> YES

<0> NO, NOT ON REGULAR MEDICATION [goto tA15a]

<r> DON'T KNOW/REFUSED [goto tA15a]

==>

>A15< Many people forget to [give / take their] medicine once in a while. During the *past week* about how often did [YOUc] miss a dose of [YOUR] medicine? Would you say

...

- <1> Every day or almost every day,
- <2> A few times during the week,
- <3> Only once or twice, or
- <4> Didn't [YOU] miss any doses at all last week
- <7> NOT ON MEDICINES IN PAST WEEK

<r> DON'T KNOW/REFUSED

PROBE: Of any of [YOUR] medicines?

PROBE: That's since [DAY OF WEEK] of last week.

==>

>tA15a< CATI CHECK: IS CLIENT IN A COMA OR IN THE HOSPITAL?

- <1> YES [goto A17]
- <0> NO

==>

>A16< At this time, [DO] [YOUc] have a chronic health condition or problem that requires medicine or other ongoing care?

PROBE: Any health condition or problem, whatever that means to you.

PROBE: By chronic, we mean a condition that a person will have for the rest of his or her life, such as diabetes or Alzheimer's disease.

- <1> YES
- <0> NO [goto tA18]

<r> DON'T KNOW/REFUSED [goto tA18]

==>

>A17< Do you feel that [YOUc] (and [YOUR] family) know(s) enough about [YOUR] condition to take good care of [YOURSELF]/ [YOU] themselves?

PROBE: For example, [DO] [YOUc] (and [YOUR] family) know the symptoms [YOU] need[S] to watch out for and the effects of [YOUR] medicines?

PROBE: Any member of [YOURc] family.

<1> YES

<0> NO

<r> DON'T KNOW/REFUSED

==>

>tA18< CATI CHECK: IS THE CLIENT UNDER FIVE YEARS OF AGE?

<1> YES [goto tB1]

<0> NO

==>

>A19< The next question is about taking a full bath, including getting the towels and soap and drawing the water. Please include taking a shower, bathing at a sink or basin, and bedbaths.

During the past two weeks, *how difficult* would it have been for [YOUm] to bathe if no one had been there to help [YOUm]? Would you say . . .

<1> Not difficult at all,

<2> Somewhat difficult,

<3> Very difficult, or

<4> Couldn't [YOU] do it at all?

<7> PROXY CANNOT REPORT ON CLIENT'S DIFFICULTY [goto tB1]

<r> DON'T KNOW/REFUSED

PROBE IF PROXY: *Your* own opinion will be fine.

PROBE: That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].

PROBE: How difficult would it *usually* have been?

==>

>A20< During the past two weeks, *how difficult* would it have been for [YOUm] to get in or out of bed if no one had been there to help [YOUm]? Would you say . . .

- <1> Not difficult at all,
- <2> Somewhat difficult,
- <3> Very difficult, or
- <4> Couldn't [YOU] do it at all?

- <7> PROXY CANNOT REPORT ON CLIENT'S DIFFICULTY [goto tB1]
- <r> DON'T KNOW/REFUSED

PROBE IF PROXY: *Your* own opinion will be fine.

PROBE: That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].

PROBE: How difficult would it *usually* have been?

==>

>A21< REPEAT PERIOD IF NECESSARY: *How difficult* would it have been for [YOUm] to use the toilet or commode if no one had been there to help [YOUm]? Would you say . . .

- <1> Not difficult at all,
- <2> Somewhat difficult,
- <3> Very difficult, or
- <4> Couldn't [YOU] do it at all?
- <7> DID NOT USE TOILET OR COMMODOE
- <8> COMBINATION OF SELF-TOILET AND HELP WITH DIAPERS
- <r> DON'T KNOW/REFUSED

PROBE IF PROXY: *Your* own opinion will be fine.

PROBE: That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].

PROBE: How difficult would it *usually* have been?

==>

B. LIVING ARRANGEMENTS AND REFERENCE PERIOD

>tB1< CATI CHECK: CLIENT VITAL AND INSTITUTIONAL STATUS

- <1> DECEASED 6 OR MORE WKS. AGO [goto tE1]
- <2> DECEASED WITHIN LAST 6 WKS. AND A4=1 (HOSP OR NH)
- <3> DECEASED WITHIN LAST 6 WKS. AND A4 NE 1 [goto tB4d]
- <4> ALIVE AND A4=1 (HOSP OR NH) [goto B4a]
- <5> ALIVE AND A4 NE 1 [goto tB4d]

==>

>B4< Between [DATE TWO MONTHS AGO] and when [YOUc] passed away, was there a period of at least two weeks when [YOUc] [WERE] at home and not in a hospital or nursing home?

- <1> YES [goto tB4d]
- <0> NO [goto E1]

- <r> DON'T KNOW/REFUSED [goto tE1]

==>

>B4a< The next questions are about services [YOUc] may have received *at home* recently. First, I need to identify the most recent two weeks [YOU] [WERE] at home and *not* in a hospital or nursing home.

Did [YOUc] stay overnight in a hospital or nursing home during *the last two weeks*?

PROBE: That is since [DAY OF WEEK], [DATE TWO WEEKS AGO].

- <1> YES
- <0> NO [goto tB4d]

- <r> DON'T KNOW/REFUSED

==>

>B4b< [HAVE] [YOUc] been living at home at least part of the last *two months* or [HAVE] [YOU] been in a hospital or nursing home *all* of the time?

PROBE: That's since [DATE TWO MONTHS AGO].

<1> HOSPITAL/NURSING HOME ALL LAST TWO MONTHS
[CONTROLS: goto tD68] [OW: goto tE1]
<0> HOME PART OF THAT TIME

<r> DON'T KNOW/REFUSED [CONTROLS: goto tD68] [OW: goto tE1]

==>

>B4c< During the last two months, was there a period of at least two weeks when [YOUc] [WERE] at home and not in a hospital or nursing home?

PROBE: Any two-week period since [DATE TWO MONTHS AGO].

<1> YES [goto tB4d]
<0> NO [CONTROLS: goto tD68] [OW: goto tE1]

<r> DON'T KNOW/REFUSED [goto tE1]

==>

>tB4d< If tB1=3 (deceased, no hosp/nh in last two months):
2-WEEK-PERIOD= "two-week period before [YOU] passed away"
THOSE-2-WEEKS= "those two weeks"
AT-THAT-TIME= "at that time"

If B4=1 (deceased and hosp/nh, but had two-week period home in last two months):
2-WEEK-PERIOD= "last two-week period [YOU][WERE] at home and not in a hospital/nursing home before [YOU] passed away"
THOSE-2-WEEKS= "those two weeks"
AT-THAT-TIME= "at that time"

If B4c=1 (hosp/nh in last 2 wks, but had two-week period home in last two months):
2-WEEK-PERIOD= "most recent two-week period [YOU][WERE] at home and not in a hospital/nursing home"
THOSE-2-WEEKS= "those two weeks"
AT-THAT-TIME= "at that time"

Otherwise (no hosp/nh in last 2 wks):
2-WEEK-PERIOD= "last two weeks"
THOSE-2-WEEKS= "the last two weeks"
AT-THAT-TIME= " "

>B4d< The next questions are about the [2-WEEK-PERIOD].

⇒

>B5< Who was living in the same household as [YOUc] during the [2-WEEK-PERIOD], or [WERE][YOU] living alone [AT-THAT-TIME]?

PROBE: Anyone else?

PROBE: Please include any employees who lived there.

PROBE: Please include anyone who was staying there temporarily.

PROBE: Are any of the people you mentioned related to [YOUc] and, if so, how?

INTERVIEWER: CODE ALL THAT APPLY.

- <1> ALONE [goto tB13]
- <2> SPOUSE
- <3> CHILD(REN)/CHILD(REN)-IN-LAW
- <4> PARENT(S)
- <5> GRANDPARENT(S)
- <6> SIBLING(S)
- <7> OTHER RELATIVE(S)
- <8> NON-RELATIVE(S) (MAY INCLUDE EMPLOYEES)
- <9> LIVING IN GROUP SITUATION
- <n> NO FURTHER RESPONSE
- <r> DON'T KNOW/REFUSED [goto tB13]

⇒

>tB6< CATI CHECK: IS THE CLIENT UNDER 18 YEARS OF AGE AND IN THE TREATMENT GROUP?

- <1> YES
- <0> NO, AGE 18+ OR CONTROL GROUP [goto B12]
- <2> LIVING IN GROUP SITUATION (B5=9)[goto tB13]

⇒

>tB7< CATI CHECK: IS THE CLIENT IN THE FNS OR SSI SAMPLE?

- <1> YES
- <0> NO, IN NEITHER SAMPLE [goto B12]

==>

>tB8< CATI CHECK: DID CLIENT LIVE WITH PARENT(S) (B5_4=4)?

- <1> YES
- <0> NO [goto tB9]

==>

>B8< Did [YOUc] live with one or both parents during [THOSE-2-WEEKS]?

PROBE: The [2-WEEK-PERIOD].

INTERVIEWER: CODE WITHOUT ASKING IF KNOWN

- <1> ONE PARENT
- <2> BOTH PARENTS
- <r>DON'T KNOW/REFUSED

==>

>tB9< CATI CHECK: DID CLIENT LIVE WITH SIBLING(S) (B5_6=6)?

- <1> YES
- <0> NO [goto B12]

==>

>B10< (Was the sister/brother) (Were any of the sisters/brothers) you mentioned *under* 18 years of age during [THOSE-2-WEEKS]?

PROBE: The sister(s)/brother(s) who were living in the same household as [YOUc] during the [2-WEEK-PERIOD].

- <1> YES
- <0> NO [goto B12]
- <r> DON'T KNOW/REFUSED [goto B12]

==>

>B11< How many of these sisters/brothers were under 18 during the [2-WEEK-PERIOD]?

INTERVIEWER: IF ONLY ONE SIBLING, CODE <1> WITHOUT ASKING.

PROBE: The sister(s)/brother(s) who were living in the same household as [YOUc]
during the [2-WEEK-PERIOD].

<1-15> NUMBER OF SIBLINGS UNDER 18

<r> DON'T KNOW/REFUSED

⇒

>B12< Including [YOUc], how many people [*altogether*] lived in that household during [THOSE-2-WEEKS]?

INTERVIEWER: CONFIRM AND CODE IF KNOWN.

PROBE: The [2-WEEK-PERIOD].[IF 2-WEEK-PERIOD="last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].

PROGRAMMER: INSERT 'altogether' IF CLIENT IS IN FNS OR SSI SAMPLE.

<2-15> HOUSEHOLD MEMBERS

<r> DON'T KNOW/REFUSED

==>

>B13< CATI CHECK: IS CLIENT DECEASED?

<1> YES

<0> NO [goto tC1]

==>

>B13< Would you be willing to answer some questions about the help that [YOUc] received during the [2-WEEK-PERIOD]?

PROBE: I realize this is difficult. Your cooperation will help us learn how to improve (personal / home) care services.

PROGRAMMER: INSERT 'personal' IF AR OR NJ; 'home' IF FL.

<1> YES, WILLING

<0> NO, NOT WILLING [goto tE1]

<r> DON'T KNOW/REFUSED [goto tE1]

==>

C. UNPAID IN-HOME CARE

>C1< CATI CHECK: SEE tB4d FOR HOW TO FILL [2-WEEK-PERIOD], [THOSE-2-WEEKS], AND [AT-THAT-TIME].

==>

>C1a< Please think about all the people who may have helped [YOU] during the [2-WEEK-PERIOD], [B5=9: and who were not paid for helping][OW: whether or not they were paid for helping]. May I have their first names, please?

INTERVIEWER: LIST ALL NAMES MENTIONED. PROBE FOR ANYONE ELSE.[B5 NE 9: THEN, FOR EACH ASK: Now, was PERSON 1 paid for any of the time spent helping [YOU] during that time?]

PROBE: Including help from a family member, friend or volunteer from a church or service organization if they sometimes help at [YOURc] home or at someone else's home.

PROBE: This will make it easier for us to ask the next few questions.

[PROBE: Please include help from any parent.]

[PROBE: Or will he/she be paid for that help?]

==> PRESS ENTER TO CONTINUE

>C2<

Please think about all the people who may have helped [YOUc] during the [2-WEEK-PERIOD], and who were *not* paid for helping [YOU], like family members, friends, and volunteers. Please include [SEE PROGRAMMER INSTRUCTIONS]. Please do *not* include friends and family members who are paid for helping, even if they help more hours than they are paid for. Later, I will ask about people who are paid.

PROBE: I will ask about paid helpers later.

PROGRAMMER:

If (PROXY=P) or (PROXY=X and CLIENT>=18 and i16d=1) or (PROXY=X and CLIENT>=18 and B5_2 NE 2): "Please include yourself."

If (PROXY=C and B5_2=2) : "Please include your [IF CLIENT FEMALE: husband] [IF CLIENT MALE: wife]."

If (PROXY=X and CLIENT>=18 and B5_2=2 and i16d NE 1): "Please include yourself and CLIENT's [IF CLIENT FEMALE: husband][IF CLIENT MALE: wife]."

If (PROXY=X and CLIENT<18): "Please include yourself and CLIENT's parent(s)/guardian."

PROBE: Including help from a family member, friend or volunteer from a church or service organization if they sometimes help at [YOURc] home or at someone else's home.

[PROBE: Please include help from any parent who was not paid.]

==>

>C4< During [THOSE-2-WEEKS], *how many different* people who were *not* paid, helped [YOUc] with personal care, things around the house or community, routine health care at home, or transportation, like family members, friends and volunteers? Please include {SEE PROGRAMMER INSTRUCTIONS}. So you told me that was...

INTERVIEWER: LIST NAMES AND THEN ASK: Is that correct?

PROBE: The [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

PROBE: Please do *not* include friends and family members who are paid for helping, even if they help more hours than they are paid for. Later, I will ask about people who are paid.

PROBE: If they were paid for their time and trouble, then do not count them here.

<0> NO UNPAID HELPERS [goto tD0]

<1-15> UNPAID HELPERS

<r> DON'T KNOW/ REFUSED [goto tD0]

==>

>C5< [IF C4=1: Is this person] [IF C4=2: Are either of these people] [IF C4>2: Are any of these people] related to [YOUc]?

INTERVIEWER: CONFIRM AND CODE IF KNOWN.

<1> YES

<0> NO [goto C7]

<r> DON'T KNOW/REFUSED [goto C7]

==>

>C6< How [C4=1:is he/she] [C4>1:are they] related to [YOUc]?

INTERVIEWER: CODE ALL THAT APPLY. CONFIRM AND CODE IF KNOWN.

PROBE IF DAUGHTER/SON REPORTED: Would that be [YOUR] (daughter or daughter-in-law / son or son-in-law)?

PROBE: Is anyone *else* who helps and is not paid related to [YOUc]?

- <1> HUSBAND / WIFE
- <2> MOTHER/MOTHER-IN-LAW
- <3> FATHER/FATHER-IN-LAW
- <4> DAUGHTER(S)
- <5> DAUGHTER(S)-IN-LAW
- <6> SON(S)
- <7> SON(S)-IN-LAW
- <8> SISTER(S)/SISTER(S)-IN-LAW
- <9> BROTHER(S)/BROTHER(S)-IN-LAW
- <10> GRANDPARENT(S)
- <11> GRANDCHILD(REN)
- <12> NIECE(S)
- <13> NEPHEW(S)
- <14> OTHER RELATIVE(S)
- <n> NO FURTHER RELATIVES

- <r> DON'T KNOW/REFUSED

==>

>C7< During [THOSE-2-WEEKS], did [C4=1: the person who was] [C4=2: either of the people who were] [C4>2: any of the people who were] *not* paid, help [YOUc] with [AGE GE 5 AND NOT COMA: taking medications, including reminders to take it] [CHILD/COMA: medications]?

PROBE: [C4=1: The person who was] [C4=2: Either of the people who were] [C4>2: Any of the people who were] *not* paid to help [YOUm].

PROBE: The [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

<1> YES

<0> NO/NO HELP NEEDED

<7> DID NOT TAKE MEDICINE

<t> DON'T KNOW/REFUSED

==>

>C8< During [THOSE-2-WEEKS], did [C4=1:that person] [C4=2:either of them] [C4>2: any of them] help [YOUc] with other *routine health care* at home, like checking blood pressure or doing exercises?

PROBE: Any help with routine health care *other than* taking medicine.

PROBE: Including help from a family member, friend or volunteer from a church or service organization if they sometimes help at [YOURc] home or at someone else's home.

PROBE: [C4=1: The person who was] [C4=2: Either of the people who were] [C4>2: Any of the people who were] *not* paid to help [YOUm].

PROBE: The [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

PROBE: Or did he/she/they remind [YOUm] to do things like that?

<1> YES

<0> NO/NO HELP NEEDED

<7> DID NOT HAVE OTHER ROUTINE HEALTH CARE

<t> DON'T KNOW/REFUSED

==>

>tC9< CATI CHECK: IS CLIENT COMATOSE OR A CHILD LESS THAN 5?

<1> COMATOSE (AGE 5+) [goto C13]

<2> AGE LESS THAN 5 [goto C16]

<3> NEITHER

==>

>C10< REPEAT PERIOD IF NECESSARY. Did [that person / either of them / any of them] help [YOUc] with *eating*? Please include helping by staying nearby just in case [YOU] needed help.

PROBE: For example, opening cartons, cutting your/his/her food, or helping [YOUm] use a spoon.

PROBE: Please don't count help preparing meals.

PROBE: [C4=1: The person who was] [C4=2: Either of the people who were] [C4>2: Any of the people who were] *not* paid to help [YOUm].

PROBE: During the [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

PROBE: Or did he/she/they make sure that [YOUc] ate?

<1> YES

<0> NO/NO HELP NEEDED

<7> DID NOT EAT AT ALL

<r> DON'T KNOW/REFUSED

==>

>C11< REPEAT PERIOD IF NECESSARY. Did [that person / either of them / any of them] help [YOUc] with *getting in or out of bed*? Please include helping by staying nearby just in case [YOUc] needed help.

PROBE: [C4=1: The person who was] [C4=2: Either of the people who were] [C4>2: Any of the people who were] *not* paid to help [YOUm].

PROBE: During the [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

PROBE: Or did he/she/they make sure that [YOUc] got out of bed?

<1> YES

<0> NO/NO HELP NEEDED

<7> DID NOT GET OUT OF BED

<t> DON'T KNOW/REFUSED

==>

>C12< REPEAT PERIOD IF NECESSARY. And, with *getting to or using the toilet?*
Please include staying nearby just in case [YOU] needed help.

PROBE: Did [that person / either of them / any of them] help [YOUc] with this or
stay nearby just in case [YOUc] needed help?

PROBE: Please include arranging clothes, transferring on and off the toilet or
commode, and cleaning [YOURSELF].

PROBE: [C4=1: The person who was] [C4=2: Either of the people who were]
[C4>2: Any of the people who were] *not* paid to help [YOUm].

PROBE: During the [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks":
That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

<1> YES

<0> NO/NO HELP NEEDED

<7> DID NOT USE TOILET OR COMMODOE

<r> DON'T KNOW/REFUSED

==>

>C13< REPEAT PERIOD IF NECESSARY. Did [that person / either of them / any of them]
help [YOUc] with *bathing or showering?* Please include bed baths, bathing at a sink
or basin, and helping by staying nearby just in case [YOU] needed help.

PROBE: [C4=1: The person who was] [C4=2: Either of the people who were]
[C4>2: Any of the people who were] *not* paid to help [YOUm].

PROBE: During the [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks":
That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

PROBE: Or did he/she/they make sure that [YOUc] bathed?

<1> YES

<0> NO/NO HELP NEEDED

<7> DID NOT BATHE/SHOWER AT ALL

<r> DON'T KNOW/REFUSED

==>

>C14< REPEAT PERIOD IF NECESSARY. And, help with other personal care?

PROBE: Such as help with dressing (or getting around inside).

PROGRAMMER: EXCLUDE "or getting around inside" IF COMATOSE.

PROBE: Please include helping by staying nearby just in case [YOU] needed help.

PROBE: Did [that person / either of them / any of them] help [YOUc] with this or stay nearby just in case [YOUc] needed help?

PROBE: [C4=1: The person who was] [C4=2: Either of the people who were]
[C4>2: Any of the people who were] *not* paid to help [YOUm].

PROBE: During the [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks":
That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

<1> YES

<0> NO/NO HELP NEEDED

<r> DON'T KNOW/REFUSED

==>

>C16< Now, I have a few questions about help [YOUc] may have had doing things around the house or community during [THOSE-2-WEEKS].

Did [C4=1:the person who was] [C4=2:either of the people who were] [C4>2: any of the people who were] *not* paid, help [YOUm] by *preparing meals* [IF AGE<18: for [YOUm]] in [YOURc] home or *bringing meals* [IF AGE>=18:to [YOUm]] [IF AGE<18: that [YOU] ate]?

PROBE: Please don't count arranging for meals from Meals-on-Wheels or a similar program.

PROBE: Including help from a family member, friend or volunteer from a church or service organization if they sometimes help at [YOURc] home or at someone else's home.

PROBE: Include picking up take-out meals from a restaurant or meals prepared at someone else's home.

PROBE: During the [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

PROBE: Even if this was for other household members, too.

<1>YES

<0> NO/NO HELP NEEDED

<r> DON'T KNOW/REFUSED

==>

>C17< REPEAT PERIOD IF NECESSARY. And, with [AGE GE 18: *light housework or laundry*, like washing dishes or clothes] [AGE<18: washing [YOURc] dishes or [YOUR] clothes]?

PROBE: Did [C4=1:that person] [C4=2:either of them] [C4>2: any of them] help [YOUm] with this?

PROBE: [C4=1: The person who was] [C4=2: Either of the people who were] [C4>2: Any of the people who were] *not* paid to help [YOUm].

PROBE: During the [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

<1> YES

<0> NO/NO HELP NEEDED

<r> DON'T KNOW/REFUSED

==>

>C18< REPEAT PERIOD IF NECESSARY. With *shopping* [AGE<18: for [YOUc]]?

PROBE: For example, getting groceries or buying things at a drug store.

PROBE: Other than transportation to the store.

PROBE: Did [C4=1:that person] [C4=2:either of them] [C4>2: any of them] help [YOUm] with this?

PROBE: [C4=1: The person who was] [C4=2: Either of the people who were] [C4>2: Any of the people who were] *not* paid to help [YOUm].

PROBE: During the [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

PROBE: Even if this was for other household members, too.

<1> YES

<0> NO/NO HELP NEEDED

<r> DON'T KNOW/REFUSED

==>

>C19< During [THOSE-2-WEEKS], did [C4=1:the person who was] [C4=2: either of the people who were] [C4>2: any of the people who were] *not* paid, drive [YOUc] somewhere or help [YOUm] ride public transportation, such as a bus, taxi, or special van?

PROBE: Include help riding ambulettes and ambulances.

PROBE: Do not include people who only arranged for the transportation or drivers.

PROBE: Include people who helped by accompanying [YOUc] or helping [YOUm] on or off, other than the driver.

PROBE: For example, to go to the doctor or shopping.

[PROBE IF CHILD: Please include help from any parent.]

[PROBE IF CHILD: Please include help riding any type of school bus.]

[PROBE IF CHILD: Did someone who was *not* paid help with taking [CLIENT] places?]

PROBE: The [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

<1> YES

<0> NO/NO HELP NEEDED

<r> DON'T KNOW/REFUSED

==>

>C20< REPEAT PERIOD IF NECESSARY. And, finally, help with doing other things around the house or community [AGE<18: for [YOUc]]?

[IF AGE GE 18: PROBE: Such as yardwork and heavy housework like scrubbing floors.]

[IF AGE<18: PROBE: Such as help with homework.]

PROBE: Including help from a family member, friend or volunteer from a church or service organization if they sometimes help at [YOURc] home or at someone else's home.

PROBE: Did [C4=1:that person] [C4=2:either of them] [C4>2: any of them] help [YOUm] with this?

PROBE: [C4=1: The person who was] [C4=2: Either of the people who were] [C4>2: Any of the people who were] *not* paid to help [YOUm].

PROBE: During the [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

<1> YES

<0> NO/NO HELP NEEDED

<r> DON'T KNOW/REFUSED

==>

>C21< Now, please think about the different *times of day* that [C4=1:the person who was] [C4=2: either of the people who were][C4>2:any of the people who were] *not* paid, helped [YOUc] during the [2-WEEK-PERIOD].

Did [C4=1:that person][C4=2:either of them][C4>2: any of them] help [YOUm] *before 8 o'clock on weekday mornings?*

PROBE: On any weekday morning before 8 o'clock during [THOSE-2-WEEKS].

PROBE: During the [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

<1> YES

<0> NO

<r> DON'T KNOW/REFUSED

⇒

>C22< REPEAT PERIOD IF NECESSARY. Did [that person / either of them / any of them] help *after 6 o'clock on weekday evenings?*

PROBE: On any weekday evening after 6 o'clock during [THOSE-2-WEEKS].

PROBE: During the [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

PROBE: [C4=1:The person who was][C4=2: Either of the people who were] [C4>2: Any of the people who were] *not* paid to help [YOUm].

<1> YES

<0> NO

<r> DON'T KNOW/REFUSED

⇒

>C23< REPEAT PERIOD IF NECESSARY: What about *weekends?*

PROBE: Did [that person / either of them / any of them] help on the weekends?

PROBE: Any time of day on any weekend during [THOSE-2-WEEKS].

PROBE: During the [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

PROBE: [C4=1:The person who was][C4=2: Either of the people who were] [C4>2: Any of the people who were] *not* paid to help [YOUm].

<1> YES

<0> NO

<r> DON'T KNOW/REFUSED

⇒

>tC23a< CATI CHECK: DOES CLIENT LIVE ALONE (B5=1)?

<1> YES [goto tC37]

<0> NO

==>

>C24< *During [THOSE-2-WEEKS], did [C4=1:the person who was][C4=2:either of the people who were][C4>2: any of the people who were] not paid to help, live in the same household as [YOUc]? Please include anyone staying in [YOURc] household at least three nights during that time.*

INTERVIEWER: CODE IF KNOWN

PROBE: Do not include people who come and stay overnight just to help [YOUc], but who live elsewhere.

PROBE: Please include anyone who was staying there temporarily.

PROBE: The [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

PROBE: [C4=1:The person who was][C4=2: Either of the people who were] [C4>2: Any of the people who were] not paid to help [YOUm].

<1> YES

<0> NO [goto tC37]

<r> DON'T KNOW/REFUSED [goto tD0]

==>

>tC25< CATI CHECK: IS THERE MORE THAN ONE UNPAID CAREGIVER (C4>1)?

<1> YES

<0> NO [goto C28]

==>

>C26< How *many* of them lived in the same household as [YOUc] during [THOSE-2-WEEKS]?

INTERVIEWER: CONFIRM AND CODE IF KNOWN

PROBE: The same household as [YOUc].

PROBE: The people who were *not* paid to help [YOUm].

PROBE: The [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

<1-15> UNPAID LIVE-IN HELPERS

<4> DON'T KNOW/REFUSED [goto tD0]

==>

>tC27< CATI CHECK: NUMBER OF LIVE-IN UNPAID CAREGIVERS:

<1> ONE (C26=1)

<2> TWO (C26=2) [goto C30]

<3> MORE THAN TWO (C26>2) [goto C29]

==>

>C28< You told me that person's *first* name was (NAME FROM C1A FORM). Is that correct?

INTERVIEWER: RECORD NAME BELOW

PROBE: The person who lived in the same household as [YOUc] during [THOSE-2-WEEKS] and who was not paid.

RECORD NAME MENTIONED: _____
[STORE IN ULNAM1]

==> [goto C31]

>C29< Please think about *all* the people who were *not* paid to help, lived in the same household as [YOUc], and helped [YOUm] with [IF C10, C11, C12, C13, or C14=1 OR AGE<5:personal care,] [OR] [IF C16, C17, C18=1, or C20=1:things around the house and community,] [OR] [IF C19=1:transportation,] [OR] [C7 or C8=1:routine health care at home] during [THOSE-2-WEEKS].

Which *two* of them helped [YOUm] the *most* with things like that during [THOSE-2-WEEKS]? May I have their *first* names please? That will make it easier to ask the next questions.

PROBE: I have recorded that people who were not paid, helped [YOUc] with [ACTIVITIES FROM ASSISTANCE BATTERY: SEE C29]. Which *two* people, who were not paid and lived in the same household as [YOUm], helped the *most* with those things?

PROBE: The [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

RECORD FIRST NAME MENTIONED: _____
[STORE IN ULNAM1]

RECORD SECOND NAME MENTIONED: _____
[STORE IN ULNAM2]

====> [goto C31]

>C30< You told me that the *first* names of these two people were (UNPAID NAMES FROM C1A LIST). Is that correct?

INTERVIEWER: RECORD NAMES BELOW

PROBE: The two people who lived in the same household as [YOUc] and who were *not* paid to help [YOUm].

PROBE: The [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

RECORD FIRST NAME MENTIONED: _____
[STORE IN ULNAM1]

RECORD SECOND NAME MENTIONED: _____
[STORE IN ULNAM2]

====>

>C31< Now I have some questions about the hours of help [YOUc] received from [ULNAM1] during [THOSE-2-WEEKS].

Doing things around the house and community--such as preparing meals, housework, laundry, shopping [AGE>=18:], and yardwork--often benefits *more than one* person in a household.

About how many *hours* would you say [ULNAM1] spent during [THOSE-2-WEEKS] doing [IF C16, C17, or C18=1:(HOUSEHOLD/COMMUNITY ACTIVITIES FROM BATTERY) or other] things around the house or community to meet the needs of everyone in the household?

PROBE: Things like preparing meals, housework, laundry, shopping [AGE>=18:], and yardwork].

PROBE: The [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

PROBE: I have recorded that [C4=1:someone who was] [C4>1: people who were] not paid helped with [HOUSEHOLD/COMMUNITY ACTIVITIES FROM ASSISTANCE BATTERY]. Did [ULNAM1] help with any of that?

PROBE: Your best estimate would be fine.

<0> HOURS [goto C33]

<1-168> HOURS [goto C32]

<d> DON'T KNOW [goto C31a]

<r> REFUSED [goto C33]

====>

>C31a< Perhaps you could tell me a range? Was it...

<1> 1-4 hours

<5> 41-60 hours

<2> 5-10 hours

<6> 61-80 hours

<3> 11-20 hours

<7> 81-120 hours

<4> 21-40 hours

<8> 121 OR MORE

<r> DON'T KNOW/REFUSED

PROBE: Your best estimate is fine.

====>

>C32< Sometimes doing things around the house or community benefits one person *more* than others. For example, one person may have *more* soiled sheets to be laundered or need to follow a special diet that takes more time to prepare.

Would you say that the time that [ULNAM1] spent doing those things like that benefitted [YOUc] *more* than the other people in the household, *less* than other people, or about the same?

PROBE IF RESPONDENT IS ONLY HOUSEHOLD MEMBER OTHER THAN CLIENT: More, less, or about the same as it benefits you.

PROBE: During [THOSE-2-WEEKS].

<1> MORE

<2> LESS

<3> ABOUT THE SAME

<r> DON'T KNOW/REFUSED

==>

>C33< About how many *hours* would you say [ULNAM1] spent during [THOSE-2-WEEKS] doing things *just* for [YOUc], such as helping with [YOUR] [IF C10, C11, C12, C13, C14 OR AGE<5:personal care,][OR] [IF C7 OR C8=1:routine health care at home,] [OR] [IF C19=1: transportation]?

PROBE: The [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

PROBE: Your best estimate would be fine.

PROBE: I have recorded that [C4=1:someone who was] [C4>1: people who were] not paid helped with [PERSONAL CARE, ROUTINE HEALTH AND TRANSPORTATION FROM ASSISTANCE BATTERY: SEE C33]. Did [ULNAM1] help with any of that?

[IF AGE<5: PROBE: Be sure to include time spent helping with eating, getting in and out of bed, toileting, bathing, and other personal care.]

<0-168> HOURS [goto tC34]

<d> DON'T KNOW [goto C33a]

<r> REFUSED [goto tC34]

==>

>C33a< Perhaps you could tell me a range? Was it...

- | | |
|------------------------|------------------|
| <1> 1-4 hours | <5> 41-60 hours |
| <2> 5-10 hours | <6> 61-80 hours |
| <3> 11-20 hours | <7> 81-120 hours |
| <4> 21-40 hours | <8> 121 OR MORE |
| <r> DON'T KNOW/REFUSED | |

PROBE: Your best estimate is fine.

==>

>tC34< CATI CHECK: IS THERE A SECOND UNPAID LIVE-IN CAREGIVER (C26>1)?

- <1> YES
- <0> NO [goto tC37]

==>

>C35< Now I would like to talk about the hours of help [YOUc] received from [ULNAM2] during [THOSE-2-WEEKS].

About how many *hours* would you say [ULNAM2] spent during [THOSE-2-WEEKS] doing [IF C16, C17, or C18=1:(HOUSEHOLD/COMMUNITY ACTIVITIES FROM BATTERY) or other] things around the house or community to meet the needs of people in the household?

PROBE: Things like preparing meals, housework, laundry, shopping [AGE GE 18:, and yardwork].

PROBE: The [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

PROBE: Your best estimate would be fine.

<0-168> HOURS [goto C36]

<d> DON'T KNOW [goto C35a]

<r> REFUSED [goto C36]

==>

>C35a< Perhaps you could tell me a range? Was it...

<1> 1-4 hours <5> 41-60 hours
<2> 5-10 hours <6> 61-80 hours
<3> 11-20 hours <7> 81-120 hours
<4> 21-40 hours <8> 121 OR MORE
<r> DON'T KNOW/REFUSED

PROBE: Your best estimate is fine.

==>

>C36< About how many *hours* would you say [ULNAM2] spent during [THOSE-2-WEEKS] doing things *just* for [YOUc], such as helping with [YOUR] [IF C10, C11, C12, C13, C14 OR AGE<5:personal care,][OR] [IF C7 OR C8=1:routine health care at home,] [OR] [IF C19=1: transportation]?

PROBE: The [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

PROBE: Your best estimate would be fine.

PROBE: I have recorded that [C4=1:someone who was] [C4>1: people who were] not paid helped with [PERSONAL CARE, ROUTINE HEALTH AND TRANSPORTATION FROM ASSISTANCE BATTERY: SEE C33]. Did [ULNAM1] help with any of that?

[IF AGE<5: PROBE: Be sure to include time spent helping with eating, getting in and out of bed, toileting, bathing, and other personal care.]

<0-168> HOURS [goto tC37]

<d> DON'T KNOW [goto C36a]

<r> REFUSED [goto tC37]

==>

>C36a< Perhaps you could tell me a range? Was it...

- <1> 1-4 hours
- <2> 5-10 hours
- <3> 11-20 hours
- <4> 21-40 hours
- <5> 41-60 hours
- <6> 61-80 hours
- <7> 81-120 hours
- <8> 121 OR MORE
- <r> DON'T KNOW/REFUSED

PROBE: Your best estimate is fine.

==>

>tC37< CATI CHECK: HOW MANY VISITING UNPAID CAREGIVERS WERE THERE?
TOTAL UNPAID CAREGIVERS=C4.
UNPAID LIVE-IN CAREGIVERS=C26 OR 1 (IF tC25=0).
UNPAID VISITING CAREGIVERS=
TOTAL UNPAID CAREGIVERS MINUS UNPAID LIVE-IN CAREGIVERS.

- <0> ZERO [goto tD0]
- <1> ONE
- <2> TWO [goto C39]
- <3>THREE [goto C40]
- <4> MORE THAN THREE [goto C41]

==>

>C38< You told me that the person who helped [YOUc] during [THOSE-2-WEEKS], who was *not* paid, and who did *not* live in the same household as [YOUm] was (READ NAME FROM C1A LIST). Is that correct?

PROBE: The [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

RECORD NAME: _____
[STORE IN UVNAM1]

==> [goto C42]

>C39< You told me that the two people who helped [YOUc] during [THOSE-2-WEEKS], who were *not* paid, and who did *not* live in the same household as [YOUm] were (READ NAMES FROM C1A LIST). Is that correct?

PROBE: The [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

RECORD FIRST NAME: _____
[STORE IN UVNAM1]

RECORD SECOND NAME: _____
[STORE IN UVNAM2]

==> [goto C42]

>C40< You told me that the three people who helped [YOUc] during [THOSE-2-WEEKS], who were *not* paid, and who did *not* live in the same household as [YOUm] were (READ NAMES FROM C1A LIST). Is that correct?

PROBE: The [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

RECORD FIRST NAME: _____
[STORE IN UVNAM1]

RECORD SECOND NAME: _____
[STORE IN UVNAM2]

RECORD THIRD NAME: _____
[STORE IN UVNAM3]

==> [goto C42]

>C41< Please think about *all* the people who were *not* paid, did *not* live in the same household as [YOUc], and helped [YOUm] with [IF C10, C11, C12, C13, or C14=1 OR AGE<5:personal care,] [OR] [IF C16, C17, C18=1, or C20=1:things around the house and community,] [OR] [IF C19=1:transportation,] [OR] [C7 or C8=1:routine health care at home] during [THOSE-2-WEEKS].

May I have the *first* names of the *three* of them who helped [YOUm] the *most* during [THOSE-2-WEEKS]? That will make it easier to ask the next questions.

PROBE: The [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

PROBE: I have recorded that people who were not paid helped [YOUc] with [ACTIVITIES FROM ASSISTANCE BATTERY: SEE C29]. Which *three* people, who were not paid and who did *not* live in the same household as [YOUm], helped the *most* with those things?

RECORD FIRST NAME: _____
[STORE IN UVNAM1]

RECORD SECOND NAME: _____
[STORE IN UVNAM2]

RECORD THIRD NAME: _____
[STORE IN UVNAM3]

==>

>C42< Now I have some questions about help [YOUc] received from [UVNAM1].

During [THOSE-2-WEEKS], *how many times* did [UVNAM1] come to help [YOUc]?

PROBE: Your best estimate would be fine.

PROBE: How many visits a day for how many days a week?

PROBE: Please don't count *purely* social visits.

<1-60> VISITS

<t> DON'T KNOW/REFUSED

==>

>C43< During [THOSE-2-WEEKS], about how long did [UVNAM1] [C42>1:usually] spend helping [C42=1:the][C42>1:each] time he/she came?

PROBE: Your best estimate would be fine.

INTERVIEWER: RECORD IN EITHER HOURS OR MINUTES, OR BOTH.

PROBE: About how long did he/she [C42>1:usually] help when he/she came to help?

PROBE: Please include any time spent helping away from [YOURc] home such as shopping for [YOUR] groceries or preparing meals to bring to [YOUm].

<0-23> HOURS

<0-59> MINUTES [goto tC50]

<97> VARIES [goto C49]

<d> DON'T KNOW

<r> REFUSED [goto tC50]

==>

>C44< Perhaps you could tell me a range? During [THOSE-2-WEEKS], did [UVNAM1] [usually] spend less than *or* more than an hour helping?

PROBE: Did he/she [usually] help less than or more than an hour?

<1> LESS THAN AN HOUR

<2> AN HOUR [goto tC50]

<3> MORE THAN AN HOUR [goto C46]

<r> DON'T KNOW/REFUSED [goto tC50]

==>

>C45< Would you say [UVNAM1] [usually] helped

PROBE: Did he/she [usually] help . . .

<1> Less than 15 minutes,

<2> At least 15 but less than 30 minutes,

<3> At least 30 but less than 45 minutes, or

<4> At least 45 minutes but less than an hour?

<r> DON'T KNOW/REFUSED

==> [goto tC50]

>C46< Was it [usually] less or more than three hours?

PROBE: Did [UVNAM1] [usually] spend less or more than three hours helping [C42=1:the][C42>1:each] time he/she came?

- <1> LESS THAN THREE HOURS
- <2> THREE HOURS [goto tC50]
- <3> MORE THAN THREE HOURS [goto C48]
- <r> DON'T KNOW/REFUSED [goto tC50]

==>

>C47< Would you say [UVNAM1] [usually] helped:

PROBE: Did he/she [usually] help . . .

- <1> Less than an hour and a half,
- <2> At least an hour and a half but less than two hours,
- <3> At least two hours but less than two and a half hours, or
- <4> More than two and a half hours?
- <r> DON'T KNOW/REFUSED

==> [goto tC50]

>C48< Would you say [UVNAM1] [usually] helped:

- <1> Less than three and a half hours,
- <2> At least three and a half hours but less than four hours, or
- <3> Four hours or more?
- <r> DON'T KNOW/REFUSED

==> [goto tC50]

>C49< About how many hours did [UVNAM1] help in all during [THOSE-2-WEEKS]?

PROBE: Your best estimate would be fine.

- <1-200> HOURS
- <d> DON'T KNOW
- <r> REFUSED

==>

>tC50< CATI CHECK: IS THERE A SECOND UNPAID VISITING CAREGIVER (SEE tC27)?

<1> YES [repeat C42 through C49 for UVNAM2, then goto tC51]

<0> NO [goto tD0]

==>

>tC51< CATI CHECK: IS THERE A THIRD UNPAID VISITING CAREGIVER (SEE tC27)?

<1> YES [repeat C42 through C49 for UVNAM3, then goto D1]

<0> NO [goto tD0]

==>

D. PAID IN-HOME CARE

>tD0< CATI CHECK: IS CLIENT LIVING IN GROUP SITUATION [B5=9]?

<1> YES [goto Te1]

<0> NO

>D1< The next question is about care [YOUc] may have received from people who were *paid* to help [YOUm] during the [2-WEEK-PERIOD]. This could be someone [YOUc] paid or someone employed by an agency, even if [YOU] did not have to pay the agency.

How many different people who were *paid*, helped [YOUc] with personal care, things around the house or community, routine health care at home, or transportation during [THOSE-2-WEEKS]? So you told me that was

INTERVIEWER: LIST NAMES, THEN ASK: Is that correct?

PROBE: Please include friends and family members who are paid for helping, even if they help more hours than they are paid for.

[PROBE: Please include help from any parent who was paid.]

PROBE: The [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

PROBE: Was any of that paid for their time and trouble?

<0> NO PAID HELPERS [CONTROLS: goto tD68] [OW: goto tE1]

<1-15> PAID HELPERS

<r> DON'T KNOW/ REFUSED [CONTROLS: goto tD68] [OW: goto tE1]

==>

>tD2< CATI CHECK: IS CLIENT IN TREATMENT GROUP?

<1> YES

<0> NO [goto D8]

==>

>D3< [IF D1=1: Is this person] [IF D1=2: Are either of these people] [IF D1>2: Are any of these people] related to [YOUc]?

INTERVIEWER: CONFIRM AND CODE IF KNOWN

<1> YES

<0> NO [goto D8]

<r> DON'T KNOW/REFUSED [goto D8]

==>

>D4< How [D1=1:is he/she] [D1>1:are they] related to [YOUc]?

INTERVIEWER: CODE ALL THAT APPLY. CONFIRM AND CODE IF KNOWN

PROBE IF DAUGHTER/SON REPORTED: Would that be [YOUR] (daughter or daughter-in-law / son or son-in-law)?

PROBE: Is anyone *else* who is paid to help related to [YOUc]?

<1> HUSBAND / WIFE

<2> MOTHER/MOTHER-IN-LAW

<3> FATHER/FATHER-IN-LAW

<4> DAUGHTER(S)

<5> DAUGHTER(S)-IN-LAW

<6> SON(S)

<7> SON(S)-IN-LAW

<8> SISTER(S)/SISTER(S)-IN-LAW

<9> BROTHER(S)/BROTHER(S)-IN-LAW

<10> GRANDPARENT(S)

<11> GRANDCHILD(REN)

<12> NIECE(S)

<13> NEPHEW(S)

<14> OTHER RELATIVE(S)

<n> NO FURTHER RELATIVES

<r> DON'T KNOW/REFUSED

==>

>D8< During [THOSE-2-WEEKS], did [D1=1: the person who was] [D1=2: either of the people who were] [D1>2: any of the people who were] paid, help [YOUc] with [AGE GE 5 AND NOT COMA: taking medications, including reminders to take it] [CHILD/COMA: medications]?

PROBE: [D1=1: The person who was] [D1=2: Either of the people who were] [D1>2: Any of the people who were] paid to help [YOUm].

PROBE: The [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

<1> YES

<0> NO/NO HELP NEEDED

<7> DID NOT TAKE MEDICINE

<r> DON'T KNOW/REFUSED

==>

>D9< During [THOSE-2-WEEKS], did [D1=1:that person] [D1=2:either of them] [D1>2: any of them] help [YOUc] with other *routine health care* at home, like checking blood pressure or doing exercises?

PROBE: Any help with routine health care *other than* taking medicine.

PROBE: [D1=1: The person who was] [D1=2: Either of the people who were] [D1>2: Any of the people who were] paid to help [YOUm].

PROBE: Including help from a family member, friend or volunteer from a church or service organization if they sometimes help at [YOURc] home or at someone else's home.

PROBE: The [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

PROBE: Or did he/she/they remind [YOUm] to do things like that?

<1> YES

<0> NO/NO HELP NEEDED

<7> DID NOT HAVE OTHER ROUTINE HEALTH CARE

<r> DON'T KNOW/REFUSED

==>

>D10< CATI CHECK: IS CLIENT IN TREATMENT GROUP AND DID HE/SHE HAVE PAID HELP WITH MEDICINES OR OTHER ROUTINE HEALTH CARE (D8, D9) AND DID HE/SHE RECEIVE CASH THIS MONTH OR PMONTH (A1c=C or PMONTH)?

<1> YES

<0> NO [goto tD13]

==>

>D11< Thinking about [D1=1:the person][D1>1: the people] who helped [YOUc] during [THOSE-2-WEEKS] with [D8=1:[AGE]>=5, NO COMA:taking medications, including reminders to take it][KID OR COMA: medications]] [or] [D9=1:other routine health care at home], [D1=1:was this person][D1>1:were *all* of these people] chosen by [YOUc] and paid with the [MONTHLY]?

PROBE: Or did someone hire [this person / these people] on [YOURc] behalf?

PROBE: [The person who was / Any of the people who were] paid to help [YOUm].

PROBE: Did [YOUc] sign [D1=1:his/her] [D1>1:their] timesheets?

PROBE: Be sure to include family members and friends if paid with the [MONTHLY].

PROBE: Do not include anyone sent by a home care agency or other company.

[IF D9=1:PROBE: Routine health care at home like checking blood pressure or doing exercises.]

PROBE: The [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

<1> YES [goto tD13]

<0> NO

<t> DON'T KNOW/REFUSED

==>

>D12< Was [D1=1:the person] [D1>1:there at least one person] who helped [YOUc] during [THOSE-2-WEEKS] with [D8=1:[AGE]>=5, NO COMA: taking medications, including reminders to take it][KID OR COMA:medications]] [or] [D9=1:other routine health care at home] [D1>1:who was] sent by a home care agency or other company, and paid using the [MONTHLY]?

PROBE: Someone working for an agency rather than chosen and hired directly by [YOUc] or by someone on [YOUR] behalf.

PROBE: Do not include someone for whom [YOUc] sign[s] a timesheet.

PROBE: Only include if [YOUc] used the [MONTHLY] to pay the agency.

[D9=1:PROBE: Routine health care at home like checking blood pressure or doing exercises.]

PROBE: The [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

<1> YES

<0> NO, NOT PAID USING [MONTHLY]

<r> DON'T KNOW/REFUSED

==>

>tD13< CATI CHECK: IS CLIENT COMATOSE?

<1> YES [goto D17]

<0> NO

==>

>D14< During [THOSE-2-WEEKS], did [D1=1: the person who was] [D1=2: either of the people who were][D1>2: any of the people who were] paid help [YOUc] with *eating*? Please include helping by staying nearby just in case [YOU] needed help.

PROBE: For example, opening cartons, cutting your/his/her food, or helping you/him/her use a spoon.

PROBE: Please don't count help preparing meals.

PROBE: [D1=1: The person who was] [D1=2: Either of the people who were] [D1>2: Any of the people who were] paid to help [YOUm].

PROBE: During the [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

PROBE: Or did he/she/they make sure that [YOUc] ate?

<1> YES

<0> NO/NO HELP NEEDED

<7> DID NOT EAT AT ALL

<r> DON'T KNOW/REFUSED

==>

>D15< REPEAT PERIOD IF NECESSARY. Did [that person / either of them / any of them] help [YOUc] with *getting in or out of bed*? Please include helping by staying nearby just in case [YOUc] needed help.

PROBE: [D1=1: The person who was] [D1=2: Either of the people who were] [D1>2: Any of the people who were] paid to help [YOUm]. This could be someone employed by an agency or someone [YOU] chose.

PROBE: During the [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

PROBE: Or did he/she/they make sure that [YOUc] got out of bed?

<1> YES

<0> NO/NO HELP NEEDED

<7> DID NOT GET OUT OF BED

<r> DON'T KNOW/REFUSEF

==>

>D16< REPEAT PERIOD IF NECESSARY. And, with *getting to or using the toilet*? Please include staying nearby just in case [YOU] needed help.

PROBE: Did [that person / either of them / any of them] help [YOUc] with this or stay nearby just in case [YOUc] needed help?

PROBE: Please include bowel care.

PROBE: Please include arranging clothes, transferring on and off the toilet or commode, and cleaning [YOURSELF].

PROBE: [D1=1: The person who was] [D1=2: Either of the people who were] [D1>2: Any of the people who were] paid to help [YOUm].

PROBE: During the [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

<1> YES

<0> NO/NO HELP NEEDED

<7> DID NOT USE TOILET OR COMMUNE

<r> DON'T KNOW/REFUSED

⇒

>D17< REPEAT PERIOD IF NECESSARY. Did [that person / either of them / any of them] help [YOUc] with *bathing or showering*? Please include bed baths, bathing at a sink or basin, and helping by staying nearby just in case [YOU] needed help.

PROBE: [D1=1: The person who was] [D1=2: Either of the people who were]
[D1>2: Any of the people who were] paid to help [YOUm].

PROBE: During the [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks":
That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

PROBE: Or did he/she/they make sure that [YOUc] bathed?

<1> YES

<0> NO/NO HELP NEEDED

<7> DID NOT BATHE/SHOWER AT ALL

<r> DON'T KNOW/REFUSED

⇒

>D18< REPEAT PERIOD IF NECESSARY. And, help with other personal care?

PROBE: Such as help with dressing (or getting around inside).

PROGRAMMER: EXCLUDE "or getting around inside" IF COMATOSE.

PROBE: Please include helping by staying nearby just in case [YOU] needed help.

PROBE: Did [that person / either of them / any of them] help [YOUc] with this or stay nearby just in case [YOUc] needed help?

PROBE: [D1=1: The person who was] [D1=2: Either of the people who were]
[D1>2: Any of the people who were] paid to help [YOUm].

PROBE: During the [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks":
That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

<1> YES

<0> NO/NO HELP NEEDED

<r> DON'T KNOW/REFUSED

⇒

>D20< Now, I have a few questions about help [YOUc] may have had doing things around the house or community during [THOSE-2-WEEKS].

Did [D1=1:the person who was] [D1=2:either of the people who were] [D1>2: any of the people who were] paid, help [YOUm] by *preparing meals* [AGE<18: for [YOUm]] in [YOURc] home or *bringing meals* [AGE>=18:to [YOUm]] [AGE<18: that [YOU] ate]?

PROBE: Please don't count arranging for meals from Meals-on-Wheels or a similar program.

PROBE: Include picking up take-out meals from a restaurant or meals prepared at someone else's home.

PROBE: Including help from a family member, friend or volunteer from a church or service organization if they sometimes help at [YOURc] home or at someone else's home.

PROBE: During the [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

<1>YES

<0> NO/NO HELP NEEDED

<r> DON'T KNOW/REFUSED

==>

>D21< REPEAT PERIOD IF NECESSARY. And, with [AGE>=18: *light housework or laundry*, like washing dishes or clothes] [AGE<18: washing [YOURc] dishes or [YOUR] clothes]?

PROBE: Did [D1=1:that person] [D1=2:either of them] [D1>2: any of them] help [YOUm] with this?

PROBE: [D1=1: The person who was] [D1=2: Either of the people who were] [D1>2: Any of the people who were] paid to help [YOUm].

PROBE: During the [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

<1> YES

<0> NO/NO HELP NEEDED

<r> DON'T KNOW/REFUSED

==>

>D22< REPEAT PERIOD IF NECESSARY. With *shopping* [AGE<18: for [YOUc]]?

PROBE: For example, getting groceries or buying things at a drug store.

PROBE: Other than transportation to the store.

PROBE: Did [D1=1:that person] [D1=2:either of them] [D1>2: any of them] help [YOUm] with this?

PROBE: [D1=1: The person who was] [D1=2: Either of the people who were] [D1>2: Any of the people who were] paid to help [YOUm].

PROBE: During the [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

<1> YES

<0> NO/NO HELP NEEDED

<r> DON'T KNOW/REFUSED

==>

>D23< During [THOSE-2-WEEKS], did [D1=1:the person who was] [D1=2: either of the people who were] [D1>2: any of the people who were] paid, drive [YOUc] somewhere or help [YOUm] ride public transportation, such as a bus, taxi, or special van?

PROBE: Include help riding ambulettes and ambulances.

PROBE: Do not include people who only arranged for the transportation or drivers.

PROBE: Include people who helped by accompanying [YOUc] or helping [YOUm] on or off, other than the driver.

PROBE: For example, to go to the doctor or shopping.

[PROBE IF CHILD: Please include help from any parent.]

[PROBE: Please include help riding any type of school bus.]

[PROBE IF CHILD: Did someone who was paid help with taking [CLIENT] places?]

PROBE: The [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

<1> YES

<0> NO/NO HELP NEEDED

<r> DON'T KNOW/REFUSED

==>

>D24< REPEAT PERIOD IF NECESSARY. And, finally, help with doing other things around the house or community [AGE<18: for [YOUc]]?

[AGE GE 18: PROBE:Such as yardwork and heavy housework like scrubbing floors.]

[IF AGE<18: PROBE: Such as help with homework.]

PROBE: Did [D1=1:that person] [D1=2:either of them] [D1>2: any of them] help [YOUm] with this?

PROBE: [D1=1: The person who was] [D1=2: Either of the people who were] [D1>2: Any of the people who were] paid to help [YOUm].

PROBE: Including help from a family member, friend or volunteer from a church or service organization if they sometimes help at [YOURc] home or at someone else's home.

PROBE: During the [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

<1> YES

<0> NO/NO HELP NEEDED

<r> DON'T KNOW/REFUSED

==>

>D25< Now, please think about the different *times of day* that [D1=1:the person who was] [D1=2: either of the people who were][D1>2:any of the people who were] paid, helped [YOUc] during the [2-WEEK-PERIOD].

Did [D1=1:that person][D1=2:either of them][D1>2: any of them] help [YOUm] *before 8 o'clock on weekday mornings?*

PROBE: On any weekday morning before 8 o'clock during [THOSE-2-WEEKS].

PROBE: During the [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

<1> YES

<0> NO

<r> DON'T KNOW/REFUSED

⇒

>D26< REPEAT PERIOD IF NECESSARY. Did [that person / either of them / any of them] help *after 6 o'clock on weekday evenings*?

PROBE: On any weekday evening after 6 o'clock during [THOSE-2-WEEKS].

PROBE: During the [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

PROBE: [D1=1:The person who was][D1=2: Either of the people who were] [D1>2: Any of the people who were] paid to help [YOUm].

<1> YES

<0> NO

<r> DON'T KNOW/REFUSED

⇒

>D27< REPEAT PERIOD IF NECESSARY: What about *weekends*?

PROBE: Did [that person / either of them / any of them] help on the weekends?

PROBE: Any time of day on any weekend during [THOSE-2-WEEKS].

PROBE: During the [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

PROBE: [D1=1:The person who was][D1=2: Either of the people who were] [D1>2: Any of the people who were] paid to help [YOUm].

<1> YES

<0> NO

<r> DON'T KNOW/REFUSED

⇒

>tD27a< CATI CHECK: DOES CLIENT LIVE ALONE (B5=1)?

<1> YES [goto tD47]

<0> NO

==>

>D28< *During [THOSE-2-WEEKS], did [D1=1:the person who was][D1=2:either of the people who were][D1>2: any of the people who were] paid to help, live in the same household as [YOUc]? Please include anyone staying in [YOURc] household at least three nights during that time.*

INTERVIEWER: CONFIRM AND CODE IF KNOWN

PROBE: Do not include people who come and stay overnight just to help [YOUc], but who live elsewhere.

PROBE: Please include anyone who was staying there temporarily.

PROBE: The [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

PROBE: [D1=1:The person who was][D1=2: Either of the people who were] [D1>2: Any of the people who were] paid to help [YOUm].

<1> YES

<0> NO [goto tD47]

<r> DON'T KNOW/REFUSED [goto tD47]

==>

>tD29< CATI CHECK: IS THERE MORE THAN ONE PAID CAREGIVER (D1>1)?

<1> YES

<0> NO [goto D32]

==>

>D30< How *many* of them lived in the same household as [YOUc] during [THOSE-2-WEEKS]?

INTERVIEWER: CONFIRM AND CODE IF KNOWN

PROBE: The same household as [YOUc].

PROBE: The people who were paid to help [YOUm].

PROBE: The [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

<1-15> PAID LIVE-IN HELPERS

<r> DON'T KNOW/REFUSED [goto tD68]

==>

>tD31< CATI CHECK: NUMBER OF LIVE-IN PAID CAREGIVERS:

<1> ONE (D30=1)

<2> TWO (D30=2) [goto D34]

<3> MORE THAN TWO (D30>2) [goto D33]

==>

>D32< You told me that person's *first* name was (READ NAMES FROM C1A LIST). Is that correct?

PROBE: The person who lived in the same household as [YOUc] during [THOSE-2-WEEKS] and who was paid.

RECORD NAME MENTIONED: _____
[STORE IN PLNAM1]

==> [goto tD35]

>D33< Please think about *all* the people who were paid to help, lived in the same household as [YOUc], and helped [YOUm] with [IF D14, D15, D16, D17, or D18=1:personal care,] [OR] [IF D20, D21, D22=1, or D24=1:things around the house and community,] [OR] [IF D23=1:transportation,] [OR] [D8 or D9=1:routine health care at home] during [THOSE-2-WEEKS].

Which *two* of them helped [YOUm] the *most* with things like that during [THOSE-2-WEEKS]? May I have their *first* names please? That will make it easier to ask the next questions.

PROBE: I have recorded that people who were paid, helped [YOUc] with [ACTIVITIES FROM ASSISTANCE BATTERY: SEE D33]. Which *two* people, who were paid and lived in the same household as [YOUm], helped the *most* with those things?

PROBE: The [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

RECORD FIRST NAME MENTIONED: _____
[STORE IN PLNAM1]

RECORD SECOND NAME MENTIONED: _____
[STORE IN PLNAM2]

==> [goto tD35]

>D34< You told me that the *first* names of these two people were (READ NAMES FROM C1A LIST). Is that correct?

PROBE: The two people who lived in the same household as [YOUc] and who were paid to help [YOUm].

PROBE: The [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

RECORD FIRST NAME MENTIONED: _____
[STORE IN PLNAM1]

RECORD SECOND NAME MENTIONED: _____
[STORE IN PLNAM2]

==>

>tD35< CATI CHECK: IS THE RESPONDENT A PROXY?

<1> YES

<0> NO [goto D37]

==>

>D36< Are you [tD29=0 or D30=1:the person who was] [D30>1:one of the people who were] paid to help, lived in the same household as [YOUc], and helped [YOUm] with [IF D14, D15, D16, D17, or D18=1:personal care,] [OR] [IF D20, D21, D22=1, or D24=1:things around the house and community,] [OR] [IF D23=1:transportation,] [OR] [D8 or D9=1:routine health care at home] during [THOSE-2-WEEKS].

INTERVIEWER: CODE IF KNOWN.

<1> YES

<0> NO

<r> DON'T KNOW/REFUSED

==>

>D37< Now I have some questions about the hours of help [YOUc] received from [PLNAM1] during [THOSE-2-WEEKS].

Doing things around the house and community--such as preparing meals, housework, laundry, shopping [IF AGE>=18:, and yardwork]--often benefits *more than one* person in a household.

About how many *hours* would you say [PLNAM1] spent during [THOSE-2-WEEKS] doing [IF D20, D21, or D22=1:(HOUSEHOLD/COMMUNITY ACTIVITIES FROM BATTERY) or other] things around the house or community to meet the needs of people in the household?

PROBE: Whether [PLNAM1] is paid for that or not.

PROBE: Things like preparing meals, housework, laundry, shopping [AGE>=18:, and yardwork].

PROBE: The [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

PROBE: I have recorded that [D1=1:someone who was] [D1>1: people who were] paid helped with [HOUSEHOLD/COMMUNITY ACTIVITIES FROM ASSISTANCE BATTERY]. Did [PLNAM1] help with any of that?

PROBE: Your best estimate would be fine.

<0> HOURS [goto D39]

<1-168> HOURS [goto D38]

<d> DON'T KNOW [goto D37a]

<r> REFUSED [goto D39]

==>

>D37a< Perhaps you could tell me a range? Was it...

<1> 1-4 hours

<2> 5-10 hours

<3> 11-20 hours

<4> 21-40 hours

<r> DON'T KNOW/REFUSED

<5> 41-60 hours

<6> 61-80 hours

<7> 81-120 hours

<8> 121 OR MORE

PROBE: Your best estimate is fine.

==>

>D38< Sometimes doing things around the house or community benefits one person *more* than others. For example, one person may have *more* soiled sheets to be laundered or need to follow a special diet that takes more time to prepare.

Would you say that the time that [PLNAM1] spent doing those things like that benefitted [YOUc] *more* than the other people in the household, *less* than other people, or about the same?

PROBE IF RESPONDENT IS ONLY HOUSEHOLD MEMBER OTHER THAN CLIENT: More, less, or about the same as it benefits you.

PROBE: During [THOSE-2-WEEKS].

<1> MORE

<2> LESS

<3> ABOUT THE SAME

<r> DON'T KNOW/REFUSED

==>

>D39< About how many *hours* would you say [PLNAM1] spent during [THOSE-2-WEEKS] doing things *just* for [YOUc], such as helping with [YOUR] [IF D14, D15, D16, D17, D18:personal care,][OR] [IF D8 OR D9=1:routine health care at home,] [OR] [IF D23=1: transportation]?

PROBE: The [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

PROBE: Your best estimate would be fine.

PROBE: I have recorded that [D1=1:someone who was] [D1>1: people who were] paid helped with [PERSONAL CARE, ROUTINE HEALTH AND TRANSPORTATION FROM ASSISTANCE BATTERY: SEE D39]. Did [PLNAM1] help with any of that?

<0-168> HOURS [goto tD40]

<d> DON'T KNOW [goto D39a]

<r> REFUSED [goto tD40]

==>

>D39a< Perhaps you could tell me a range? Was it...

- | | |
|------------------------|------------------|
| <1> 1-4 hours | <5> 41-60 hours |
| <2> 5-10 hours | <6> 61-80 hours |
| <3> 11-20 hours | <7> 81-120 hours |
| <4> 21-40 hours | <8> 121 or more |
| <r> DON'T KNOW/REFUSED | |

PROBE: Your best estimate is fine.

==>

>tD40< CATI CHECK: IS CLIENT IN TREATMENT GROUP?

- <1> YES
- <0> NO [goto tD42]

==>

>D41< For how many hours will [PLNAM1] be paid for caring for [YOUc] during [THOSE-2-WEEKS]? Please include any hours during that period for which he/she has already been paid.

PROBE: The [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

- <0-160> PAID HOURS [goto tD42]
- <997> NOT PAID BY HOUR [goto tD42]
- <d> DON'T KNOW [goto D41a]
- <r> REFUSED [goto tD42]

==>

>D41a< During [THOSE 2-WEEKS], did [PLNAM1] spend time helping [YOUc] for which he/she was not, or will not, be paid?

- <1> YES
- <0> NO
- <d> DON'T KNOW
- <r> REFUSED

==>

>tD42< CATI CHECK: IS THERE A SECOND PAID LIVE-IN CAREGIVER (D30>1)?

<1> YES

<0> NO [goto tD47]

==>

>D43< Now I would like to talk about the hours of help [YOUc] received from [PLNAM2] during [THOSE-2-WEEKS].

About how many *hours* would you say [PLNAM2] spent during [THOSE-2-WEEKS] doing [IF D20, D21, or D22=1:(HOUSEHOLD/COMMUNITY ACTIVITIES FROM BATTERY) or other] things around the house or community to meet the needs of people in the household?

PROBE: Whether [PLNAM2] is paid for that or not.

PROBE: Things like preparing meals, housework, laundry, shopping [AGE>=18:, and yardwork].

PROBE: The [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

PROBE: Your best estimate would be fine.

<0-168> HOURS [goto D44]

<d> DON'T KNOW [goto D43a]

<r> REFUSED [goto D44]

==>

>D43a< Perhaps you could tell me a range? Was it...

<1> 1-4 hours

<2> 5-10 hours

<3> 11-20 hours

<4> 21-40 hours

<r> DON'T KNOW/REFUSED

<5> 41-60 hours

<6> 61-80 hours

<7> 81-120 hours

<8> 121 or more?

PROBE: Your best estimate is fine.

==>

>D44< About how many *hours* would you say [PLNAM2] spent during [THOSE-2-WEEKS] doing things *just* for [YOUc], such as helping with [YOUR] [IF D14, D15, D16, D17, D18:personal care,][OR] [IF D8 OR D9=1:routine health care at home,] [OR] [IF D23=1: transportation]?

PROBE: The [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

PROBE: Your best estimate would be fine.

PROBE: I have recorded that [D1=1:someone who was] [D1>1: people who were] paid helped with [PERSONAL CARE, ROUTINE HEALTH AND TRANSPORTATION FROM ASSISTANCE BATTERY: SEE D39]. Did [PLNAM1] help with any of that?

<0-168> HOURS [goto tD45]

<d> DON'T KNOW [goto D44a]

<r> REFUSED [goto tD45]

==>

>D44a< Perhaps you could tell me a range? Was it...

<1> 1-4 hours

<5> 41-60 hours

<2> 5-10 hours

<6> 61-80 hours

<3> 11-20 hours

<7> 81-120 hours

<4> 21-40 hours

<8> 121 or more?

<r> DON'T KNOW/REFUSED

PROBE: Your best estimate is fine.

==>

>tD45< CATI CHECK: IS CLIENT IN TREATMENT GROUP?

<1> YES

<0> NO [goto tD47]

==>

>D46< For how many hours will [PLNAM2] be *paid* for caring for [YOUc] during [THOSE-2-WEEKS]? Please include any hours during that period for which he/she has already been paid.

PROBE: The [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

<0-160> PAID HOURS [goto tD47]
<997> NOT PAID BY HOUR [goto tD47]
<d> DON'T KNOW [goto D46a]
<r> REFUSED [goto tD47]

==>

>D46a< During [THOSE 2-WEEKS], did [PLNAM1] spend time helping [YOUc] for which he/she was not, or will not, be paid?

<1> YES
<0> NO
<d> DON'T KNOW
<r> REFUSED

==>

>tD47< CATI CHECK: HOW MANY VISITING PAID CAREGIVERS WERE THERE?
TOTAL PAID CAREGIVERS=D1.
PAID LIVE-IN CAREGIVERS=D30 OR 1 (IF tD29=0).
PAID VISITING CAREGIVERS=
TOTAL PAID CAREGIVERS MINUS PAID LIVE-IN CAREGIVERS.

<0> ZERO [goto tD68]
<1> ONE
<2> TWO [goto D49]
<3> THREE [goto D50]
<4> MORE THAN THREE [goto D51]

==>

>D48< You told me that the person who helped [YOUc] during [THOSE-2-WEEKS], who was paid, and who did *not* live in the same household as [YOUm] was (READ NAME FROM C1A LIST). Is that correct?

PROBE: The [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

RECORD NAME: _____
[STORE IN PVNAM1]

==> [goto tD52]

>D49< You told me that the two people who helped [YOUc] during [THOSE-2-WEEKS], who were paid, and who did *not* live in the same household as [YOUm] were (READ NAMES FROM C1A LIST). Is that correct?

PROBE: The [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

RECORD FIRST NAME: _____
[STORE IN PVNAM1]

RECORD SECOND NAME: _____
[STORE IN PVNAM2]

==> [goto tD52]

>D50< You told me that the three people who helped [YOUc] during [THOSE-2-WEEKS], who were paid, and who did *not* live in the same household as [YOUm] were (READ NAMES FROM C1A LIST). Is that correct?

PROBE: The [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

RECORD FIRST NAME: _____
[STORE IN PVNAM1]

RECORD SECOND NAME: _____
[STORE IN PVNAM2]

RECORD THIRD NAME: _____
[STORE IN PVNAM3]

==> [goto tD52]

>D51< Please think about *all* the people who were paid, did *not* live in the same household as [YOUc], and helped [YOUm] with [IF D14, D15, D16, D17, or D18=1:personal care,] [OR] [IF D20, D21, D22=1, or D24=1:things around the house and community,] [OR] [IF D23=1:transportation,] [OR] [D8 or D9=1:routine health care at home] during [THOSE-2-WEEKS].

May I have the *first* names of the *three* of them who helped [YOUm] the *most* during [THOSE-2-WEEKS]? That will make it easier to ask the next questions.

PROBE: The [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

PROBE: I have recorded that people who were paid helped [YOUc] with [ACTIVITIES FROM ASSISTANCE BATTERY: SEE D33]. Which *three* people, who were paid and who did *not* live in the same household as [YOUm], helped the *most* with those things?

RECORD FIRST NAME: _____
[STORE IN PVNAM1]

RECORD SECOND NAME: _____
[STORE IN PVNAM2]

RECORD THIRD NAME: _____
[STORE IN PVNAM3]

==>

>tD52< CATI CHECK: IS THE RESPONDENT A PROXY OR DO WE ALREADY KNOW RESPONDENT IS A PAID WORKER?

<1> PROXY=X OR R AND D36 =0 AND D36 ON PATH OR PROXY=X OR R AND D36 OFF PATH

<0> NOT A PROXY OR D36 = 1 [goto D54]

==>

>D53< Are you [tD47=1:the person who was] [tD47>1:one of the people who were] paid to help, did not live in the same household as [YOUc], and helped [YOUm] with [IF D14, D15, D16, D17, or D18=1:personal care,] [OR] [IF D20, D21, D22=1, or D24=1:things around the house and community,] [OR] [IF D23=1:transportation,] [OR] [D8 or D9=1:routine health care at home] during [THOSE-2-WEEKS].

INTERVIEWER: CODE IF KNOWN.

<1> YES

<0> NO

<r> DON'T KNOW/REFUSED

==>

>D54< Now I have some questions about help [YOUc] received from [PVNAM1].

During [THOSE-2-WEEKS], *how many times* did [PVNAM1] come to help [YOUc]?

PROBE: Your best estimate would be fine.

PROBE: How many visits a day for how many days a week?

PROBE: Please don't count *purely* social visits.

<1-70> VISITS

<r> DON'T KNOW/REFUSED

==>

>tD54a< CATI CHECK: IS RESPONDENT A PAID WORKER?

<1> YES [goto D57]

<0> NO

==>

>D55< During [THOSE-2-WEEKS], did [PVNAM1] ever *not come* to help when he/she was scheduled to come?

PROBE: Sometimes people just have so much to do that they can't do everything they are supposed to.

PROBE: Even if he/she called ahead.

- <1> YES
- <0> NO [goto D57]
- <7> NOT SCHEDULED [goto D57]
- <d> DON'T KNOW [goto D57]
- <r> REFUSED [goto D57]

==>

>D56< How many times did he/she *not* come when scheduled during [THOSE-2-WEEKS]?

PROBE: Your best estimate is fine.

- <1-28> TIMES
- <d> DON'T KNOW
- <r> REFUSED

==>

>D57< During [THOSE-2-WEEKS], about how long did [PVNAM1] [D54>1:usually] spend helping [D54=1:the][D54>1:each] time he/she came?

PROBE: Your best estimate would be fine.

PROBE: Please include any time spent helping away from [YOURc] home such as shopping for [YOUR] groceries or preparing meals to bring [YOUm}.

INTERVIEWER: RECORD IN EITHER HOURS OR MINUTES.

PROBE: About how long did he/she [D54>1:usually] stay when he/she came to help?

- <0-23> HOURS [goto tD64]
- <0-59> MINUTES [goto tD64]
- <97> VARIES [goto D63]
- <d> DON'T KNOW
- <r> REFUSED [goto tD64]

==>

>D58< Perhaps you could tell me a range? During [THOSE-2-WEEKS], did [PVNAM1] [usually] spend less than *or* more than an hour helping?

PROBE: Did he/she [usually] help less than or more than an hour?

<1> LESS THAN AN HOUR

<2> AN HOUR [goto tD64]

<3> MORE THAN AN HOUR [goto D60]

<r> DON'T KNOW/REFUSED [goto tD64]

==>

>D59< Would you say [PVNAM1] [usually] helped:

PROBE: Did he/she [usually] help . . .

- <1> Less than 15 minutes,
- <2> At least 15 but less than 30 minutes,
- <3> At least 30 but less than 45 minutes, or
- <4> At least 45 minutes but less than an hour?
- <r> DON'T KNOW/REFUSED

==> [goto tD64]

>D60< Was it [usually] less or more than three hours?

PROBE: Did [PVNAM1] [usually] spend less or more than three hours helping
[D54=1:the][D54>1:each] time he/she came?

- <1> LESS THAN THREE HOURS
- <2> THREE HOURS [goto tD64]
- <3> MORE THAN THREE HOURS [goto D62]
- <r> DON'T KNOW/REFUSED [goto tD64]

==>

>D61< Would you say [PVNAM1] [usually] helped:

PROBE: Did he/she [usually] help . . .

- <1> Less than an hour and a half,
- <2> At least an hour and a half but less than two hours,
- <3> At least two hours but less than two and a half hours, or
- <4> More than two and a half hours?
- <r> DON'T KNOW/REFUSED

==> [goto tD64]

>D62< Would you say [PVNAM1] [usually] helped:

- <1> Less than three and a half hours,
- <2> At least three and a half hours but less than four hours, or
- <3> Four hours or more?
- <r> DON'T KNOW/REFUSED

==> [goto tD64]

>D63< About how many hours did [PVNAM1] help in all during [THOSE-2-WEEKS]?

PROBE: Your best estimate would be fine.

<1-200> HOURS

<d> DON'T KNOW

<r> REFUSED

==>

>D64< CATI CHECK: IS CLIENT IN TREATMENT GROUP?

<1> YES

<0> NO [goto tD66]

==>

>D65< For how many hours will [PVNAM1] be *paid* for helping [YOUc] during [THOSE-2-WEEKS]? Please include any hours during that period for which he/she has already been paid.

PROBE: The [2-WEEK-PERIOD]. [IF 2-WEEK-PERIOD= "last two weeks": That's since [DAY OF WEEK], [DATE TWO WEEKS AGO].]

<0-160> PAID HOURS [goto tD66]

<997> NOT PAID BY HOUR [goto tD66]

<d> DON'T KNOW [goto D65a]

<r> REFUSED [goto tD66]

==>

>D65a< During [THOSE 2-WEEKS], did [PLNAM1] spend time helping [YOUc] for which he/she was not, or will not, be paid?

<1> YES

<0> NO

<d> DON'T KNOW

<r> REFUSED

==>

>tD66< CATI CHECK: IS THERE A SECOND PAID VISITING CAREGIVER (SEE tD47)?

<1> YES [repeat D54 through tD66 for PVNAM2, then goto tD67]
<0> NO [goto tD68]

==>

>tD67< CATI CHECK: IS THERE A THIRD PAID VISITING CAREGIVER (SEE tD47)?

<1> YES [repeat D54 through tD66 for PVNAM3, then goto tD68]
<0> NO [goto tD68]

==>

>tD68< CATI CHECK (FOR PAID WORKER SURVEY):

IF TREATMENT GROUP:
AND NOT DEAD,
AND NOT DISENROLLED,
AND GOT CASH WITHIN LAST 2 MONTHS [goto D69]
OTHERWISE [goto tE1]

IF CONTROL GROUP:
AND NOT DEAD,
AND NOT IN HOSPITAL/NURSING HOME (i1 OR i1c OR i2a NE 8,9) [goto D69]

OTHERWISE [goto tE1]

==>

>D69< With [YOURc] permission, we would like to interview the person who is *paid* [TREATMENTS: from PROG] and who [CONTROLS: is now helping [YOUc] the most] [TREATMENTS: helped [YOUc] the most during [THOSE-2-WEEKS] with personal care, things around the house and community, and routine health care at home.

The interview would be conducted by telephone *outside* of working hours and would take about 25 to 30 minutes. May I have the full name of that person?

[IF D1=1: PROBE: Would that be [PLNAM1][PVNAM1]?)

[OW: PROBE: I have recorded that [PLNAM1] [and] [PLNAM2] [and] [PVNAM1] [and] [PVNAM2] [and] [PVNAM3] are the people who were paid and who helped [YOUc] during [THOSE-2-WEEKS]. Which of these people [CONTROLS: is now helping [YOUc] the most?] [TREATMENTS: helped [YOUc] the most during [THOSE-2-WEEKS]?)

PROBE: As [YOUc] may remember, [YOU] signed a consent form in EMONTH stating that we may interview [YOUR] caregiver.

[CONTROLS: PROBE: By "now" we mean the last two weeks.]

- <1> YES / RECORD FULL NAME [STORE IN PPCG]
- <0> NO [TREATMENT: DIRECTLY HIRED] PAID [CONTROL: AGENCY] WORKER [CONTROLS: NOW] [CONTROLS: goto D80] [TREATMENTS: goto tE1]
- <r> NO, REFUSED / DO NOT CONTACT CAREGIVER [goto tE1]

==>[TREATMENTS: goto D69a]
[CONTROLS: goto D75]

>D69a< Is [PPCG]/this person related to [YOUc]?

INTERVIEWER: CODE IF KNOWN

PROBE: Related by blood, marriage, or adoption.

- <1> YES [goto D70]
- <0> NO
- <r> DON'T KNOW/REFUSED [goto tE1]

==>

>D69b< Was [PPCG]/this person [YOURc] friend or neighbor before he/she started getting paid with the [MONTHLY]?

PROBE: Was this person a friend before he/she started getting paid by anyone to help?

- <1> YES
- <0> NO
- <r> DON'T KNOW/REFUSED [goto tE1]

==>

>D70< May I please have a telephone number at which we could reach him/her *outside* of working hours?

- <1> YES, ENTER PHONE NUMBER
- <2> CAREGIVER HAS NO PHONE
- <d> DON'T KNOW PHONE NUMBER OF CAREGIVER
- <r> REFUSED TO GIVE CAREGIVER PHONE NUMBER

==>

>D70@PHN< INTERVIEWER: RECORD CAREGIVER TELEPHONE NUMBER.

() _____ - _____

==> [CONTINUE WITH D72]

>D72< May I please have a mailing address for [fill PPCG]?

- <1> YES
- <d> DON'T KNOW ADDRESS OF CAREGIVER [goto tD74]
- <r> REFUSED TO GIVE CAREGIVER ADDRESS [goto tD74]

==>

>D73< INTERVIEWER: RECORD CAREGIVER ADDRESS.

street1 _____
street2 _____
city, state, zip _____

==>

>tD74< CATI CHECK: ARE WE MISSING PHONE NUMBER OR ADDRESS FOR PPCG (D70 ne 1 AND [D72=d. r OR D73=d)?

<1> YES [goto D74]

<0> NO [goto tE1]

>D74< Would it be okay if we tried to reach [PPCG] by p hone at your house or sent a letter to him/her at [YOURc] address?

<1> YES [CONFIRM PHONE NUMBER AND ADDRESS, PUT IN "NEEDS LETTER" FOLDER AS NEEDED]

<1> NO/DON'T KNOW / REFUSED

==>[goto tE1]

>D75< I'd like to set up an appointment with [PPCG] to conduct the interview with him/her **outside** of working hours. By any chance, is he/she there now?
IF YES: Can I speak to him/her for **just a moment**, please?

<1> YES, PAID CAREGIVER COMES TO PHONE

<0> NO [goto D77]

<2> CURRENT WORKER NEVER COMING BACK [goto tE1]

>D76< My name is _____ from Mathematica Policy Research. [CLIENT] has been participating in a study about care for [CLIENT >65: older people] [CLIENT 18-64: people with disabilities] [CLIENT <18: people of all ages with disabilities]. As part of this study, we would like to know what it is like to give care. We'd like to arrange to ask you some questions about that outside of your working hours. What day and time would be convenient?

PROBE: Unfortunately, we cannot do the interview today, because it will take us a day to set it up. (How about tomorrow?)

PROBE: My supervisor won't allow me to conduct interviews with anyone during (his/her) work hours.

PROBE: My company has assured home care agencies in [fill STAT] that we would not conduct interviews with their staff during work hours.

PROBE: [CLIENT] signed a consent form in EMONTH stating that we may interview (his/her) caregiver.

INTERVIEWER: ASK FOR PHONE NUMBER, SET UP APPT. TIME WITH CAREGIVER FOR ANY TIME AFTER TODAY. MARK APPT. AND PHONE NUMBER ON ATTACHED CAREGIVER CONTACT SHEET.

Thank you. Can you please put [RESPONDENT] back on the phone now?

<1> PHONE NUMBER/APPT. TIME MARKED ON CONTACT SHEET
<r> NO/REFUSED

====> [goto tE1]

>D77< If it's okay with you, I'd like to call back when [fill PPCG] is there to speak to him/her for just a moment. When would I be able to reach him/her here?

PROBE: Just to set up an appointment to do the interview at a later time.

<1> INDICATED DATE AND TIME (MARK APPT. ON CLIENT'S CONTACT SHEET) [goto tE1]
<2> CURRENT WORKER NEVER COMING BACK [goto tE1]
<d> DON'T KNOW (MARK AS SUCH ON CLIENT'S CONTACT SHEET) [goto tE1]
<r> NOT OKAY/REFUSED

====>

>D78< Would it be okay if we sent a letter to [fill PPCG] at [YOURc] address?

<1> YES (CONFIRM ADDRESS, PUT IN "NEEDS LETTER" FOLDER) [goto tE1]

<2> CURRENT WORKER NEVER COMING BACK [goto tE1]

<r> NO/REFUSED

==>

>D79< I would like to leave a toll-free telephone number for [fill PPCG] to call us back at his/her convenience. Please ask him/her to call Chris Carter at 1-877-840-4741. This is a toll-free number.

<1> LEFT NUMBER

<0> DID NOT LEAVE NUMBER/REFUSED

==> [goto tE1]

>D80< Although no one who is paid is helping [YOUc] now, [HAVE] [YOU] had help like that from someone who was paid at *any* time during the last nine months?

PROBE: That's since [EMONTH] of [EYEAR].

PROBE: For example, someone paid by the Medicaid program.

PROBE: Usually, paid helpers come to the home to help, but sometimes they live in.

PROBE: Help with personal care, things around the house or community, or routine health care.

<1> YES [goto D82]

<0> NO

<2> HAS PAID HELP NOW, JUST NOT THRU AGENCY [goto tE1]

<d> DON'T KNOW

<r> REFUSED [goto tE1]

>D81< Sometimes people *try* to get help with personal care, things around the house or community, or routine health care, but none is available. During the last nine months, did [YOUc] *try* to get help like that from someone who was paid?

PROBE: That's since [EMONTH] of [EYEAR].

- <1> YES
- <0> NO
- <d> DON'T KNOW
- <r> REFUSED

==> [goto tE1]

>D82< Why [DO] [YOUc] no longer have help like that?

PROBE: But you did have help like that in the last nine months.

PROBE: From someone paid to help you.

PROBE: Why didn't [YOU] get someone else who was paid to help?

PROBE: What happened after the worker left?

PROBE: IF APPLICABLE: What happened after the agency was told the service was unsatisfactory?

INTERVIEWER: CODE ALL THAT APPLY

- <1> NOT AT HOME ALL OR MOST OF TIME, RECENTLY
- <2> AGENCY WAS UNABLE/UNWILLING TO PROVIDE ANOTHER WORKER WHEN CONSUMER REQUESTED
- <3> CONSUMER NO LONGER WANTED/ DISCONTINUED SERVICE
- <4> CONSUMER HEALTH IMPROVED, NO LONGER ELIGIBLE
- <5> NO LONGER ELIGIBLE FOR MEDICAID
- <6> OTHER (SPECIFY) _____
- <n> NO FURTHER RESPONSES
- <d> DON'T KNOW
- <r> REFUSED

E. SATISFACTION WITH CARE AND UNMET NEED

>tE1< CATI CHECK: IS THE CURRENT RESPONDENT A PROXY?

<1> RESPONDENT IS CLIENT OR PARENT [goto E10]

<2> RESPONDENT IS PROXY [goto E6]

==>

>E6< INTERVIEWER CHECK: IS RESPONDENT A PAID CAREGIVER?

CODE IF KNOWN

ASK IF NECESSARY: [AREd] you someone who [ISd] paid to help [YOUc]?

<1> YES [goto tE29]

<0> NO

<t> DON'T KNOW/REFUSED [goto tE29]

==>

>tE7< CATI CHECK: IS CLIENT COMATOSE AND 18 OR OVER?

<1> CLIENT IS COMATOSE ADULT [goto E36]

<2> RESPONDENT IS CLIENT OR PARENT (FOR CHILD CLIENT) [goto E10]

<3> PROXY RESPONDENT / NON-PARENT PROXY RESPONDENT

==>

>E9< [CLIENT>=18:]
The next questions are about satisfaction with the help [YOU] has received. Some of the questions coming up are about people who [AREd] paid to help. Would you be able to tell us how [YOUc] [FEELd] about that?

[CLIENT<18:]
The next questions are about satisfaction with the help [YOU] has received. Some of the questions coming up are about people who [AREd] paid to help. Would you be able to tell us how [YOURc] parents [FEELd] about that?

PROBE IF RESPONDENT HESITANT: How about trying a few questions to see if you are comfortable answering them?

PROBE: We will, of course, treat the information as confidential, and the questions are worded so that you need only answer with a "yes" or "no."

<1> YES
<0> NO [goto tE29]
<7> CLIENT MENTALLY UNABLE TO FORM OPINION [goto tE29]
<d> DON'T KNOW [goto tE29]
<r> REFUSED [goto tE29]

==>

>E10< [IF E9 OFF-PATH: The next questions are about satisfaction with the help [YOUc] [HAS] received. Some of the questions coming up are about people who [AREd] paid to help.] We will, of course, treat the information as confidential, and the questions are worded so that you need only answer with a "yes" for satisfied, or "no" for dissatisfied. (However, people may be uncomfortable answering these questions if someone who is paid to help is standing nearby. If there are people who [HELPd] [YOUc] in the room with you, you may want to ask them to excuse you for a few minutes.)

==> CONTINUE WITH tE11

>tE11< CATI CHECK:

<1> IF CLIENT COMATOSE OR DECEASED [goto E14]
<0> OTHERWISE

==>

>E13< [CLIENT>=18:]
Overall, [ARE] [YOUc] satisfied or dissatisfied with the way [YOU] [ARE] spending [YOUR] life these days? Please answer with a "yes" for satisfied, or a "no" for dissatisfied.

[CLIENT<18, PROX=P:]
Overall, are you satisfied or dissatisfied with the way your child is spending [YOUR] life these days? Please answer with a "yes" for satisfied, or a "no" for dissatisfied.

[CLIENT<18, PROX=X:]
Overall, are [YOURc] parents satisfied or dissatisfied with the way their child is spending [YOUR] life these days? Please answer with a "yes" for satisfied, or a "no" for dissatisfied.

<1> YES (SATISFIED)
<0> NO (DISSATISFIED)

<d> DON'T KNOW [goto E14]
<r> REFUSED [goto E14]

==>

>E13a< Would that be very (dis)satisfied or somewhat (dis)satisfied?

<1> VERY
<2> SOMEWHAT

<d> DON'T KNOW
<r> REFUSED

==>

>E14< Now, please think about different types of services [YOUc] [RECEIVED], including people who [AREd] paid to help with [IF D OFF-PATH: personal care and things around the house or community and routine health care at home] [SEE D8--D24: [personal care,] [and] [things around the house or community,] [and] [routine health care at home,] [as well as] community services like [IF CLIENT>=18: adult] day care and transportation and various kinds of equipment.

[CLIENT>=18:]

Overall, [AREd] [YOUc] satisfied (or dissatisfied) with the arrangements for [YOUR] care? (Please answer with a "yes" for satisfied, or a "no" for dissatisfied.)

[CLIENT<18, PROX=P:]

Overall, [AREd] you satisfied (or dissatisfied) with the arrangements for your child's care? (Please answer with a "yes" for satisfied, or a "no" for dissatisfied.)

[CLIENT<18, PROX=X:]

Overall, [AREd] [YOURc] parents satisfied (or dissatisfied) with the arrangements for their child's care (considering both of their views)? (Please answer with a "yes" for satisfied, or a "no" for dissatisfied.)

[PROBE IF PROXY: In *your* judgment.]

[PROBE IF DECEASED: In the weeks before [YOU] passed away.]

PROBE: Personal care, such as eating and bathing; things around the house or community, such as preparing meals, laundry, shopping [ADULT:; housework, and yardwork][CHILD: for [YOUc]]; transportation; or routine health care at home, such as checking blood pressure, doing exercises, and [NON-COMATOSE ADULT: taking medications, including reminders to take it][COMA or CHILD: medications].

<1> YES/SATISFIED

<0> NO/DISSATISFIED

<7> PARENTS OF MINOR DIFFERED ON SATISFACTION [goto E16]

<n> PROXY CANNOT REPORT [CLIENT'S/PARENTS'] SATISFACTION [goto E29]

<d> DON'T KNOW [goto E16]

<r> REFUSED [goto E16]

==>

>E14a< Would that be very (dis)satisfied or somewhat (dis)satisfied?

<1> VERY

<2> SOMEWHAT

<d> DON'T KNOW

<r> REFUSED

==>

>E16< [CLIENT>=18:]
[AREd] [YOUc] satisfied (or dissatisfied) with [YOUR] ability to get help with transportation *when* [YOU] [NEEDd] it? (Please answer with a "yes" for satisfied, or a "no" for dissatisfied.)

[CLIENT<18, PROX=P:]

[AREd] you satisfied (or dissatisfied) with your ability to get help with transportation *when* your child [NEEDd] it? (Please answer with a "yes" for satisfied, or a "no" for dissatisfied.)

[CLIENT<18, PROX=X:]

[AREd] [YOURc] parents satisfied (or dissatisfied) with their ability to get help with transportation *when* their child [NEEDd] it (considering both of their views)? (Please answer with a "yes" for satisfied, or a "no" for dissatisfied.)

[PROBE IF DECEASED: In the weeks before [YOU] passed away.]

[PROBE IF PROXY: In your judgment.]

<1> YES/SATISFIED

<0> NO/DISSATISFIED

<7> PARENTS OF MINOR DIFFERED ON SATISFACTION [goto tE17]

<n> NO ATTEMPT TO GET HELP WITH TRANSPORTATION [goto tE17]

<d> DON'T KNOW [goto tE17]

<r> REFUSED [goto tE17]

==>

>E16a< Would that be very (dis)satisfied or somewhat (dis)satisfied?

<1> VERY

<2> SOMEWHAT

<d> DON'T KNOW

<r> REFUSED

==>

>tE17< CATI CHECK: DID THE CLIENT HAVE PAID CAREGIVERS IN
(LAST/THOSE) TWO WEEKS: D1>0?

<1> YES

<0> NO [goto tE30A]

==>

>E20< Now, please think about the [D1=1: person who [ISd]] [D1>1: people who [AREd]] paid to help [YOUc] with [SEE D8-D24:]{personal care,} [and] [things around the house or community] [and] [transportation,] [and] [routine health care at home] during the [2-WEEK PERIOD].

[CLIENT>=18:]
[AREd] [YOUc] satisfied (or dissatisfied) with the *times of day* that people who are paid [COMEd] to help [YOUm]? (Please answer with a "yes" for satisfied, or a "no" for dissatisfied.)

[CLIENT<18, PROX=P:]
[AREd] you satisfied (or dissatisfied) with the *times of day* that people who are paid [COMEd] to help your child? (Please answer with a "yes" for satisfied, or a "no" for dissatisfied.)

[CLIENT<18, PROX=X:]
[AREd] [YOURc] parents satisfied (or dissatisfied) with the *times of day* that people who are paid [COMEd] to help their child (considering both of their views)? (Please answer with a "yes" for satisfied, or a "no" for dissatisfied.)

PROBE: The [D1=1:person who [ISd]] [D1>1: people who [AREd]] paid to help [YOUc], during [THOSE-2-WEEKS].

[PROBE IF PROXY: In your judgment.]

<1> YES/SATISFIED

<0> NO/ DISSATISFIED

<7> PARENTS OF MINOR DIFFERED ON SATISFACTION [goto E20b]

<d> DON'T KNOW [goto E20b]

<r> REFUSED [goto E20b]

==>

>E20a< Would that be very (dis)satisfied or somewhat (dis)satisfied?

<1> VERY

<2> SOMEWHAT

<d> DON'T KNOW

<r> REFUSED

==>

>E20b< How difficult would it be/have been for [YOUc] to change the times when people who are paid, [HELpd] [YOUm]? Would [YOUc] say or have said...

<1> Very difficult,

<2> Somewhat difficult, or

<3> Not at all difficult?

<4> DON'T THINK CAN DO THAT

<7> PARENTS OF MINOR DIFFERED ON SATISFACTION

<d> DON'T KNOW

<r> REFUSED

PROBE: Either the day or the time of day.

PROBE: Either when [D1=1: he/she] [D1>1: they] [COMEd] to [YOUR] home or when [he/she] [they] [PERFORMd] a task when [he/she] [they] [AREd] there.

[PROBE IF PROXY: In your judgement.]

==>

>tE21< CATI CHECK: DID CLIENT HAVE PAID ASSISTANCE WITH PERSONAL CARE IN (LAST/THOSE) TWO WEEKS: D14, D15, D16, D17, OR D18=1?

<1> YES

<0> NO [goto tE23]

==>

>E22< [CLIENT>=18:]
[AREd] [YOUc] satisfied (or dissatisfied) with the way [D1=1:this person
[CARRIESd]] [D1>1: they [CARRYd]] out their duties in helping [YOUm] with
personal care? (Please answer with a "yes" for satisfied, or a "no" for "dissatisfied".)

[CLIENT<18, PROX=P:]
[AREd] you satisfied (or dissatisfied) with the way [D1=1:this person [CARRIESd]]
[D1>1: they [CARRYd]] out their duties in helping your child with personal care? (Please answer with a "yes" for satisfied, or a "no" for "dissatisfied".)

[CLIENT<18, PROX=X:]
[AREd] [YOURc] parents satisfied (or dissatisfied) with the way [D1=1:this person
[CARRIESd]] [D1>1: they [CARRYd]] out their duties in helping their child with
personal care (considering both their views)? (Please answer with a "yes" for
satisfied, or a "no" for "dissatisfied".)

[PROBE IF PROXY: In your judgment.]

PROBE: The [D1=1:person who [ISd]] [D1>1: people who [AREd]] paid to help
[YOUc], during [THOSE-2-WEEKS].

PROBE: I have recorded that people who [AREd] paid helped with personal care
activities.

<1> YES/SATISFIED

<0> NO/ DISSATISFIED

<7> PARENTS OF MINOR DIFFERED ON SATISFACTION [goto tE23]

<d> DON'T KNOW [goto tE23]

<r> REFUSED [goto tE23]

==>

>E22a< Would that be very (dis)satisfied or somewhat (dis)satisfied?

<1> VERY

<2> SOMEWHAT

<d> DON'T KNOW

<r> REFUSED

==>

>tE23< CATI CHECK: DID CLIENT HAVE PAID ASSISTANCE WITH HOUSEHOLD TASKS IN (LAST / THOSE) TWO WEEKS: D20, D21, D22, or D24=1?

<1> YES

<0> NO [goto tE25]

==>

>E24< [CLIENT>=18:]
[AREd] [YOUc] satisfied (or dissatisfied) with the way [D1=1: this person [HELpd]] [D1>1: they [HELpd]] with doing things around the house or community? Please do not count help with transportation. (Please answer with a "yes" for satisfied, or a "no" for "dissatisfied".)

[CLIENT<18, PROX=P:]
[AREd] you satisfied (or dissatisfied) with the way [D1=1: this person [HELpd]] [D1>1: they [HELpd]] with doing things around the house or community for your child? Please do not count help with transportation. (Please answer with a "yes" for satisfied, or a "no" for "dissatisfied".)

[CLIENT<18, PROX=X:]
[AREd] [YOURc] parents satisfied (or dissatisfied) with the way [D1=1: this person [HELpd]] [D1>1: they [HELpd]] with doing things around the house or community for their child (considering both of their views)? Please do not count help with transportation. (Please answer with a "yes" for satisfied, or a "no" for "dissatisfied".)

PROBE: The [D1=1:person who [ISd]] [D1>1: people who [AREd]] paid to help [YOUc], during [THOSE-2-WEEKS].

PROBE: I have recorded that people who [AREd] paid helped with things around the house or community.

<1> YES/SATISFIED

<0> NO/ DISSATISFIED

<7> PARENTS OF MINOR DIFFERED ON SATISFACTION [goto tE25]

<d> DON'T KNOW [goto tE25]

<r> REFUSED [goto tE25]

==>

>E24a< Would that be very (dis)satisfied or somewhat (dis)satisfied?

<1> VERY

<2> SOMEWHAT

<d> DON'T KNOW

<r> REFUSED

==>

>tE25< CATI CHECK: DID CLIENT HAVE PAID ASSISTANCE WITH MEDICINES OR ROUTINE HEALTH CARE AT HOME IN (LAST / THOSE) TWO WEEKS: D8 or D9=1?

<1> YES

<0> NO [goto tE28]

==>

>E26< [CLIENT>=18:]
[AREd] [YOUc] satisfied (or dissatisfied) with the way [this person [HELPd]] [they [HELPd]] [YOUm] with [D8=1&NON-COMA: taking medications, including reminders to take it][D8=1&COMA:medications] [and other] [D9=1:routine health care at home]? (Please answer with a "yes" for satisfied, or a "no" for "dissatisfied".)

[CLIENT<18, PROX=P:]
[AREd] you satisfied (or dissatisfied) with the way [this person [HELPd]] [they [HELPd]] your child with [D8=1:medications] [and other] [D9=1:routine health care at home]? (Please answer with a "yes" for satisfied, or a "no" for "dissatisfied".)

[CLIENT<18, PROX=X:]
[AREd] [YOURc] parents satisfied (or dissatisfied) with the way [this person [HELPd]] [they [HELPd]] their child with [D8=1:medications] [and other] [D9=1:routine health care at home] (considering both their views)? (Please answer with a "yes" for satisfied, or a "no" for "dissatisfied".)

PROBE: Routine health care like checking blood pressure, and doing exercises.

[PROBE IF PROXY: In your judgment.]

PROBE: The [D1=1:person who [ISd]] [D1>1: people who [AREd]] paid to help [YOUc], during [THOSE-2-WEEKS].

PROBE: I have recorded that people who [AREd] paid helped with routine health care.

<1> YES/SATISFIED

<0> NO/ DISSATISFIED

<7> PARENTS OF MINOR DIFFERED ON SATISFACTION [goto E28]

<d> DON'T KNOW [goto E28]

<r> REFUSED [goto E28]

==>

>E26a< Would that be very (dis)satisfied or somewhat (dis)satisfied?

<1> VERY

<2> SOMEWHAT

<d> DON'T KNOW

<r> REFUSED

==>

>E28< [CLIENT>=18:]

[AREd] [YOUc] satisfied (or dissatisfied) with the way [YOU] *[GETd]* along with [D1=1:this person][D1>1:them]? (Please answer with a "yes" for satisfied, or a "no" for "dissatisfied".)

[CLIENT<18, PROX=P:]

[AREd] you satisfied (or dissatisfied) with the way your child *[GETSd]* along with [D1=1:this person][D1>1:them]? (Please answer with a "yes" for satisfied, or a "no" for "dissatisfied".)

[CLIENT<18, PROX=X:]

[AREd] [YOURc] parents satisfied (or dissatisfied) with the way their child *[GETSd]* along with [D1=1:this person][D1>1:them] (consider both of their views)? (Please answer with a "yes" for satisfied, or a "no" for "dissatisfied".)

PROBE: The [D1=1:person who [ISd]] [D1>1: people who [AREd]] paid to help [YOUc], during [THOSE-2-WEEKS].

<1> YES/SATISFIED

<0> NO/ DISSATISFIED

<7> PARENTS OF MINOR DIFFERED ON SATISFACTION [goto tE29]

<d> DON'T KNOW [goto tE29]

<r> REFUSED [goto tE29]

==>

>E28a< Would that be very (dis)satisfied or somewhat (dis)satisfied?

<1> VERY

<2> SOMEWHAT

<d> DON'T KNOW

<r> REFUSED

==>

>tE29< CATI CHECK: IS CLIENT IN TREATMENT GROUP?

<1> YES [goto tE30a]

<0> NO

==>

>tE29a< CATI CHECK: DOES CLIENT HAVE PAID HELP?

<1> YES

<0> NO [goto tE30a]

==>

>E30< Sometimes people help even though they will not be paid for their time. During [THOSE-2-WEEKS], did [D1=1:the person who was paid][D1>1:someone who was paid] spend time helping [YOUc] for which he/she was not, or will not, be paid?

PROBE: For example, they might stay longer or run an errand on their own time.

<1> YES

<0> NO

<d> DON'T KNOW

<r> REFUSED

==>

>tE30a< CATI CHECK: IS RESPONDENT A PAID PROXY FOR CLIENT AGED 18-75 AND CAN PROXY REPORT CLIENT'S SATISFACTION?

<1> YES, PAID {E6=1 or r} AND CLIENT 18-75 [goto tE50]

<2> YES, PAID {E6=1 or r} AND CLIENT ne 18-75 [goto F1]

<3> NO, NOT PAID {E6=0} AND CAN REPORT SATISFACTION {E9 NE1}[goto E31]

<4> NO, NOT PAID {E6=0} BUT CAN'T REPORT SATISFACTION {E9 ne 1}
[goto E36]

<5> OTHERWISE, CONTINUE

==>

>E31< The next questions are about problems that people sometimes have with those who are paid to help them. Please think about *all* the people who [NON-DECEASED:have been][DECEASED:were] paid to help [YOUc] [NON-DECEASED:since ENROLLMENT MONTH] [between ENROLLMENT MONTH and when [YOU] passed away] with personal care, things around the house or community, or routine health care at home.

[Since then,] [During that time,] how often did people who were paid, complete their tasks?

IF YES:

[CLIENT>=18, NON-DECEASED:] Would [YOUc] say...

[CLIENT>=18, DECEASED:] Would [YOUc] have said...

[CLIENT<18, PROX=P:] Would you say...

[CLIENT<18, PROX=X:] Would [YOURc] parents say...

<4> Always [goto E33]

<3> Almost always,

<0> Usually?

<2> Sometimes, or

<1> Rarely?

<7> HAD NO PAID WORKER SINCE ENROLLMENT [goto E37]

<d> DON'T KNOW [goto E33]

<r> REFUSED [goto E33]

PROBE: Tasks that [D1=1:he/she ISd] [D1>1:they AREd] supposed to perform.

PROBE: Please remember that all the information you give us will only be reported as averages for groups of people.

PROBE: Think about all the people who have been paid to help [YOUc] since [EMONTH][including those from before [YOU] started getting the [MONTHLY].

==>

>E32< [NON-DEC: Since ENROLLMENT MONTH] [DEC: Between ENROLLMENT MONTH and when [YOU] passed away],
[CLIENT>=18:]
[DOd] [YOUc] feel that [YOUR] care was *ever neglected* by people who were paid to help?

[CLIENT<18, PROX=P:]
[DOd] you feel that your child's care was *ever neglected* by people who were paid to help?

[CLIENT<18, PROX=X:]
[DOd] [YOURc] parents feel that their child's care was *ever neglected* by people who were paid to help?

PROBE: For example, [YOUc/you/YOURc parents] may [feel / have felt] that [YOUc WERE / your child was / their child was] left alone for a long time when [YOU] needed care, or that an important task was not done for a long time.

PROBE: Think about all the people who have been paid to help [YOU] since [EDATE] [,including those from before [YOU] started getting the [MONTHLY]].

PROBE: People who were paid to help with personal care, things around the house or community, or routine health care at home.

[PROBE IF PROXY: In your judgment.]

<1> YES

<0> NO

<d> DON'T KNOW

<r> REFUSED

==>

>E33< [NON-DEC: Since ENROLLMENT MONTH] [DEC: Between ENROLLMENT MONTH and when [YOU] passed away], about how often have people who were paid, *left early or arrived late*?
[CLIENT>=18, NON-DECEASED:] Would [YOUc] say...
[CLIENT>=18, DECEASED:] Would [YOUc] have said...
[CLIENT<18, PROX=P:] Would you say...
[CLIENT<18, PROX=X:] Would [YOURc] parents say...

- <1> Very often
- <2> Often
- <3> Sometimes, or
- <4> Never?
- <7> NO REGULAR SCHEDULE
- <d> DON'T KNOW
- <r> REFUSED

PROBE: People who were paid to help with personal care, things around the house or community, or routine health care at home.

PROBE: Leave more than half an hour early or arrive more than half an hour late.

PROBE: Think about all the people who have been paid to help [YOU] since [EDATE] [,including those from before [YOU] started getting the [MONTHLY]].

PROBE: [Since [ENROLLMENT MONTH]][Between [ENROLLMENT MONTH] and when [YOU] passed away.

==>

>E34< [NON-DEC: Since ENROLLMENT MONTH] [DEC: Between ENROLLMENT MONTH and when [YOU] passed away], about how often were the people who were paid *rude or disrespectful*?
[CLIENT>=18, NON-DECEASED:] Would [YOUc] say...
[CLIENT>=18, DECEASED:] Would [YOUc] have said...
[CLIENT<18, PROX=P:] Would you say...
[CLIENT<18, PROX=X:] Would [YOURc] parents say...

- <1> Very often
- <2> Often
- <3> Sometimes, or
- <4> Never?
- <d> DON'T KNOW
- <r> REFUSED

PROBE: People who were paid to help with personal care, things around the house or community, or routine health care at home.

PROBE: Think about all the people who have been paid to help [YOU] since [EDATE] [,including those from before [YOU] started getting the [MONTHLY]].

PROBE: Rude or disrespectful in [YOURc] opinion.

==>

>E35< [NON-DEC: Since ENROLLMENT MONTH] [DEC: Between ENROLLMENT MONTH and when [YOU] passed away], about how often have people who were paid, helped [YOUc] do something when [YOU] did *not want help*?
[CLIENT>=18, NON-DECEASED:] Would [YOUc] say...
[CLIENT>=18, DECEASED:] Would [YOUc] have said...
[CLIENT<18, PROX=P:] Would you say...
[CLIENT<18, PROX=X:] Would [YOURc] parents say...

PROBE: Even if YOU/CLIENT might have needed the help, did YOU/HE not **want** the help YOU/HE received?

PROBE: People who were paid to help with personal care, things around the house or community, or routine health care at home.

PROBE: Think about all the people who have been paid to help [YOU] since [EDATE] [,including those from before [YOU] started getting the [MONTHLY]].

==>

- <1> Very often
- <2> Often
- <3> Sometimes, or
- <4> Never?
- <d> DON'T KNOW
- <r> REFUSED

>E36< [CLIENT>=18:]

Thinking back over the past nine months, did someone who was paid to help [YOUc], take any money or belongings from the household without letting someone know?

[CLIENT<18, PROX=P:]

Thinking back over the past nine months, did someone who was paid to help your child, take your money or belongings without letting you know?

[CLIENT<18, PROX=X:]

Thinking back over the past nine months, did someone who was paid to help [YOUc], take [YOUR] parents' money or belongings without letting them know?

PROBE: Someone who was paid to help with personal care, things around the house or community, or routine health care at home.

PROBE: Without letting someone in the household know.

PROBE: [NON-DEC: Since ENROLLMENT MONTH] [DEC: Between ENROLLMENT MONTH and when [YOU] passed away].

<1> YES

<0> NO

<7> NO PAID WORKERS

<d> DON'T KNOW

<r> REFUSED

==>

>E37< The next questions are about the *need* for assistance that [YOUc] may [NON-DECEASED:have at the present time][DECEASED:have had].

[D0d] [YOUc] need [C10, C11, C12, C13, C14, D14, D15, D16, D17, AND D18 NE 1:help] [otherwise: more help than [YOU] [AREd] receiving], with *personal care* such as [NON-COMATOSE: eating or] bathing?

PROBE:

[CLIENT>=18, NON-DECEASED, NON-COMA, PROX=X:] What would you say [YOUc] thinks...

[CLIENT>=18, DECEASED:] What would you say [YOUc] thought...

[CLIENT<18, PROX=P:] What do you think...

[CLIENT<18, PROX=X:] What do [YOURc] parents think...

PROBE IF DECEASED: In general, between ENROLLMENT MONTH and when [YOU] passed away.

PROBE: Help or more help than [YOU] [ARE] receiving.

<1> YES

<0> NO

<d> DON'T KNOW

<r> REFUSED

==>

>tE38< CATI CHECK: IS CLIENT COMATOSE?

<1> COMATOSE [goto tE43]

<2> NON-COMATOSE

==>

>E40< [DO] [YOUc] need [C16, C17, C18, C20, D20, D21, D22, AND D24 NE 1: help]
[otherwise: more help than [YOU] [AREd] receiving], with doing *things around the house* such as preparing meals, laundry, (and) housework (for client){, and yardwork]?

PROBE:

[CLIENT>=18, NON-DECEASED, PROX=X:] What would you say [YOUc] thinks...
[CLIENT>=18, DECEASED:] What would you say [YOUc] thought...

[CLIENT<18: PROBE: Such as help with homework.]

PROBE IF DECEASED: In general, between ENROLLMENT MONTH and when [YOU] passed away.

PROBE IF HOSPITAL/NURSING HOME: In general, between ENROLLMENT MONTH and when [YOU] entered the hospital/nursing home?

PROBE IF ALIVE: At the present time.

PROBE: Help or more help than [YOU] [ARE] receiving.

<1> YES

<0> NO

<d> DON'T KNOW

<r> REFUSED

==>

>E41< [DO] [YOUc] need [C19, D23 NE 1:help] [otherwise: more help than [YOU] [AREd] receiving] with *transportation*?

PROBE: For example, transportation to a doctor's office, shopping, [CLIENT<18:school][CLIENT>=18:work], and recreational and social activities?

PROBE:
[CLIENT>=18, NON-DECEASED, PROX=X:] What would you say [YOUc] thinks...
[CLIENT>=18, DECEASED:] What would you say [YOUc] thought...
[CLIENT<18, PROX=P:] What do you think...
[CLIENT<18, PROX=X:] What do [YOURc] parents think...

PROBE IF DECEASED: In general, between ENROLLMENT MONTH and when [YOU] passed away.

PROBE IF HOSPITAL/NURSING HOME: In general, between ENROLLMENT MONTH and when [YOU] entered the hospital/nursing home?

PROBE IF ALIVE: At the present time.

PROBE: Help or more help than [YOU] [ARE] receiving.

PROBE: Help with taking [YOUc] places.

<1> YES
<0> NO
<d> DON'T KNOW
<r> REFUSED

⇒

>E42< [DO] [YOUc] need [C7, C8, D8 AND D9 NE 1: help] [otherwise: more help than [YOU] [AREd] receiving] with *medications* [CLIENT>=18:, including reminders to take it] or with *routine health care* at home, such as checking blood pressure or doing exercises?

PROBE:

[CLIENT>=18, NON-DECEASED, PROX=X:] What would you say [YOUc] thinks...

[CLIENT>=18, DECEASED:] What would you say [YOUc] thought...

[CLIENT<18, PROX=P:] What do you think...

[CLIENT<18, PROX=X:] What do [YOURc] parents think...

PROBE IF ALIVE: At the present time.

PROBE IF DECEASED: In general, between ENROLLMENT MONTH and when [YOU] passed away.

PROBE IF HOSPITAL/NURSING HOME: In general, between ENROLLMENT MONTH and when [YOU] entered the hospital/nursing home?

PROBE: Help or more help than [YOU] {ARE} receiving.

<1> YES

<0> NO

<d> DON'T KNOW

<r> REFUSED

==>

>tE43< CATI CHECK: IS CLIENT FROM FLORIDA?

<1> YES

<0> NO [goto tE45]

==>

>E44< [DO] [YOUc] need supplies, or more supplies than [YOU] [ARE] receiving for [YOUR] personal care?

PROBE: For example, incontinence pads, [CLIENT>=18: adult] diapers, ostomy and feeding bags, and disposable gloves.

PROBE: Please don't count medicine.

PROBE:

[CLIENT>=18, NON-DECEASED, NON-COMA, PROX=X:] What would you say [YOUc] thinks...

[CLIENT>=18, DECEASED:] What would you say [YOUc] thought...

[CLIENT<18, PROX=P:] What do you think...

[CLIENT<18, PROX=X:] What do [YOURc] parents think...

PROBE IF DECEASED: In general, between ENROLLMENT MONTH and when [YOU] passed away.

PROBE IF HOSPITAL/NURSING HOME: In general, between ENROLLMENT MONTH and when [YOU] entered the hospital/nursing home?

PROBE IF ALIVE: At the present time.

<1> YES

<0> NO

<d> DON'T KNOW

<r> REFUSED

==>

>tE45< CATI CHECK: IS CLIENT COMATOSE?

<1> YES [goto F1]

<0> NO

>E46< Sometimes people cannot do things that they would like or need to do *because* of their health or because they do not have enough personal assistance.

[NON-DECEASED: Can] [DECEASED: Could] [YOUc] go to recreational, cultural, [CLIENT<18:school,] religious, or social activities or do volunteer work as much as [YOU] would [NON-DECEASED:like] [DECEASED: have liked]?

PROBE FOR CHILDREN: For example, activities on the school grounds in the late afternoon or evening.

PROBE IF DECEASED: In general, between ENROLLMENT MONTH and when [YOU] passed away.

PROBE IF HOSPITAL/NURSING HOME: In general, between ENROLLMENT MONTH and when [YOU] entered the hospital/nursing home?

PROBE:

[CLIENT>=18, NON-DECEASED, PROX=X:] What would you say [YOUc] thinks...

[CLIENT>=18, DECEASED:] What would you say [YOUc] thought...

[CLIENT<18, PROX=P:] What do you think...

[CLIENT<18, PROX=X:] What do [YOURc] parents think...

PROBE IF ALIVE: At the present time.

<1> YES

<0> NO

<2> NOT INTERESTED/NOT AVAILABLE

<d> DON'T KNOW

<r> REFUSED

==>

>tE47< CATI CHECK: IS CLIENT AT LEAST 18 AND LESS THAN 75 YEARS OF AGE (OR WAS HE/SHE AT TIME OF DEATH)?

<1> YES

<0> NO [goto F1]

==>

>E48< [Can/Could] [YOUc] go to school or college as much as [YOU] would [like / have liked]? Please include special courses such as those at some community colleges.

PROBE IF ALIVE: At the present time.

PROBE: Sometimes people cannot do things that they would like or need to do because of their health, or because they do not have enough personal assistance.

PROBE IF DECEASED: In general, between ENROLLMENT MONTH and when [YOU] passed away.

PROBE IF HOSPITAL/NURSING HOME: In general, between ENROLLMENT MONTH and when [YOU] entered the hospital/nursing home?

PROBE:

[CLIENT>=18, NON-DECEASED, PROX=X:] What would you say [YOUc] thinks...

[CLIENT>=18, DECEASED:] What would you say [YOUc] thought...

[CLIENT<18, PROX=P:] What do you think...

[CLIENT<18, PROX=X:] What do [YOURc] parents think...

<1> YES

<0> NO

<2> NOT INTERESTED/NOT AVAILABLE

<d> DON'T KNOW

<r> REFUSED

==>

>E49< [Can/Could] [YOUc] work *for pay* as much as [YOU] would [like / have liked]?

PROBE IF ALIVE: At the present time.

PROBE: Sometimes people cannot do things that they would like or need to do because of their health, or because they do not have enough personal assistance.

PROBE IF DECEASED: In general, between ENROLLMENT MONTH and when [YOU] passed away.

PROBE IF HOSPITAL/NURSING HOME: In general, between ENROLLMENT MONTH and when [YOU] entered the hospital/nursing home?

PROBE:

[CLIENT>=18, NON-DECEASED, PROX=X:] What would you say [YOUc] thinks...

[CLIENT>=18, DECEASED:] What would you say [YOUc] thought...

[CLIENT<18, PROX=P:] What do you think...

[CLIENT<18, PROX=X:] What do [YOURc] parents think...

<1> YES

<0> NO

<2> NOT INTERESTED [goto F1]

<d> DON'T KNOW

<r> REFUSED

==>

>tE50< CATI CHECK: IS CLIENT DECEASED?

<1> YES [goto F1]

<0> NO

==>

>E51< Now, please think about *paid* work. During the past two weeks, did [YOUc] work for pay?

<1> YES

<0> NO [goto F1]

<r> DON'T KNOW/REFUSED [goto F1]

==>

>E52< *How many hours* did [YOUc] work for pay *last week*, from [IF NOT SUNDAY OR MONDAY: a week ago Monday through last Sunday] [IF SUNDAY: last Monday through today] [IF MONDAY: last Monday through yesterday]?

<1-80> HOURS WORKED
<r> DON'T KNOW/REFUSED

==>

>E53a< What is [YOURc] current wage or salary?

PROBE: Before taxes and other deductions.

INTERVIEWER: ENTER AMOUNT HERE, AND UNITS ON NEXT SCREEN.

<3-50,000> DOLLARS
<d> DON'T KNOW
<r> REFUSED

==>

>E53b< INTERVIEWER: ENTER UNIT HERE.

<1> PER HOUR
<2> PER DAY
<3> PER WEEK
<4> PER MONTH
<5> ANNUAL
<6> OTHER (SPECIFY)

==>

F. EQUIPMENT, SUPPLIES, AND MODIFICATIONS

>F1< The next questions are about [IF FLORIDA:supplies and] equipment [YOUc] (or [YOUR] family) may have obtained, either through a program, or purchase or rental, or modifications to [YOUR] home or [YOUR] car, [NON-DECEASED: since ENROLLMENT DATE] [DECEASED: between ENROLLMENT DATE and when [YOUc] passed away]. Please do *not* count any [FL:supplies or] equipment obtained *before* that.

====> CONTINUE WITH tF2

>tF2< CATI CHECK: IS STATE FLORIDA?

<1> YES

<0> NO [goto F4]

====>

>F3< [NON-DECEASED:Since then, [HAVE] [YOUc] (or [YOUR] family) obtained] [DECEASED: During that period, did [YOUc] (or [YOUR] family) obtain] personal care supplies for [YOUR] [PROX=C: own]use, such as [AGE>=18: adult] diapers, disposable gloves, or catheter bags?

PROBE IF NOT DECEASED:Since ENROLLMENT DATE, about nine months ago.

PROBE IF DECEASED: Between ENROLLMENT DATE and when [YOUc] passed away.

PROBE: Other examples include pads to protect bedding and feeding and ostomy bags.

<1> YES

<0> NO

<r> DON'T KNOW/REFUSED

====>

>F4< Sometimes people modify a house to make it easier for them to do things. For example, they put in ramps, grab bars, shower stalls, elevators; widen doorways; lower counters, and replace door knobs with handles.

[NON-DECEASED:Since then,] [DECEASED: During that period,] was [YOURc] home modified to make it easier for [YOUm] to do things, or to make it safer for [YOU]?

PROBE IF NOT DECEASED: Since ENROLLMENT DATE, about nine months ago.

PROBE IF DECEASED: Between ENROLLMENT DATE and when [YOUc] passed away.

PROBE: I will ask later about equipment that does not have to be installed, such as a lift to help get out of bed, or a wheelchair or scooter for getting around.

PROBE: Some other examples are putting in handrails and push bars on doors, adjusting sinks and faucets, and adapting wall sockets and light switches.

<1> YES

<0> NO

<r> DON'T KNOW/REFUSED

==>

>F5< [NON-DECEASED:Since then, [HAVE] [YOUc] (or [YOUR] family) modified a car or van or purchased] [DECEASED: During that period, did [YOUc] (or [YOUR] family) modify a car or van or purchase] a modified car or van so that [YOU] could [AGE>=18: drive it or] ride in it more easily?

PROBE IF NOT DECEASED: Since ENROLLMENT DATE, about nine months ago.

PROBE IF DECEASED: Between ENROLLMENT DATE and when [YOUc] passed away.

PROBE: Or arranged for someone to modify the car or van.

PROBE: Or some other kind of vehicle.

PROBE: Perhaps before [YOUc] became so ill?

<1> YES

<0> NO

<r> DON'T KNOW/REFUSED

==>

>F8< [NON-DECEASED: Since then, [HAVE] [YOUc] (or [YOUR] family) obtained] [DECEASED: During that period, did [YOUc] (or [YOUR] family) obtain] any equipment to help [YOUm] with personal activities or communication, or to help keep [YOUm] safe? Please do *not* include equipment that you've already told us about

PROBE: I asked earlier about equipment that has to be installed, such as grab bars, and stairway lifts.

PROBE: Some examples of equipment to help with personal activities are a lift to help get out of bed, raised seat for the toilet, tub seat for bathing, and a wheelchair or scooter for getting around.

PROBE: Some examples of equipment to help with communication are computers, hearing aids, Braille materials, speech devices, special telephone systems, flashing lights or beds with rails, such as hospital beds.

PROBE: Some examples of equipment to help keep [YOUm] safe are personal emergency response systems and home alarm systems.

PROBE IF NOT DECEASED: Since ENROLLMENT DATE, about nine months ago.

PROBE IF DECEASED: Between ENROLLMENT DATE and when [YOUc] passed away.

PROBE: Was this equipment prescribed by a health care provider? IF SO, DO NOT COUNT HERE UNLESS LISTED AS AN EXAMPLE.

<1> YES

<0> NO

<r> DON'T KNOW/REFUSED

==>

>F9< [NON-DECEASED:Since then,] [DECEASED: During that period,] were repairs made on any of the equipment that [YOUc] use[S]?

PROBE IF NOT DECEASED: Since ENROLLMENT DATE, about nine months ago.

PROBE IF DECEASED: Between ENROLLMENT DATE and when [YOUc] passed away.

PROBE: Please include repairs to equipment [YOU] had before ENROLLMENT DATE.

PROBE: Repairs on equipment to make personal [AGE>=18:or household] activities easier or repairs on equipment for communication or safety.

<1> YES

<0> NO

<r> DON'T KNOW/REFUSED

==>

G. USE OF CASH BENEFIT FOR EQUIPMENT AND SUPPLIES

>tG1< CATI CHECK: IS CLIENT IN TREATMENT GROUP AND DID CLIENT EVER RECEIVE [MONTHLY] ALLOWANCE (tA1b=1 or A1b=1)?

<1> YES

<0> NO [goto H1]

==>

>tG1a< DID CLIENT HAVE SUPPLIES (F3=1) OR HOME MODIFICATIONS (F4=1) OR VEHICLE MODIFICATIONS (F5=1) OR HOUSEHOLD EQUIPMENT (F7=1) OR OTHER EQUIPMENT (F8 OR F9=1)?

<1> YES

<0> NO [goto H1]

==>

>G2< The next questions are about using the [MONTHLY] to buy [FLORIDA: supplies and] equipment during the entire time [A1a=1: [YOUc] [HAVE] been] [A1a ne 1 AND A1a ON PATH OR DECEASED: [YOUc] [WERE]] getting this benefit. If you have records of [YOURc] expenses, I would be happy to wait until you get them. Records will also be helpful for some questions later on.

PROBE: The records are only to help you answer our questions. Remember that all of your answers will be kept confidential.

==> CONTINUE WITH tG3

>tG3< CATI CHECK: IS CLIENT FROM FLORIDA AND WAS RECEIPT OF SUPPLIES REPORTED (F3=1)?

<1> YES

<0> NO [goto tG9]

==>

>G5< During the entire time [A1a=1: [YOUc] [HAVE] been] [A1a ne 1: [YOUc] [WERE]] getting the [MONTHLY], was *any* of it spent to buy *personal care supplies* for [YOUm], such as [AGE>=18:adult] diapers, disposable gloves, or catheter bags?

PROBE: Please count any supplies bought with the [MONTHLY] even if they are not yet paid for.

PROBE: Other examples include pads to protect bedding and feeding and ostomy bags.

<1> YES

<0> NO [goto tG9]

<r> DON'T KNOW/REFUSED [goto tG9]

==>

>G6< How *much* of the [MONTHLY] was spent in *all* on personal care supplies?

PROBE: During the entire time, [A1a=1: [YOUc] [HAVE] been] [A1a ne 1: [YOUc] [WERE]] getting the [MONTHLY].

PROBE: How much was spent a month and for how many months?

PROBE IF NO RECORDS: Your best estimate will be fine.

PROBE: Such as [AGE>=18:adult] diapers, disposable gloves, or catheter bags?

PROBE: Please count what will be spent for any supplies bought recently even if the bill is not yet paid, and any expenses paid by a [FISCAL] acting for [AGE>=18:[YOUc]] [AGE<18, PROX=P: you] [AGE<18, PROX=X: [YOURc] parents].

<1-5000> DOLLARS [goto tG9]

<9996> RESPONSE IN MONTHS

<d> DON'T KNOW [goto tG9]

<r> REFUSED [goto tG9]

==>

>G7< <1-500> [MONTHLY] AMOUNT

==>

>G8< <1-9> NUMBER OF MONTHS

==>

>tG9< CATI CHECK: WAS RECEIPT OF HOME MODIFICATIONS REPORTED (F4=1)?

<1> YES

<0> NO [goto tG15]

==>

>G11<During the entire time [A1a=1: [YOUc] [HAVE] been] [A1a ne 1 AND A1a ON PATH] OR DECEASED: [YOUc] [WERE]] getting the [MONTHLY], was *any* of it spent to modify [YOUR] home?

PROBE:For example, putting in ramps, grab bars, shower stalls, elevators, or widening doorways, lowering counters, and replacing door knobs with handles.

<1> YES

<0> NO [goto tG15]

<r> DON'T KNOW/REFUSED [goto tG15]

==>

>G12<How *much* of the [MONTHLY] was spent [A1a=1:, or will be spent,] for *all* these home modifications during the entire time [A1a=1: [YOUc] [HAVE] been] [A1a ne 1AND A1a ON PATH] OR DECEASED: [YOUc] [WERE]] getting the [MONTHLY]?

PROBE: The modifications to make it easier for [YOUc] to do things.

PROBE: During the entire time [A1a=1: [YOUc] [HAVE] been] [A1a ne 1: [YOUc] [WERE]] getting the [MONTHLY].

PROBE: Please count any home modifications already made or for which a contract was signed, even if they are not yet paid for, and any expenses paid by a [FISCAL] acting for [AGE>=18:[YOUc]] [AGE<18, PROX=P: you] [AGE<18, PROX=X: [YOURc] parents].

PROBE: How much was spent each month and for how many months?

<1-10000> DOLLARS [goto tG15]

<99996> RESPONSE IN MONTHS

<d> DON'T KNOW [goto tG15]

<r> REFUSED [goto tG15]

==>

>G13<<1-2500> [MONTHLY] AMOUNT

==>

>G14<<1-9> NUMBER OF MONTHS

==>

>tG15< CATI CHECK: WAS RECEIPT OF VEHICLE MODIFICATIONS REPORTED
(F5=1)?

<1> YES

<0> NO [goto tG21]

==>

>G17<During the entire time [A1a=1: [YOUc] [HAVE] been] [A1a ne 1 AND A1a ON PATH]
OR DECEASED: [YOUc] [WERE]] getting the [MONTHLY], was *any* of it spent to
modify a car or van to make it easier for [YOUc] to ride in [AGE>=18: or drive], or to
buy a car or van like that?

PROBE: Please include buying parts and having them installed.

PROBE: Or some other type of vehicle.

<1> YES

<0> NO [goto tG21]

<r> DON'T KNOW/REFUSED [goto tG21]

==>

>G18<How *much* of the [MONTHLY] was spent in *all* on a modified car or van?

PROBE: The modifications to make it easier for [YOUc] to ride in [AGE>=18] the car or van.

PROBE: Or on modifying more than one vehicle.

PROBE: During the entire time [A1a=1: [YOUc] [HAVE] been] [A1a ne 1: [YOUc] [WERE]] getting the [MONTHLY].

PROBE: How much did you spend each month and for how many months so far?

PROBE: Please count any car or van modifications already made, even if they are not yet paid for, and any expenses paid by a [FISCAL] acting for [AGE>=18:[YOUc]] [AGE<18, PROX=P: you] [AGE<18, PROX=X: [YOURc] parents].

<1-5000> DOLLARS [goto tG21]
<9996> RESPONSE IN MONTHS
<d> DON'T KNOW [goto tG21]
<r> REFUSED [goto tG21]

==>

>G19<<1-1250> [MONTHLY] AMOUNT

==>

>G20<<1-9> NUMBER OF MONTHS

==>

>tG21< CATI CHECK: WAS RECEIPT OF HOUSEHOLD EQUIPMENT REPORTED (F7=1) OR (F9=1)?

<1> YES
<0> NO [goto tG27]

==>

>G23<During the entire time [A1a=1: [YOUc] [HAVE] been] [A1a ne 1 AND A1a ON PATH] OR DECEASED: [YOUc] [WERE]] getting the [MONTHLY], was *any* of it spent to buy or rent equipment to help with *meal preparation or housekeeping*?

PROBE: Such as a microwave oven or clothes washer or dryer.

<1> YES

<0> NO [goto tG27]

<9> DON'T KNOW/REFUSED [goto tG27]

==>

>G24<*How much* of the [MONTHLY] was spent *in all* to buy, rent or repair that type of equipment ?

PROBE: Please count what will be spent for equipment like that bought, rented or repaired recently, even if the bill is not yet paid, and any expenses paid by a [FISCAL] acting for [AGE>=18:[YOUc]] [AGE<18, PROX=P: you] [AGE<18, PROX=X: [YOURc] parents].

PROBE: How much was spent a month and for how many months?

PROBE: Equipment to help with meal preparation or housekeeping.

PROBE: During the entire time [A1a=1: [YOUc] [HAVE] been] [A1a ne 1 AND A1a ON PATH] OR DECEASED: [YOUc] [WERE]] getting the [MONTHLY].

PROBE IF NO RECORDS: Your best estimate will be fine.

<1-5000> DOLLARS [goto tG27]

<9996> RESPONSE IN MONTHS

<d> DON'T KNOW [goto tG27]

<r> REFUSED [goto tG27]

==>

>G25<<1-1250> [MONTHLY] AMOUNT

==>

>G26<<1-9> NUMBER OF MONTHS

==>

>G27< CATI CHECK: WAS RECEIPT OF OTHER EQUIPMENT REPORTED (F8=1)
OR (F9=1)?

<1> YES
<0> NO [goto H1]

==>

>G29< During the entire time [A1a=1: [YOUc] [HAVE] been] [A1a ne 1 AND A1a ON PATH]
OR DECEASED: [YOUc] [WERE]] getting the [MONTHLY], was *any* of it spent to *buy*
or rent equipment to help with personal activities, with communication, or to keep
[YOUm] safe?

PROBE: Some examples of equipment to help with personal activities are a lift to help get out of bed, raised toilet seat, tub seat, and a walker or scooter for getting around.

PROBE: Some examples of communication equipment are computers, hearing aids, speech devices, special telephone systems, and flashing lights.

PROBE: Some examples of equipment to keep you/him/her safe are personal emergency response and alarm systems, which are activated when someone wanders off.

PROBE: Please do not include equipment that requires installation such as grab bars, stairway lifts, and remote control devices. I asked about that earlier.

<1> YES
<0> NO [goto H1]
<d> DON'T KNOW [goto H1]
<r> REFUSED [goto H1]

==>

>G30< *How much* of the [MONTHLY] was spent *in all* to buy or rent these types of equipment?

PROBE: Please count what will be spent for equipment like that bought or rented recently, even if the bill is not yet paid, and any expenses paid by a [FISCAL] acting for [AGE>=18:[YOUc]] [AGE<18, PROX=P: you] [AGE<18, PROX=X: [YOURc] parents].

PROBE: How much was spent a month and for how many months?

PROBE: Equipment to help with personal activities or communication or to help keep [YOUm] safe.

PROBE IF NO RECORDS: Your best estimate will be fine.

PROBE: During the entire time [A1a=1: [YOUc] [HAVE] been] [(A1a ne 1 AND A1a ON PATH) OR DECEASED]: [YOUc] [WERE]] getting the [MONTHLY].

<1-5000> DOLLARS [goto H1]
<9996> RESPONSE IN MONTHS
<d> DON'T KNOW [goto H1]
<r> REFUSED [goto H1]

>G31<<1-1250> [MONTHLY] AMOUNT

==>

>G32<<1-9> NUMBER OF MONTHS

==>

H. RECEIPT OF COMMUNITY SERVICES AND USE OF CASH

>H1< The next questions are about community services [YOUc] may have used
[NON-DECEASED: since EDATE, about nine months ago] [DECEASED: between
EDATE and when [YOU] passed away].

==> CONTINUE WITH tH2

>tH2< CATI CHECK: IS THE CLIENT LESS THAN 18?

<1> YES [goto H4]

<0> NO

==>

>H3< [NON-DECEASED: Since then] [DECEASED: During that period] did [YOUc] *move* to
a new place?

IF YES: Was it to a place with *staff* to help [YOUm] with things such as personal care,
housework, or preparing meals? Please do not count temporary stays.

PROBE: These places are sometimes called supported housing, assisted living
facilities, foster care, board and care homes, or continuing care communities.

PROBE: [NON-DECEASED: Since EDATE, about nine months ago]
[DECEASED: Between EDATE and when [YOUc] passed away].

<1> YES, MOVED TO A PLACE LIKE THAT

<2> YES, MOVED, BUT NOT TO A PLACE LIKE THAT

<0> NO, DIDN'T MOVE

<r> DON'T KNOW/REFUSED

==>

>H4< [NON-DECEASED: Since then, [HAVE] [YOUc] attended] [DECEASED: During that period, [DID] [YOUc] attend] a[AGE>=18:n adult] day care center or some other day program [FLORIDA:, including a sheltered workshop,] that has staff to help [YOUm] with personal care?

PROBE: [NON-DECEASED: Since EDATE, about nine months ago]
[DECEASED: Between EDATE and when [YOUc] passed away].

PROBE: Some of these programs provide health care as well.

PROBE: People typically go to this type of program during the day and come home at night.

PROBE: Even if [YOU] only attended once.

PROBE: Some examples of personal care are help with eating, bathing, getting in or out of bed, using the toilet, and dressing.

<1> YES

<0> NO

<r> DON'T KNOW/REFUSED

==>

>H5< [Since then, [HAVE] [YOUc] attended] [During that period did [YOUc] attend] social or recreational group programs, such as those in community [AGE>=65: or senior] [AGE<18: or youth] centers or in schools or churches? Please do not include attending religious services.

PROBE: Even if [YOU] only attended once.

PROBE: [NON-DECEASED: Since EDATE, about nine months ago]
[DECEASED: Between EDATE and when [YOUc] passed away].

PROBE: Perhaps before [YOUc] became so ill?

[PROBE IF H3=1: Except for programs provided by the place [YOUc] lived in.]

<1> YES

<0> NO

<r> DON'T KNOW/REFUSED

==>

>H6< [Since then, [HAVE] [YOUc] received] [During that period did [YOUc] receive] home-delivered meals from Meals-on-Wheels or a program like that?

PROBE: [NON-DECEASED: Since EDATE, about nine months ago]
[DECEASED: Between EDATE and when [YOUc] passed away].

PROBE: Even if [YOU] only received home-delivered meals once.

PROBE: Some churches have these programs.

PROBE IF H3=1: Except for meals provided by the place [YOUc] lived in.

<1> YES

<0> NO

<r> DON'T KNOW/REFUSED

==>

>H7< [Since then, [HAVE] [YOUc] used] [During that period, did [YOUc] use] transportation services provided by an organization or agency, such as special vans or buses [CLIENT<18: , or special school buses]? Please don't count regular public transportation.

PROBE: [NON-DECEASED: Since EDATE, about nine months ago]
[DECEASED: Between EDATE and when [YOUc] passed away].

PROBE: Even if [YOU] only used these services once.

PROBE: Transportation intended for [CLIENT>65: older people] [OW: people with disabilities], for which arrangements must be made.

PROBE IF H3=1: Except for services provided by the place [YOUc] lived in.

<1> YES

<0> NO [goto H10]

<r> DON'T KNOW/REFUSED [goto H10]

==>

>H8< Did [YOUc] use these transportation services to go to a hospital, doctor's office, clinic, or place like that?

PROBE: [NON-DECEASED: Since EDATE, about nine months ago]
[DECEASED: Between EDATE and when [YOUc] passed away].

PROBE: To visit any type of health care provider.

<1> YES

<0> NO

<r> DON'T KNOW/REFUSED

==>

>H9< Did [YOUc] [H8=1: also] use them to go other types of places?

PROBE: *Other* than to a hospital, doctor's office, clinic, or place like that?

PROBE: [NON-DECEASED: Since EDATE, about nine months ago]
[DECEASED: Between EDATE and when [YOUc] passed away].

<1> YES

<0> NO

<r> DON'T KNOW/REFUSED

==>

>H10< [Since then, has] [During that period, did] someone like a social worker, counselor, nurse, or case manager *[told] [tell]* [YOUc] (or [YOUR] family) about community services like the ones I've been asking about?

PROBE: For example, someone might have given [YOUm] the name or the telephone number of a program.

PROBE: [NON-DECEASED: Since EDATE, about nine months ago]
[DECEASED: Between EDATE and when [YOUc] passed away].

PROBE: Community services like supported housing, [CLIENT>=18:adult] day care, social or recreational programs, home-delivered meals, and transportation.

PROBE: Please do not include [PROG] or similar programs.

<1> YES

<0> NO

<r> DON'T KNOW/REFUSED

==>

>H11< Sometimes family members and friends help to arrange for community services.
[NON-DECEASED: Has] [DECEASED: Did] a family member or friend [done][do] that
for [YOUm] [since then][during that period]?

PROBE: [NON-DECEASED: Since EDATE, about nine months ago]
[DECEASED: Between EDATE and when [YOUc] passed away].

<1> YES
<0> NO
<t> DON'T KNOW/REFUSED

==>

>tH12< CATI CHECK: CLIENT STATUS DURING LAST CALENDAR MONTH?

<3> DECEASED [goto t1]
<1> (ALIVE) TREATMENT GROUP AND RECEIVED CASH BENEFIT (A1c=
PMONTH OR CURRENT MONTH OR A1e=1)
<2> OTHERWISE [goto tH15]

PROGRAMMER: DETERMINE VITAL STATUS LAST MONTH BY LOOKING AT
DATE OF DEATH IN INTRO (OR WHETHER DECEASED AS OF 4-MONTH
INTERVIEW).

==>

>H14< Now please think about last month, that is [fill PREVIOUS CALENDAR MONTH].

During that month, did [YOUc] write **any** of the checks to pay the people hired under [PROG] or for anything else listed in [YOUR] [PLAN], or did someone from [PROG] write **all** of the checks?

PROBE: Or did a family member or friend acting on [YOURc] behalf write any of these checks?

PROBE: The [FISCAL] is the one from [PROG] who would write the checks.

PROBE: The [PLAN] to spend the [PROG] [MONTHLY].

PROBE: Not counting *small* things paid with cash.

PROBE: Or, did [YOUc], or a family member or friend acting on [YOUR] behalf, pay *some* bills and have the [PROG] pay *others*?

<1> CLIENT/REP DID NOT WRITE ANY CHECKS ([FISCAL] WROTE ALL CHECKS)

<0> CLIENT/REP WROTE SOME CHECKS

<r> DON'T KNOW/REFUSED [goto H14a]

==>

>H14a< IF G2 OFF PATH AND TREATMENT GROUP AND H14 NE 1:

If you have records of [YOURc] expenses, I would be happy to wait while you get them. Records may also be helpful for some questions later on.

PROBE: The records are only to help you answer our questions. Remember that all of your answers will be kept confidential.

==>

>tH15< CATI CHECK: DID CLIENT ATTEND DAY CARE DURING NINE MONTHS (H4=1)?

<1> YES

<0> NO [goto tH20]

==>

>H16< Did [YOUc] attend a [AGE>=18:n adult] *day care center* or some other day program [FLORIDA: including a sheltered workshop,] in [PMONTH]?

PROBE: People typically go to this type of program during the day and come home at night.

<1> YES

<0> NO [goto tH20]

<r> DON'T KNOW/REFUSED [goto tH20]

==>

>H17< On *how many days* in [PMONTH], did [YOU] attend a [n adult] day care center or similar program?

PROBE: How many days a week did [YOU] attend and for how many weeks in [PMONTH]?

<1-31> DAYS

<r> DON'T KNOW/REFUSED

==>

>tH18< CATI CHECK:

<1> TREATMENT GROUP AND H14 NE 1

<0> CONTROL GROUP OR H14=1 OR DID NOT GET CASH THIS MONTH OR PMONTH [goto tH20]

>H19<How much of the [MONTHLY] did [YOU] spend, or will [YOU] spend, for [adult] day care or day program services received in [PMONTH]?

PROBE: Or how much did, or will, someone spend on [YOUR] behalf? Please count any bills paid by a [FISCAL].

PROBE: Or, didn't [YOU] spend any of [MONTHLY] on day program services in [PMONTH]?

[IF FLORIDA: PROBE: Please include a sheltered workshop.]

<0-1000> DOLLARS

<d> DON'T KNOW

<r> REFUSED

==>

>tH20< CATI CHECK: DID CLIENT ATTEND SOCIAL PROGRAM DURING NINE MONTHS (H5=1)?

<1> YES

<0> NO [goto tH25]

==>

>H21<Did [YOUc] attend a *social or recreational program* in [PMONTH]?

PROBE: Such as those in community [AGE>=65:or senior] [AGE<18: or youth] centers or in *schools* or churches. Please do not include attending religious services.

<1> YES

<0> NO [goto tH25]

<r> DON'T KNOW/REFUSED [goto tH25]

==>

>H22<On *how many days* in [PMONTH], did [YOU] attend a social or recreational program?

PROBE: How many days a week did [YOU] attend and for how many of weeks in [PMONTH]?

<1-31> DAYS

<r> DON'T KNOW/REFUSED

==>

>tH23< CATI CHECK:

- <1> TREATMENT GROUP AND H14 NE 1
- <0> CONTROL GROUP OR H14=1 OR NEVER GOT CASH [goto tH25]

==>

>H24< How much of the [MONTHLY] did [YOUc] spend, or will [YOU] spend, for services at a *community [or senior] [or youth] center* received in [PMONTH]?

PROBE: Or how much did, or will, someone spend on [YOUR] behalf? Please count any bills paid by a [FISCAL].

PROBE: Or, didn't [YOU] spend any of the [MONTHLY] on center services in [PMONTH]?

- <0-1000> DOLLARS
- <d> DON'T KNOW
- <r> REFUSED

==>

>tH25< CATI CHECK: DID CLIENT GET HOME-DELIVERED MEALS DURING NINE MONTHS (H6=1)?

- <1> YES
- <0> NO [goto tH28]

==>

>H26< In [PMONTH], did [YOUc] receive *home-delivered meals* from Meals-on-Wheels or a similar program?

- <1> YES
- <0> NO [goto tH28]
- <r> DON'T KNOW/REFUSED [goto tH28]

==>

>H27< *How many home-delivered meals* like that did [YOU] receive in [PMONTH]?

PROBE: Please do not count snacks delivered with the meals.

PROBE: How many days in [PMONTH] did [YOU] receive meals and how many meals a day?

PROBE: From Meals-on-Wheels or a similar program.

<1-99> MEALS

<t> DON'T KNOW/REFUSED

==>

>tH28< CATI CHECK:

<1> TREATMENT GROUP AND H14 NE 1 AND GOT CASH

<0> CONTROL GROUP OR H14=1 AND NEVER GOT CASH [goto tH30]

==>

>H29< Now, please think about meals delivered by restaurants as well as special programs like Meals-on-Wheels. How much of the [MONTHLY] did [YOU] spend, or will [YOU] spend, for *meals* delivered to [YOUR] home in [PMONTH] by special programs or restaurants?

PROBE: For example, from Meals-on-Wheels or a similar program or pizza or other meals delivered to [YOUR] home by a restaurant.

PROBE: Or, didn't [YOU] spend any of the [MONTHLY] on home-delivered meals in [PMONTH]?

PROBE: Or how much did, or will, someone spent on [YOUR] behalf? Please count any bills paid by a [FISCAL].

<0-1000> DOLLARS

<d> DON'T KNOW

<r> REFUSED

==>

>tH30< CATI CHECK: DID CLIENT USE TRANSPORTATION FOR MEDICAL TRIPS DURING NINE MONTHS (H8=1)?

<1> YES

<0> NO [goto tH33]

==>

>H31< In [PMONTH], did [YOUc] use a special van or bus or other *transportation* services from an organization or agency, to go to see a doctor or other health care provider?

PROBE: Please do *not* count regular public transportation such as taxi cabs or city buses.

PROBE: Transportation intended for [CLIENT>65: older people] [OW: people with disabilities], for which arrangements must be made.

PROBE: Even if [YOU] only used these services once.

[PROBE: Please include help riding any type of school bus.]

<1> YES

<0> NO [goto tH33]

<r> DON'T KNOW/REFUSED [goto tH33]

==>

>H32< In [PMONTH], for *how many trips* did [YOU] use those transportation services to see a doctor or other health care provider?

PROBE: Please count trips on which [YOU] saw a health care provider even if [YOU] made other stops.

<1-62> TRIPS

<r> DON'T KNOW/REFUSED

==>

>tH33< CATI CHECK: DID CLIENT USE TRANSPORTATION FOR NON-MEDICAL TRIPS DURING NINE MONTHS (H9=1)?

<1> YES

<0> NO [goto tH36]

==>

>H34< Did [YOUc] use a special van or bus [or special school bus] or other transportation services from an organization or agency for *other* types of trips in [PMONTH]? Please do *not* count trips on which [YOU] saw a doctor or other health care provider.

PROBE: Please don't count regular transportation services such as taxi cabs or city buses.

PROBE: Transportation intended for [CLIENT>65: older people] [OW: people with disabilities], for which arrangements must be made.

PROBE: Even if [YOU] only used these services once.

<1> YES

<0> NO [goto tH36]

<r> DON'T KNOW/REFUSED [goto tH36]

==>

>H35< In [PMONTH], how many trips like that did [YOUc] take on special vans or buses [or special school buses] from an organization or agency?

PROBE: Trips *other than* those to see a health care provider.

PROBE: Please don't count trips in which [YOU] also saw a health care provider.

PROBE: Transportation intended for [CLIENT>65: older people] [OW: people with disabilities], for which arrangements must be made.

<1-62> TRIPS

<r> DON'T KNOW/REFUSED

==>

>tH36< CATI CHECK:

<1> TREATMENT GROUP AND H14 NE 1 AND GOT CASH

<0> CONTROL GROUP OR H14=1 AND NEVER GOT CASH [goto tH38]

==>

>H37< Now please think about *all* types of transportation services, including regular public transportation, such as taxi cabs, and special vans and buses [and special school buses] from an organization or agency.

How much of the [MONTHLY] did [YOUc] spend, or will [YOU] spend, on all types of transportation services *to see doctors or other health care providers* in [PMONTH]?

PROBE: Please don't count the expense of driving a car or other vehicle.

PROBE: Transportation intended for [CLIENT>65: older people] [OW: people with disabilities], for which arrangements must be made.

PROBE: Please count the expense of trips on which [YOU] saw a health care provider even if [YOU] made other stops.

[PROBE: Please include riding any type of school bus.]

PROBE: Or how much did, or will, someone spend on [YOUR] behalf? Please count any bills paid by a [FISCAL].

<0-1000> DOLLARS

<d> DON'T KNOW

<r> REFUSED

==>

>tH38< CATI CHECK:

<1> TREATMENT GROUP AND H14 NE 1 AND GOT CASH

<0> CONTROL GROUP OR H14=1 AND NEVER GOT CASH [goto tI1]

==>

>H39<Now please think [IF H37 ON-PATH: again] about *all* types of transportation services, including regular public transportation, such as taxi cabs and special vans and buses from an agency or organization.

How much of the [MONTHLY] did [YOUc] spend, or will [YOU] spend on all types of transportation to *other* types of places in [PMONTH]?

PROBE: Transportation intended for [CLIENT>65: older people] [OW: people with disabilities], for which arrangements must be made.

PROBE: Trips other than those to see a health care provider.

PROBE: Please do not count trips on which [YOU] *also* saw a health care provider.

PROBE: Or how much did, or will, someone spend on [YOUR] behalf? Please count any bills paid by a [FISCAL].

<0-1000> DOLLARS

<d> DON'T KNOW

<r> REFUSED

==>

>H40<In [PMONTH], did [YOUc] use the [MONTHLY] to buy any *other* community services such as laundry services, grocery delivery, chore services, or to live in a place with staff to help with things like personal care?

<1> YES

<0> NO [goto t11]

<r> DON'T KNOW/REFUSED [goto t11]

==>

>H41<How much of the [MONTHLY] did [YOU] spend, or will [YOU] spend, for other community services in [PMONTH]?

PROBE: Or how much did, or will, someone spend on [YOUR] behalf? Please count any bills paid by a [FISCAL].

<0-1000> DOLLARS

<d> DON'T KNOW

<r> REFUSED

==>

I. USE OF CASH TO HIRE WORKERS AND PURCHASE HOME-CARE SERVICES

>t11< CATI CHECK: IS CLIENT IN TREATMENT GROUP
<1> YES
<0> NO [goto END]

==>

>t12< CATI CHECK: DID CLIENT DROP OUT OR DIE BEFORE [PMONTH], AND
MANAGE OWN CASH?

<2> ENROLLED AND MANAGED OWN CASH (H14 NE 1 ON PATH) In
[PMONTH] [goto I4]
<3> ENROLLED AND USED FISCAL (H14=1) In [PMONTH] [goto t121]
<1> DROPPED OUT BEFORE [PMONTH] (A1a=0 AND (A1c<[PMONTH]
OR A1E=0)) OR DIED BEFORE [PMONTH] (SEE INTRO OR
WHETHER DECEASED AT 4-MONTH) OR NEVER GOT MONTHLY
(A1b=0) [goto t121]

==>

>I4<

[CLIENT>=18:]

Now, please think about how [YOUc] used the [MONTHLY] in [PMONTH]. Did [YOU] use the [MONTHLY] to pay a home-care agency to send one of its workers to help [YOUm] *in [PMONTH]*?

[CLIENT<18, PROX=P:]

Now, please think about how you used the [MONTHLY] in [PMONTH]. Did you use the [MONTHLY] to pay a home-care agency to send one of its workers to help your child *in [PMONTH]*?

[CLIENT<18, PROX=X:]

Now, please think about how [YOURc] parents used the [MONTHLY] in [PMONTH]. Did they use the [MONTHLY] to pay a home-care agency to send one of its workers to help [YOUc] *in [PMONTH]*?

PROBE: To help with personal care, such as eating and bathing; doing things around the house or community, such as preparing meals, housework, laundry, shopping, yardwork, and transportation; or routine health care at home, such as checking blood pressure, doing exercises, and [COMA OR CHILD: medications] [NON-COMATOSE ADULT: taking medicines, including reminders to take it]?

PROBE: Someone working for an agency rather than chosen and hired directly by [YOUc].

PROBE: Do not include a worker for whom [YOUc] sign[S] timesheets.

PROBE: Either one or more than one worker.

PROBE: Or did someone use it to pay a home care agency on [YOURc] behalf? Please count any bills paid by a [FISCAL] from [PROG].

<1> YES

<0> NO [goto I6]

<r> DON'T KNOW/REFUSED [goto I6]

==>

>I5< How much of the [MONTHLY] did [YOUc], or will [YOU] spend, to pay for home care agency services in [PMONTH]?

PROBE: Or did, or will, someone spend on [YOUR] behalf? Please count any bills paid by a [FISCAL].

<1-10,000> DOLLARS

<d> DON'T KNOW

<r> REFUSED

==>

>I6< In [PMONTH], did [YOUc] use the [MONTHLY] to pay anyone who was chosen and hired by [YOUm] to help [YOUm]? Be sure to include family members and friends *if they were paid* with the [MONTHLY], but don't count anyone sent by a home care agency or other company.

PROBE: To help with personal care, such as eating and bathing; doing things around the house or community, such as preparing meals, housework, laundry, shopping, yardwork, and transportation; or routine health care at home, such as checking blood pressure, doing exercises, and [COMA OR CHILD: medications] [NON-COMATOSE ADULT: taking medicines, including reminders to take it]?

PROBE: [DO] [YOUc] sign a timesheet for anyone hired to help?

PROBE: Or did someone use it to hire someone directly on [YOUR] behalf? Please count any bills paid by a [FISCAL].

<1> YES

<0> NO [goto tI21]

<r> DON'T KNOW/REFUSED [goto tI21]

==>

I7< *How many different* people who were hired directly and paid with the [MONTHLY], helped [YOUc] in [PMONTH]?

<1-10> PEOPLE

<r> DON'T KNOW/REFUSED

==>

>I8< CATI CHECK: HOW MANY DIRECTLY HIRED CAREGIVERS WERE THERE
In [PMONTH] (I7)?

<1> ONE

<2> TWO, THREE, FOUR OR FIVE [goto I10]

<3> MORE THAN FIVE [goto I11]

==>

>I9< May I have the *first* name of the person who was hired directly and paid with the
[MONTHLY], who helped [YOUc] in [PMONTH]?

PROBE: The first name will make it easier to ask the next questions.

RECORD NAME: _____
[STORE IN DIRNAM1]

==>[goto I12]

>I10< May I have the *first* names of all the people who were hired directly and paid with the
[MONTHLY], who helped [YOUc] in [PMONTH]?

PROBE: Their first names will make it easier to ask the next questions.

RECORD FIRST NAME MENTIONED:
[STORE IN DIRNAM1]

RECORD SECOND NAME MENTIONED:
[STORE IN DIRNAM2]

RECORD THIRD NAME MENTIONED:
[STORE IN DIRNAM3]

RECORD FOURTH NAME MENTIONED:
[STORE IN DIRNAM4]

RECORD FIFTH NAME MENTIONED:
[STORE IN DIRNAM5]

==>[goto I12]

>I11< May I have the *first* names of the *five* people who were hired directly, paid with the [MONTHLY], and who helped [YOUc] the *most* in [PMONTH] with personal care, doing things around the house or community, or routine health care at home?

PROBE: Their first names will make it easier to ask the next questions.

RECORD FIRST NAME MENTIONED:
[STORE IN DIRNAM1]

RECORD SECOND NAME MENTIONED:
[STORE IN DIRNAM2]

RECORD THIRD NAME MENTIONED:
[STORE IN DIRNAM3]

RECORD FOURTH NAME MENTIONED:
[STORE IN DIRNAM4]

RECORD FIFTH NAME MENTIONED:
[STORE IN DIRNAM5]

==>

>I12< The next [I7=1: question is] [I7>1: questions are] about expenses in [PMONTH] for [I7=1: the person] [I7>1: people] hired directly with the [MONTHLY]. (You may want to refer to [YOURc] records.)

Including wages, social security, and any other fringe benefits, *how much* did [YOUc] spend, or will [YOU] spend, from the [MONTHLY] for help from [DIRNAM1] in [PMONTH]?

PROBE: Some examples of other fringe benefits are paid sick leave, paid vacation, and paid health insurance. Also, [YOUc] [ARE] required to pay for state worker's compensation insurance.

PROBE: Or did, or will, someone spend on [YOURc] behalf? Please count any bills paid by a [FISCAL].

<1-2500> DOLLARS

<d> DON'T KNOW

<r> REFUSED

==>

>tI13< CATI CHECK: REPEAT I12 (EXCLUDING INTRODUCTORY SENTENCE) FOR UP TO FOUR MORE WORKERS (DIRNAM2—DIRNAM5): I14, I15, I16, AND I17.

==>

>tI21< CATI CHECK: WHEN DID CLIENT DISENROLL OR DIE?

<3> ALIVE AND ENROLLED

<1> BEFORE 4-MONTH INTERVIEW [goto J34]

<0> SINCE 4-MONTH INTERVIEW (ENROLLED AT 4-MONTH INTERVIEW AND A1a=0, OR tA1=3)

==>

>tI21a< CATI CHECK: DID CLIENT EVER RECEIVE CASH?

<1> YES

<0> NO [goto J1]

==>

>tI24< CATI CHECK: WAS DIRECT HIRE REPORTED FOR In [PMONTH] (I6=1)?

<1> YES [goto J1]

<0> NO

==>

>I25<

Now, please think about how [YOUc] used the [MONTHLY] [NOT DISENROLLED AND NOT DECEASED: since we last spoke] [DISENROLLED OR DECEASED: between when we last spoke and when [YOU] [DISENROLLED: left the cash program] [DECEASED: passed away]]. [Since then] [During that period], did [YOUc] use the [MONTHLY] to pay anyone who was chosen and hired directly to help you?

INTERVIEWER: CONFIRM AND CODE IF KNOWN.

PROBE: [NOT DIS/NOT DEC: Since we last spoke] [DISENROLLED OR DECEASED: Between when we last spoke and when [YOU] [DISENROLLED: left the cash program] [DECEASED: passed away]].

PROBE: We last spoke on [4-MO-INTDATE], about five months ago.

[IF I4 ON-PATH: PROBE: Before I was asking about in [PMONTH], but now I am asking about the time period since we last spoke.]

PROBE: To help with personal care, such as eating and bathing; doing things around the house or community, such as preparing meals, housework, laundry, shopping, yardwork, and transportation; or routine health care at home, such as checking blood pressure, doing exercises, and [COMA OR CHILD: medications] [NON-COMATOSE ADULT: taking medicines, including reminders to take it]?

PROBE: Either one or more than one worker.

PROBE: Please include family members and friends *if they are/were paid* with the [MONTHLY].

PROBE: Please do not include anyone employed by a home care agency.

PROBE: Please include anyone (new) who was paid for their time and trouble using the [MONTHLY].

<1> YES

<0> NO

<r> DON'T KNOW/REFUSED

==>

J. CASH EXPENDITURE PLAN AND EMPLOYER RESPONSIBILITIES

>J1< The next question is about revising [YOURc] *budget or plan* for spending the [MONTHLY], which is also called a [PLAN], [ENROLLED: since we last spoke] [DIS/DEC: between when we last spoke and when [YOUc] [DIS: left the [PROG] program] [DEC: passed away].

[ENROLLED:Since then] [DIS/DEC: During that period], did a [COUNS] from [PROG] help [YOUc] revise this plan? Please include help deciding what services to buy.

PROBE: We last spoke on [4-MO-INTDATE].

PROBE: A counselor is the person who visits [YOURc] home, may help put the [PLAN] on paper, approves the [PLAN], and is the person [YOU] would call with any problems.

PROBE: For example, after [YOURc] need for personal assistance was reassessed.

PROBE: Or, did a [COUNS] help someone acting on [YOURc] behalf?

<1> YES

<0> NO

<7> NO NEED TO REVISE PLAN

<d> DON'T KNOW

<r> REFUSED

==>

>tJ2< CATI CHECK: DID CLIENT EVER RECEIVE CASH?

<1> YES

<0> NO [goto J4]

==>

>J3< The next questions are about recruiting and hiring people directly [since we last spoke] [between when we last spoke and when [YOUc] [left the [PROG] program] [passed away]].

[Since then] [During that period], was someone new hired that [YOUc] chose to help [YOU] with personal care, things around the house and community, routine health care at home, or transportation, who was paid with the [MONTHLY] from [PROG]?

PROBE: Do not include anyone recruited or hired before we last spoke on [4-MO INTERVIEW DATE].

PROBE: Or did someone do this on [YOUR] behalf?

PROBE: Do not include anyone sent by a home care agency or other company.

PROBE: [DO] [YOUc] sign a timesheet for anyone hired to help?

PROBE:

Please include any backup workers who worked for pay for the first time since we last spoke.

<1> YES [goto J6]

<0> NO

<d> DON'T KNOW [goto sum_J]

<r> REFUSED [goto sum_J]

==>

>J4< (The next questions are about recruiting and hiring people directly [since we last spoke] [between when we last spoke and when [YOUc] [left the [PROG] program] [passed away]].) (Since then/During that time,) did [YOUc] *try* to hire someone else directly?

PROBE: For example, [YOUc] might not have been able to locate someone [YOU] [WERE] satisfied with or someone who would accept the work offered.

PROBE: Someone to help with personal care, doing things around the house and community, routine health care at home, and transportation, who would have been paid with the [MONTHLY] from [PROG]?

PROBE: Did anyone try to hire someone for [YOUm]?

PROBE: [Since we last spoke on [4-MO-INTDATE]] [Between when we last spoke on [4-MO-INTDATE] and when [YOUc] [left the [PROG] program] [passed away]]?

PROBE: Do not include anyone hired by an agency, for whom [YOUc] or someone acting on [YOUR] behalf did not sign timesheets.

<1> YES

<0> NO [goto sum_J]

<d> DON'T KNOW [goto sum_J]

<r> REFUSED [goto sum_J]

==>

>J5< In that case, I will be asking about *trying* to recruit and hire people to help [YOUc] [since we last spoke on [4-MO-INTDATE]] [between when we last spoke on [4-MO-INTDATE] and when [YOUc] [left the [PROG] program] [passed away]].

==> CONTINUE WITH J6

>J6< [Since then] [During that period], when [YOUc] or [YOUR] family were trying to locate someone to hire, who did [YOU] ask to work for [YOUm]? A family member, friend or neighbor, a former home-care-agency worker, or none of these?

PROBE: Anyone else?

PROBE: For anyone hired directly.

PROBE: Or did anyone do this on [YOUR] behalf?

PROBE: Please do not include anyone recruited or hired *before* we last spoke, that is, before [4-MO-INTDATE].

INTERVIEWER: READ RESPONSE CATEGORIES AS PROBES, IF NECESSARY.
CODE ALL THAT APPLY.

<1> ASKED FAMILY TO WORK FOR PAY OR HAD FAMILY MEMBER IN MIND

<2> ASKED FRIENDS, NEIGHBORS, OR CHURCH MEMBERS TO WORK FOR PAY OR HAD IN MIND

<3> ASKED CLIENT'S FORMER HOME-CARE-AGENCY WORKER OR HAD IN MIND

<n> NO FURTHER RESPONSES/NONE OF THE ABOVE

<d> DON'T KNOW

<r> REFUSED

====>

>J6a< Did [YOUc] [SEE J6: also] ask family or friends to recommend someone [YOU] did not know to work for [YOUm] [since then] [during that period]?

PROBE: For anyone hired directly.

PROBE: Ask family, friends, church members, or someone else [YOU] know[S] to recommend someone.

PROBE: Or did anyone do this on [YOUR] behalf?

PROBE: Please do not include anyone recruited or hired *before* we last spoke, that is, before [4-MO-INTDATE].

<1> YES

<0> NO

<d> DON'T KNOW

<t> REFUSED

⇒

>J6b< Did [YOUc] [SEE J6, J6a: also] *place* an ad on a bulletin board or in a newspaper or *see* an ad in a place like that [since then] [during that period]? IF YES: Which did you do?

PROBE: For anyone hired directly.

PROBE: Or did anyone do this on [YOUR] behalf?

PROBE: Anything else?

PROBE: Bulletin boards in places like grocery stores, community centers, churches and places like that.

PROBE: Any kind of newspaper, including a community or major daily paper, or a community or church newsletter or bulletin.

PROBE: Please do not include anyone recruited or hired *before* we last spoke, that is, before [4-MO-INTDATE].

INTERVIEWER: READ RESPONSE CATEGORIES AS PROBES, I F NECESSARY.

CODE ALL THAT APPLY.

- <1> PUT A NOTICE ON A BULLETIN BOARD
- <2> SAW "FOR HIRE" NOTICE ON BULLETIN BOARD
- <3> PUT AN AD IN NEWSPAPER OR BULLETIN
- <4> SAW "FOR HIRE" AD IN A NEWSPAPER OR BULLETIN

<n> NO FURTHER RESPONSES/NONE OF THE ABOVE

<d> DON'T KNOW

<r> REFUSED

==>

>J6c< Did [YOUc] [SEE J6,J6a,J6b: also] contact an employment agency [since then] [during that period]?

PROBE: For anyone hired directly.

PROBE: Or did anyone do this on [YOUR] behalf?

PROBE: An organization with a list of people looking for work.

PROBE: Please do not include anyone recruited or hired *before* we last spoke, that is, before [4-MO-INTDATE].

<1> YES

<0> NO

<d> DON'T KNOW

<r> REFUSED

==>

>J6d< Did [YOUc] do anything else to *try* to locate someone to hire [since then] [during that period]?

PROBE: For anyone hired directly.

PROBE: Or did anyone do this on [YOUR] behalf?

PROBE: Please do not include anyone recruited or hired *before* we last spoke, that is, before [4-MO-INTDATE].

<1> YES [SPECIFY]

<0> NO

<d> DON'T KNOW

<r> REFUSED

==>

>sumJ6< CATI CHECK: DID CLIENT HIRE AT LEAST ONE CAREGIVER DIRECTLY SINCE ENROLLMENT DATE (J3=1 OR 4-MONTH:C2=1)?

<1> YES

<0> NO (J3 NE 1 AND ON PATH) OR NEVER GOT MONTHLY ALLOWANCE (4_A4 NE 1 AND A1b NE 1 AND 4_C2 NE 1) [goto tJ11]

CATI CHECK: IS NUMBER OF RESPONSES CODED FOR J6 AND J6a-d LESS THAN 2?

<1> YES [goto J8]

<0> NO

⇒

>J6e< Of the ways (you:C,P / [fill FCNM] [fill LCNM]'s parents:X2/ (Mr./Ms.:{CLIENT ge 18}) [fill FCNM] [fill LCNM]:OW) tried, how did you/they/he/she finally hire someone?

PROBE: Please include anything anyone did on your/his/her/their behalf.

PROBE: Anything else?

INTERVIEWER: IF NECESSARY READ RESPONSE CATEGORIES. CODE ALL THAT APPLY.

CONFIRM AND CODE; IF KNOWN.

<01> HIRED FAMILY TO WORK FOR PAY

<02> HIRED FRIENDS, NEIGHBORS OR CHURCH MEMBERS TO WORK FOR PAY

<03> HIRED CLIENT'S FORMER HOME-CARE-AGENCY WORKER

<04> HIRED PERSON THAT FAMILY OR FRIENDS RECOMMENDED

<05> THROUGH A NOTICE CLIENT PUT ON A BULLETIN BOARD

<06> THROUGH "FOR HIRE" NOTICE SEEN ON A BULLETIN BOARD

<07> THROUGH AN AD CLIENT PUT IN NEWSPAPER OR BULLETIN

<08> THROUGH "FOR HIRE" AD SEEN IN A NEWSPAPER OR BULLETIN

<09> THROUGH EMPLOYMENT AGENCY (ORGANIZATION WITH LIST OF PEOPLE LOOKING FOR WORK)

<10> OTHER

<n> NO FURTHER RESPONSES

<d> DON'T KNOW

<r> REFUSED

⇒

>J8< Now, please think about fringe benefits, such as paid sick days, paid vacation, paid insurance, and free room and board. [ENROLLED: Are any fringe benefits *now* provided] [DIS/DEC: Did [YOUc] provide any fringe benefits] to anyone hired directly to help [YOUc] since [EDATE]? Do not include social security.

PROBE: Hired either before or after we last spoke on [4-MO-INTDATE].

PROBE: Was there an agreement that this would be provided as a fringe benefit?

<1> YES
<0> NO [goto tJ11]
<d> DON'T KNOW [goto tJ11]
<r> REFUSED [goto tJ11]

==>

>tJ9< CATI CHECK: DID CLIENT PROVIDE ANY BENEFITS AT 4-MONTH (4-MO: D8) (SUMS BENEFITS @D9 IN 4-MONTH)?

<1> YES
<0> NO [goto tJ11]

==>

>J10< According to information from our last interview, [FRINGE BENEFITS FROM 4-MONTH D9] [was/were] being provided at that time. Were any fringe benefits *added* since then?

PROBE: For anyone hired directly.

<1> YES
<0> NO
<7> INFORMATION FROM LAST INTERVIEW INCORRECT
<d> DON'T KNOW
<r> REFUSED

==>

>tJ11< CATI CHECK: DID CLIENT HIRE AT LEAST ONE PERSON DIRECTLY SINCE
LAST INTERVIEW (J3=1) OR ATTEMPT TO HIRE SOMEONE (J4=1)?

<1> YES

<0> NO [goto tJ14]

==>

>J12< The next question is about help [YOUc] may have received from a [COUNS]
[ENROLLED: since we last spoke] [DIS/DEC: between when we last spoke and when
[YOUc] [DIS: left the [PROG] program] [DEC: passed away].

[Since then] [During that period], did [YOURc] [COUNS] help [YOUm] with
recruiting and hiring, for example by training [YOUm] or giving [YOUm] materials or
advice?

PROBE: Or, by training or giving advice or materials to anyone acting on [YOUR]
behalf.

PROBE: Any [COUNS] from [PROG].

PROBE: Please include materials, training, and advice on setting wage levels and
(whether to offer) benefits.

<1> YES

<0> NO

<d> DON'T KNOW

<r> REFUSED

==>

>tJ13< CATI CHECK: IS THE RESPONDENT A PAID WORKER (E6=1 OR r)?

<1> YES [goto tJ14]

<0> NO

>J13< [Since then] [During that period], how hard was it, *overall*, for [YOUc] to find someone to help that [YOU] [WERE] satisfied with? Was it very hard, somewhat hard, or not very hard?

PROBE: [ENROLLED: Since we last spoke] [DIS/DEC: Between when we last spoke and when [YOUc] [DIS: left the [PROG] program] [DEC: passed away].

- <1> VERY HARD
- <2> SOMEWHAT HARD
- <3> NOT VERY HARD
- <d> DON'T KNOW [goto tJ13a]
- <r> REFUSED

==> [goto tJ14]

>tJ13a< INTERVIEWER: DID RESPONDENT SAY "HARD?"

- <1> YES
- <0> NO

==>

>tJ14< CATI CHECK: DID CLIENT--

- <1> HIRE OR TRY TO HIRE SINCE LAST INTERVIEW (J3=1 OR J4=1)
- <2> HIRE SOMEONE BEFORE LAST INTERVIEW BUT NOT SINCE (4-MO: C2)
- <3> NEVER HIRE SOMEONE DIRECTLY [goto tJ21]

==>

>J15< Sometimes people change the wages (or benefits) they offer, the hours they want help, or the tasks they want help with. The next questions are about changes [YOUc] may have made [ENROLLED: since we last spoke] [DIS/DEC: between when we last spoke and when [YOUc] [DIS: left the [PROG] program] [DEC: passed away].

==> CONTINUE WITH J16

>J16< [Since then] [During that period], did [YOUc] change the wages (or benefits) [YOU] [WERE] offering?

PROBE: Including anyone hired before we last spoke.

PROBE: For example, [YOU] might have increased someone's hourly wage or added another paid sick day.

PROBE: Or, did anyone acting on [YOURc] behalf do that?

PROBE: [ENROLLED: Since we last spoke] [DIS/DEC: Between when we last spoke and when [YOUc] [DIS: left the [PROG] program] [DEC: passed away].

<1> YES

<0> NO

<d> DON'T KNOW

<r> REFUSED

==>

>J17< [Since then] [During that period], did [YOUc] change the hours [YOU] wanted someone to work, for example, by making the starting time later?

PROBE: Including anyone hired before we last spoke.

PROBE: Or, did anyone acting on [YOURc] behalf do that?

PROBE: [ENROLLED: Since we last spoke] [DIS/DEC: Between when we last spoke and when [YOUc] [DIS: left the [PROG] program] [DEC: passed away].

<1> YES

<0> NO

<d> DON'T KNOW

<r> REFUSED

==>

>J18< [Since then] [During that period], did [YOUc] change the tasks [YOU] wanted done?

PROBE: Including anyone hired before we last spoke.

PROBE: For example, did [YOU] drop some jobs or tasks from the list of things to be done?

PROBE: Or, did anyone acting on [YOURc] behalf do that?

PROBE: [ENROLLED: Since we last spoke] [DIS/DEC: Between when we last spoke and when [YOUc] [DIS: left the [PROG] program] [DEC: passed away]].

<1> YES

<0> NO

<d> DON'T KNOW

<r> REFUSED

==>

>tJ19< CATI CHECK: WAS AT LEAST ONE PERSON HIRED DIRECTLY SINCE LAST INTERVIEW (J3=1)?

<1> YES

<0> NO [goto tJ21]

==>

>J20< [ENROLLED: Since we last spoke] [DIS/DEC: Between when we last spoke and when [YOUc] [DIS: left the [PROG] program] [DEC: passed away], were any of the people hired given a *contract* or work agreement to sign stating what was expected?

PROBE: For *any* of the people who were hired [since then] [during that period]?

<1> YES

<0> NO

<d> DON'T KNOW

<r> REFUSED

==>

>tJ21< CATI CHECK: DID CLIENT HIRE SOMEONE DIRECTLY (J3=1) SINCE LAST INTERVIEW?

<1> YES

<0> NO [goto tJ27]

==>

>J22< The next questions are about training the people who were paid and who started helping [YOUc] [since we last spoke] [between when we last spoke and when [YOUc] [DIS: left the [PROG] program] [DEC: passed away]].

Were any of those people *shown how to carry out* tasks since they started getting paid using the [MONTHLY]? *Shown*, not just explained?

PROBE: *Any* person hired directly or *any* home-care agency worker who started helping for pay since we last spoke.

PROBE: For any task.

PROBE: Physically shown.

PROBE: Shown either by [YOUc], by anyone acting on [YOUR] behalf, or by someone else, such as a visit nurse, either at home or elsewhere.

<1> YES

<0> NO

<d> DON'T KNOW

<r> REFUSED

==>

>J23< Did any of those people get training *outside* of [YOURc] home?

PROBE: *Any* person hired directly or *any* home-care agency worker who started helping for pay since we last spoke.

PROBE: For any task.

PROBE: Either after [YOUc] hired them or earlier.

<1> YES

<0> NO

<d> DON'T KNOW

<r> REFUSED

==>

>J24< Did [YOURc] [COUNS] help with *training* people who started to help for pay after we last spoke? Or did the [COUNS] provide any training materials or advice on training after we last spoke, whether or not they were used?

PROBE: For example, by teaching [YOUm], or a family member or friend, how to train workers, by providing materials, or by giving advice?

PROBE: Any [COUNS] from [PROG].

PROBE: Please include helping anyone acting on [YOURc] behalf.

PROBE: Please include *any* person hired directly who started helping for pay since we last spoke.

<1> YES

<0> NO

<d> DON'T KNOW

<r> REFUSED

==>

>J25< Overall, how hard was it to arrange for or provide *training* for the people who started to help [YOUc] for pay [since we last spoke] [between when we last spoke and when [YOUc] [DIS: left the [PROG] program] [DEC: passed away]]? Would [YOUc] say very hard, somewhat hard, or not very hard?

PROBE: Please consider [YOURc] views as well as the views of anyone acting on [YOUR] behalf.

INTERVIEWER: CONFIRM AND CODE IF NO TRAINING

<1> VERY HARD
<2> SOMEWHAT HARD
<3> NOT VERY HARD
<7> NO TRAINING
<d> DON'T KNOW [goto tJ25a]
<r> REFUSED

==> [goto J26]

>tJ25a< INTERVIEWER CHECK: DID RESPONDENT SAY "HARD"?

<1> YES
<0> NO

==>

>J26< [Since we last spoke] [Between when we last spoke and when [YOUc] [DIS: left the [PROG] program] [DEC: passed away]], was there a time when someone who was hired did not come when expected and [YOU] had a serious problem finding someone else to help [YOUm]?

PROBE: Or, did [YOURc] family or friends have a problem getting someone for backup help for [YOUm]?

<1> YES
<0> NO
<7> NOT NEEDED SO FAR
<d> DON'T KNOW
<r> REFUSED

==>

>tJ27< CATI CHECK: DOES STATE PROGRAM HAVE PEER COUNSELING?
(AR, FL, AND NJ HAVE PEER COUNSELING)

<1> YES
<0> NO [goto tJ28a]

==>

>J28< [Since we last spoke, [HAVE] [YOUc] received] [Between when we last spoke and when [YOUc] [DIS: left the [PROG] program] [DEC: passed away] did [YOU] receive] any training or advice from (*other*) people who [are] [were] *getting the [MONTHLY]*?

PROBE: Or, has anyone acting on [YOURc] behalf received any training or advice from people like that?

PROBE: This is sometimes called peer counseling or peer support.

<1> YES
<2> NO
<d> DON'T KNOW
<r> REFUSED

==>

>tJ28a< CATI CHECK: DID CLIENT EVER RECEIVE CASH?

<1> YES
<0> NO [goto tJ32]

==>

>tJ29< CATI CHECK: DID CLIENT USE [FISCAL] LAST MONTH (H14) OR AT 4-MONTH INTERVIEW (4-MO: D36)?

<1> YES [goto J31]
<0> NO

==>

>J30< [H14 NE 1: I have recorded that [YOUc] [WERE] *not* using a [FISCAL] from [PROG] in [PMONTH]. Did [YOU] *ever* use a [FISCAL] [since [YOU] began] [while [YOU] [WERE]] getting the [MONTHLY]?

PROBE: Even for a short time?

PROBE: Or, did anyone use a [FISCAL] on [YOURc] behalf?

<1> YES

<0> NO

<r> DON'T KNOW/REFUSED

==>

>J31< How hard was it to carry out the payroll responsibilities of an employer [tJ29=1 or J30=1: with] [tJ29 ne 1 AND J30 ne 1: without] the help of a [FISCAL] from [PROG]? Would [YOUc] say very hard, somewhat hard, or not very hard?

PROBE IF PROXY: What would [YOUc] or anyone acting on [YOUR] behalf say?

<1> VERY HARD

<2> SOMEWHAT HARD

<3> NOT VERY HARD

<7> DID NOT HIRE ANYONE

<d> DON'T KNOW [goto tJ31a]

<r> REFUSED

==> [goto tJ32]

>tJ31a< INTERVIEWER: DID RESPONDENT SAY "HARD?"

<1> YES

<0> NO

==>

>tJ32< CATI CHECK: DID CLIENT EVER USE [FISCAL] (tJ29=1 or J30=1)?

<1> YES

<0> NO [goto J34]

==>

>J33< Overall, [ARE] [WERE] [YOUc] satisfied or dissatisfied with the services that the [FISCAL] from [PROG] provided?

- <1> SATISFIED
- <2> DISSATISFIED

- <d> DON'T KNOW [goto J34]
- <r> REFUSED [goto J34]

==>

>J33a< Would that be very or somewhat (dis)satisfied?

- <1> VERY (DIS)SATISFIED
- <2> SOMEWHAT (DIS)SATISFIED

- <d> DON'T KNOW
- <r> REFUSED

==>

>J34< Would [YOUc] [NOT-DEC: recommend] [DEC: have recommended] the [PROG] program to others who wanted more control over [AR, NJ: personal] [FL: home] care services? Or would [YOURc] family and friends recommend/have recommended it?

PROBE: Would [YOU] [recommend] [have recommended] it *overall*?

- <1> YES
- <0> NO
- <2> DEPENDS
- <d> DON'T KNOW
- <r> REFUSED

==>

>tJ34a< CATI CHECK: DID CLIENT EVER RECEIVE CASH?

- <1> YES
- <0> NO [goto tJ38]

==>

>J35< Overall, [NON-DEC, NON-DIS: has] [DEC, DIS: did] having the [MONTHLY] [*improved*] [*improve*] the quality of [YOURc] life, [*reduced*] [*reduce*] the quality of [YOUR] life, or [is] [was] it *about the same* as before [YOU] started getting the [MONTHLY]?

PROBE IF PRIOR PAS RECIPIENT (STRATKEY=1 OR 3): Compared to before, when Medicaid paid a home-care-agency worker to come to help [YOUm] at home.

PROBE IF PROXY: What would [YOUc] (or [YOUR] family) [say] [have said]?

- <1> IMPROVED
- <2> REDUCED
- <3> ABOUT THE SAME [goto tJ38]
- <d> DON'T KNOW [goto tJ38]
- <r> REFUSED [goto tJ38]

==>

>J36< Did the [MONTHLY] [J35=1:improve] [J35=2:reduce] the quality of [YOURc] life *a great deal or somewhat*?

PROBE IF PROXY: What would [YOUc] (or [YOUR] family) [say] [have said]?

- <1> A GREAT DEAL
- <2> SOMEWHAT
- <d> DON'T KNOW [goto tJ38]
- <r> REFUSED [goto tJ38]

==>

>J37< What [is] [was] the *most important* way that the [MONTHLY] [*improved*] [*reduced*] the quality of [YOUR] life?

PROBE IF PROXY: What would [YOUc] (or [YOUR] family) [say] [have said]?

TYPE <1> TO RECORD RESPONSE:

- <d> DON'T KNOW
- <r> REFUSED

==>

Worker Termination

>tJ38< CATI CHECK: DID CLIENT EVER HIRE A WORKER DIRECTLY (J3=1 OR 4-MONTH:C2=1)?

<1> YES
<0> NO [goto tK1]

==>

>J39< Now, please think about the entire time [since [YOUc] [HAVE] been] [that [YOUc] [WERE] getting the [MONTHLY].

Is there anyone *who was hired* directly who [*is*] [*was*] *no longer* getting paid to help [YOU] [when [YOU] left the [PROG] program] [when [YOU] passed away]?

PROBE: Anyone who resigned or was asked to leave.

<1> YES
<0> NO [goto tK1]
<d> DON'T KNOW [goto tK1]
<r> REFUSED [goto tK1]

==>

>J40< *How many* people who were hired directly, [are] [were] no longer getting paid to help [YOUc] [at that time]?

<1-15> PEOPLE
<d> DON'T KNOW
<r> REFUSED

==>

>J41< Sometimes it is necessary to fire someone who is not working out. Was it necessary to fire [J40=1: this person] [J40=2: either of these people] [J40>2: any of these people]?

<1> YES
<0> NO [goto tK1]
<d> DON'T KNOW [goto tK1]
<r> REFUSED [goto tK1]

==>

>tJ42< CATI CHECK: IS THE NUMBER WHO ARE NO LONGER EMPLOYED
GREATER THAN ONE (J40>1)?
<1> YES, GREATER THAN ONE
<0> NO, ONE [goto tK1]

==>

>J43< *How many people had to be fired?*

PROBE: Please include anyone a family member or friend fired.

<1-10> PEOPLE
<d> DON'T KNOW
<r> REFUSED

==>

K. REASONS FOR DROPPING OUT

>tK1< CATI CHECK: IS THE CLIENT IN THE TREATMENT GROUP STILL PARTICIPATING IN THE [MONTHLY] PROGRAM (notDIS) AND DID CLIENT EVER RECEIVE MONTHLY (tA1b=1 or A1b=1)?

- <1> STILL PARTICIPATING [goto tL0]
- <2> NO, DROPPED OUT BEFORE 4-MONTH [goto tL0]
- <3> NO, DROPPED OUT SINCE 4-MONTH; GOT [MONTHLY]
- <4> NO, DROPPED OUT SINCE 4-MONTH; NO [MONTHLY] [goto KK]

==>

>K2< [NON-DEC:The next questions are about [YOURc] disenrolling from the [PROG] program.][DEC: I have just a few more questions for you.]

==> CONTINUE WITH tK3.

>tK3< CATI CHECK: IS THE CLIENT DEAD?

- <1> YES
- <0> NO [goto tK5]

==>

>K4< Did [YOUc] leave the [PROG] program *before* [YOU] passed away?

- <1> YES [goto tK9]
- <0> NO, DIED WHILE IN PROGRAM [goto tL0]
- <d> DON'T KNOW [goto tL0]
- <r> REFUSED [goto tL0]

==>

>tK5< CATI CHECK: HAS THE CLIENT MOVED [FROM INTRO]?

- <1> YES [goto tKK5]
- <0> NO [goto tK7]

==>

>tKK5< CATI CHECK: DID CLIENT MOVE OUT OF STATE [FROM INTRO]?

<1> YES [goto K6]
<0> NO [goto tKKK5]

==>

>tKKK5< CATI CHECK: IS STATE=FLORIDA?

<1> YES [goto K6a]
<0> NO [goto tK7]

==>

>K6a< Did [YOUc] move to a part of Florida that does not offer the [PROG] program?

PROBE: For certain types of participants, [PROG] is only offered in certain counties in Florida.

<1> YES [goto K6]
<0> NO [goto tK7]

<r> DON'T KNOW / REFUSED [goto tK7]

==>

>K6< Did [YOUc] leave the [PROG] program *before* [YOU] moved out of the [IF tKK5=1: state] [IF K6a=1: area served by [PROG]]?

PROBE IF FL :For certain types of participants, [PROG] is only offered in certain counties in Florida.

<1> YES
<0> NO, LEFT WHEN MOVED [goto tL0]

<r> DON'T KNOW/ REFUSED [goto tL0]

==>

>tK7< CATI CHECK: IS CLIENT LESS THAN AGE 18?

<1> YES [goto K7a]
<0> NO [goto tKK7]

==>

>tK7< CATI CHECK: IS THE CLIENT CURRENTLY IN A HOSPITAL OR NURSING HOME (INCLUDING ICF/MR) ?

<1> YES [goto K8]

<0> NO [goto tK9]

==>

>K7a< [ARE] [YOUc] currently in a hospital or nursing home?

INTERVIEWER: CODE IF KNOWN.

PROBE: Or other type of care facility, such as ICF/MR (intermediate care facilities for the mentally retarded or developmentally disabled).

<1> YES, HOSPITAL

<2> YES, NURSING HOME OR OTHER FACILITY

<0> NO [goto tK9]

<r> DON'T KNOW / REFUSED [goto tK9]

==>

>K8< Did [YOUc] leave the [PROG] program *before* [YOU] entered the [FROM INTRO OR IF K7a=1: hospital] [FROM INTRO OR IF K7a=2:nursing home]?

<1> YES

<0> NO, LEFT WHEN ENTERED HOSPITAL / NURSING HOME [goto tL0]

<d> DON'T KNOW [goto tL0]

<r> REFUSED [goto tL0]

==>

>tK9< CATI CHECK: DID THE CLIENT HAVE A REPRESENTATIVE AT ENROLLMENT?

<1> YES

<0> NO / UNKNOWN [goto tK14]

==>

>K10< Did [YOUc] leave the [PROG] program because [YOU] no longer had someone to manage the [MONTHLY] for [YOUm]?

PROBE: In [PROG] such a person is called a “representative.”

PROBE: [YOUc] may have had more than one representative while [YOU][WERE] participating in the [PROG] program. Please think about the *last* representative [YOU] had *before* leaving the program.

<1> YES

<0> NO [goto tK14]

<d> DON'T KNOW [goto tK14]

<r> REFUSED [goto tK14]

==>

>K11< Why did the person who had been managing the [MONTHLY] for [YOUc] give up doing that?

PROBE: [YOURc] *last* representative.

PROBE: Give up managing the [MONTHLY] or allotment.

PROBE: Any other reason?

INTERVIEWER: CODE ALL THAT APPLY.

<01> HEALTH PROBLEMS

<02> (OTHER) FAMILY OR WORK RESPONSIBILITIES

<03> MOVED OUT OF AREA

<04> MORE WORK REQUIRED THAN REPRESENTATIVE EXPECTED

<05> DISSATISFIED WITH PROGRAM

<06> DISPUTE WITH CLIENT

<07> DECEASED

<08> OTHER SPECIFY:

<n> NONE/NO FURTHER RESPONSES

<d> DON'T KNOW

<r> REFUSED

====>

>tK12< CATI CHECK: WAS DISSATISFACTION WITH PROGRAM GIVEN AS REASON THAT REPRESENTATIVE LEFT? (k11_05=5?)

<1> YES [goto tL0]

<0> NO

====>

>K13< When the person who had been managing the [MONTHLY] gave up doing that, was he/she dissatisfied with the [PROG] program?

PROBE: The last person who managed the [MONTHLY] for [YOUc] before [YOU] left the program.

PROBE: The [MONTHLY] or allotment from [PROG].

<1> YES
<0> NO
<d> DON'T KNOW
<r> REFUSED

==> [goto tL0]

>tK14< CATI CHECK: WAS THE CLIENT RESPONSIBLE FOR MANAGING THE MONTHLY AT ENROLLMENT?

<1> YES
<0> NO [goto K16]

==>

>K15< [WERE] [YOUc] not able to stay in the [PROG] program because [YOUR] condition had gotten worse and there was no one who could manage the [MONTHLY] for [YOU]?

PROBE: The [MONTHLY] or allotment from [PROG].

<1> YES [goto tL0]
<0> NO

<d> DON'T KNOW
<r> REFUSED

==>

>K16< Instead of the [MONTHLY], [DECEASED OR IN HOSPITAL/NURSING HOME:
[WERE] [YOUc]][[OTHERWISE: [ARE] [YOUc] now] getting [IF AR OR NJ:
services from a home-care-agency worker paid by Medicaid under the personal
assistance benefit] [IF FL:home care under a Medicaid home and community-based
waiver program] [before [YOU] passed away/entered the hospital/nursing
home/ICF/MR]?

PROBE: After [YOUc] left the [PROG] program.

PROBE: In the other personal care program, Medicaid pays home-care-agency
workers to come to a person's home.

PROBE: If no and from Florida DS Program: [ARE YOU] [IS CLIENT] still eligible
for Medicaid or Medicaid home and community-based waiver services?

<1> YES

<0> NO [goto tL0]

<d> DON'T KNOW [goto tL0]

<r> REFUSED [goto T10]

==>

>K17< [DECEASED:Before [YOUc] passed away, who] [OTHERWISE:Who] made the
decision to leave the [PROG] program? [YOUc] or [YOUR] family or someone from
the [PROG] program?

INTERVIEWER: IF CLIENT CODE <1>.

<1> CLIENT/FAMILY DECISION

<0> PROGRAM DECISION [goto tL0]

<7> WASN'T ABLE TO HIRE IN TIME ALLOTTED BY PROGRAM

<d> DON'T KNOW [goto tL0]

<r> REFUSED [goto tL0]

==> [goto K18]

>K18< Why did [YOUc] *decide* to leave the [PROG] program?

PROBE: Or why did someone (else) acting on [YOUR] behalf decide to leave?

INTERVIEWER: ENTER NUMBER FOR GENERAL CATEGORY TO BRING UP SPECIFIC RESPONSES. CODE ALL THAT APPLY.

- <1> MONTHLY AMOUNT/PAYMENT [goto K18a]
- <2> PROGRAM LIMITATIONS/CONFLICT/CHANGED MIND [goto K18b]
- <3> EMPLOYER RESPONSIBILITIES [goto K18c]
- <4> FAMILY AND HEALTH [goto K18d]
- <5> FISCAL RESPONSIBILITIES [goto K18e]
- <6> OTHER [goto K18f]

- <n> NO OTHER RESPONSES [goto K19]
- <d> DON'T KNOW [goto tL0]
- <r> REFUSED [goto tL0]

====>

>K18a< MONTHLY AMOUNT / PAYMENT

PROBE: Could you be more specific please?

PROBE: Anything else?

REPEAT IF NECESSARY: Why did [YOUc] or someone acting on [YOUR] behalf *decide* to leave the PROG program?

- <1> MONTHLY AMOUNT NOT ENOUGH TO COVER NEEDS OR
COMPARABLE SERVICES
- <2> PAYING ONLY SOME OF HELPERS CAUSED CONFLICT
- <3> TOOK TOO LONG TO GET MONTHLY

- <p> GO BACK TO MAIN SCREEN (NO OTHER REASONS ON THIS SCREEN)
[goto K18]
- <n> NO OTHER/FURTHER REASONS [goto K19]

====>

>K18b< PROGRAM LIMITATIONS / CONFLICT / CHANGED MIND

PROBE: Could you be more specific please?

PROBE: Anything else?

REPEAT IF NECESSARY: Why did [YOUc] or someone acting on [YOUR] behalf *decide* to leave the PROG program?

- <1> CONFLICT WITH PROGRAM STAFF ABOUT HOW SPENDING MONTHLY
- <2> TOO MUCH MONITORING OF HOW TO SPEND MONTHLY OR TOO MANY RULES ABOUT THAT
- <3> CHANGED MIND/DECIDED TO STAY WITH CURRENT PROGRAM
- <4> HOME CARE AGENCY WOULD NOT PROVIDE OTHER SERVICES IF NOT PROVIDING PERSONAL ASSISTANCE SERVICES

<p> GO BACK TO MAIN SCREEN (NO OTHER REASONS ON THIS SCREEN)
[goto K18]

<n> NO OTHER/FURTHER REASONS [goto K19]

==>

>K18c< EMPLOYER RESPONSIBILITIES

PROBE: Could you be more specific please?

PROBE: Anything else?

REPEAT IF NECESSARY: Why did [YOUc] or someone acting on [YOUR] behalf *decide* to leave the PROG program?

- <1> RECRUITING, SCREENING, AND HIRING WORKERS TOO DIFFICULT
- <2> TURNOVER/ WORKER(S) RESIGNED
- <3> TRAINING OR SUPERVISING WORKERS TOO DIFFICULT
- <4> TOO DIFFICULT TO GET BACKUP WORKERS
- <5> PERFORMANCE PROBLEMS WITH WORKERS
- <6> ABUSE/THEFT BY WORKER
- <7> LANGUAGE PROBLEM

<p> GO BACK TO MAIN SCREEN (NO OTHER REASONS ON THIS SCREEN)
[goto K18]

<n> NO OTHER/FURTHER REASONS [goto K19]

==>

>K18d< FAMILY AND HEALTH

PROBE: Could you be more specific please?

PROBE: Anything else?

REPEAT IF NECESSARY: Why did [YOUc] or someone acting on [YOUR] behalf *decide* to leave the PROG program?

- <1> FAMILY MEMBER / FRIEND NO LONGER AVAILABLE AS WORKER
- <2> FAMILY MEMBER / FRIEND NO LONGER AVAILABLE TO HELP MANAGE CARE (BUT NOT AS REPRESENTATIVE)
- <3> HEALTH DETERIORATED / NEEDED HIGHER LEVEL OF CARE
- <4> WANTED A NURSE TO SUPERVISE WORKER / CHECK ON CLIENT

<p> GO BACK TO MAIN SCREEN (NO OTHER REASONS ON THIS SCREEN)
[goto K18]

<n> NO OTHER/FURTHER REASONS [goto K19]

==>

>K18e< FISCAL RESPONSIBILITIES

PROBE: Could you be more specific please?

PROBE: Anything else?

REPEAT IF NECESSARY: Why did [YOUc] or someone acting on [YOUR] behalf *decide* to leave the PROG program?

- <1> PAYROLL/FILING TAXES TOO DIFFICULT
- <2> KEEPING TRACK OF EXPENSES TOO MUCH TROUBLE

<p> GO BACK TO MAIN SCREEN (NO OTHER REASONS ON THIS SCREEN)
[goto K18]

<n> NO OTHER/FURTHER REASONS [goto K19]

==>

>K18f< OTHER

PROBE: Could you be more specific please?

PROBE: Anything else?

REPEAT IF NECESSARY: Why did [YOUc] or someone acting on [YOUR] behalf *decide* to leave the [PROG] program?

<1> SPECIFY

<p> GO BACK TO MAIN SCREEN (NO OTHER REASONS ON THIS SCREEN)
[goto K18]

<n> NO OTHER/FURTHER REASONS

==>

>tk19< CATI CHECK: IS NUMBER OF RESPONSES CODED FOR K18a-f LESS THAN 2?

<1> YES [goto tL0]

<0> NO

==>

>K19< Of the reasons you just told me about, what was the most important reason [YOUc] *decided* to leave the [PROG] program?

PROBE: Could you be more specific please?

PROBE: Or why did someone (else) acting on [YOURc] behalf decide to leave?

INTERVIEWER: READ CHOICES IF NEEDED.

PROGRAMMER: DISPLAY REASONS FROM K18a, K18b, K18c, K18d, K18e, and K18f.

<1> FILL REASON1

<2> FILL REASON2

<3> FILL REASON3

<4> FILL REASON4

<d> DON'T KNOW

<r> REFUSED

==> [goto tL0]

KX. REASONS FOR DROPPING OUT FOR THOSE NEVER RECEIVING MONTHLY

>KX2< [NON:DEC: The next questions are about [YOURc] deciding not to participate in the [PROG] program.] [DEC: I just have a few more questions.]

==> CONTINUE WITH tKX3

>tKX3< CATI CHECK: IS THE CLIENT DECEASED?

<1> YES

<0> NO [goto tKX5]

==>

>KX4< Did [YOUc] decide not to participate in [PROG] before [YOU] passed away?

<1> YES [goto tKX9]

<0> NO, DIED WHILE IN PROGRAM [goto tL0]

<d> DON'T KNOW [goto tL0]

<r> REFUSED [goto tL0]

==>

>tKX5< CATI CHECK: HAS THE CLIENT MOVED?

<1> YES [goto tKKX5]

<0> NO [goto tKX7]

==>

>tKKX5< CATI CHECK: DID CLIENT MOVE OUT OF STATE ?

<1> YES [goto KX6]

<0> NO [goto tKKKX5]

==>

>tKKKX5< CATI CHECK: IS STATE=FLORIDA?

<1> YES [goto KX6a]

<0> NO [goto tKX7]

==>

>KX6a< Did [YOUc] move to a part of Florida that does not offer the [PROG] program?

PROBE: For certain types of participants, [PROG] is only offered in certain counties in Florida.

<1> YES [goto KX6]

<0> NO [goto tKX7]

<r> DON'T KNOW / REFUSED [goto tKX7]

==>

>KX6< Did [YOUc] decide not to participate in the [PROG] program before [YOU] moved out of the [IF tKX5=1: state] [IF KX6a=1: area served by [PROG]]?

PROBE: For certain types of participants, [PROG] is only offered in certain counties in Florida.

<1> YES

<0> NO, LEFT WHEN MOVED [goto tL0]

<r> DON'T KNOW/ REFUSED [goto tL0]

==>

>tKX7< CATI CHECK: IS CLIENT LESS THAN AGE 18?

<1> YES [goto KX7a]

<0> NO [goto TKKX7]

==>

>tKKX7< CATI CHECK: IS THE CLIENT CURRENTLY IN A HOSPITAL [FROM INTRO] OR NURSING HOME [FROM INTRO]?

<1> YES [goto KX8]

<0> NO [goto tKX9]

==>

>KX7a< [ARE] [YOUc] currently in a hospital or nursing home?

INTERVIEWER: CODE IF KNOWN.

PROBE: Or other type of care facility, such as ICF/MR (intermediate care facilities for the mentally retarded or developmentally disabled).

<1> YES, HOSPITAL [goto KX8]

<2> YES, NURSING HOME OR OTHER FACILITY [goto KX8]

<0> NO [goto tKX9]

<r> DON'T KNOW / REFUSED [goto tKX9]

==>

>KX8< Did [YOUc] decide not to participate in the [PROG] program before [YOU] entered the [FROM INTRO OR IF KX7A=1: hospital] [FROM INTRO OR IF KX7A=2: nursing home/ICF/MR]?

<1> YES

<0> NO, LEFT WHEN ENTERED HOSPITAL / NURSING HOME [goto TL0]

<d> DON'T KNOW [goto tL0]

<r> REFUSED [goto tL0]

==>

>tKX9< CATI CHECK: DID THE CLIENT HAVE A REPRESENTATIVE AT ENROLLMENT?

<1> YES

<0> NO / UNKNOWN [goto tKX14]

==>

>KX10< Did [YOUc] decide not to participate in the [PROG] program because [YOU] no longer had someone to manage the [MONTHLY] for [YOUm]?

PROBE: Or would not have had someone to manage the [MONTHLY] when it did come?

PROBE: In [PROG] such a person is called a "representative."

<1> YES

<0> NO [goto tKX14]

<d> DON'T KNOW [goto tKX14]

<r> REFUSED [goto tKX14]

==>

>KX11< Why did the person who was going to be managing the [MONTHLY] for [YOUc] change his/her [=< do not fill] mind about doing that?

PROBE: Any other reason?

INTERVIEWER: CODE ALL THAT APPLY.

<01> HEALTH PROBLEMS

<02> (OTHER) FAMILY OR WORK RESPONSIBILITIES

<03> MOVED OUT OF AREA

<04> MORE WORK REQUIRED THAN REPRESENTATIVE EXPECTED

<05> DISSATISFIED WITH PROGRAM

<06> DISPUTE WITH CLIENT

<07> DECEASED

<08> OTHER SPECIFY:

<n> NONE/NO FURTHER RESPONSES

<d> DON'T KNOW

<r> REFUSED

==>

>tKX12< CATI CHECK: WAS DISSATISFACTION WITH PROGRAM GIVEN AS REASON THAT REPRESENTATIVE LEFT? (KX11_05=5?)

<1> YES [goto TL0]

<0> NO

==>

>KX13< When the person who had been managing the [MONTHLY] gave up doing that, was he/she dissatisfied with the [PROG] program?

PROBE: The last person who managed the [MONTHLY] for [YOUc] before [YOU] left the program.

PROBE: The [MONTHLY] or allotment from [PROG].

<1> YES

<0> NO

<d> DON'T KNOW

<r> REFUSED

==> [goto tL0]

>tKX14< CATI CHECK: WAS THE CLIENT RESPONSIBLE FOR MANAGING THE [MONTHLY] AT ENROLLMENT?

<1> YES

<0> NO [goto KX16]

==>

>KX15< Did [YOUc] decide not to participate in the [PROG] program because [YOUR] condition had gotten worse and there was no one who could manage the [MONTHLY] for [YOUm]?

<1> YES [goto tL0]

<0> NO

<d> DON'T KNOW

<r> REFUSED

==>

>KX16< [IF DECEASED OR IN HOSPITAL/NURSING HOME: [WERE] [YOUc]
[OTHERWISE: [ARE] [YOU] now] getting [IF AR OR NJ: services from a home-
care-agency worker paid by Medicaid under the personal assistance benefit] [IF FL:
home care under a Medicaid home and community-based waiver program] [IF
DECEASED OR IN HOSPITAL/NURSING HOME: before [YOU] passed away
/entered the hospital/ nursing home/ICF/MR]?

PROBE: In the other personal care program, Medicaid pays home-care-agency
workers to come to a person's home.

PROBE: If no and from Florida DS Program: [ARE YOU] [IS CLIENT] still eligible
for Medicaid or Medicaid home and community-based waiver services?

<1> YES

<0> NO [goto tL0]

<d> DON'T KNOW [goto tL0]

<r> REFUSED [goto tL0]

==>

>KX17< [DECEASED: Before [YOU] passed away, who] [OTHERWISE: Who] made the
decision not to participate in the [PROG] program? [YOUc] or [YOUR] family or
someone from [PROG]?

<1> CLIENT/FAMILY DECISION

<0> PROGRAM DECISION [goto tL0]

<7> WASN'T ABLE TO HIRE IN TIME ALLOTTED BY PROGRAM

<d> DON'T KNOW [goto tL0]

<r> REFUSED [goto tL0]

==> [goto KX18]

>KX18< Why did [YOUc] *decide* not to participate in the [PROG] program?

PROBE: Or why did someone (else) acting on [YOUR] behalf decide not to participate?

INTERVIEWER: ENTER NUMBER FOR GENERAL CATEGORY TO BRING UP SPECIFIC RESPONSES. CODE ALL THAT APPLY.

- <1> MONTHLY AMOUNT/PAYMENT [goto KX18a]
- <2> PROGRAM LIMITATIONS/CONFLICT/CHANGED MIND [goto KX18b]
- <3> EMPLOYER RESPONSIBILITIES [goto KX18c]
- <4> FAMILY AND HEALTH [goto KX18d]
- <5> FISCAL RESPONSIBILITIES [goto KX18e]
- <6> OTHER [goto KX18f]

- <n> NO OTHER RESPONSES [goto tKX19]
- <d> DON'T KNOW [goto tL0]
- <r> REFUSED [goto tL0]

==>

>KX18a< MONTHLY AMOUNT / PAYMENT

PROBE: Could you be more specific please?

PROBE: Anything else?

REPEAT IF NECESSARY: Why did [YOUc] or anyone acting on [YOUR] behalf *decide* not to participate in the [PROG] program?

- <1> MONTHLY AMOUNT NOT ENOUGH TO COVER NEEDS OR
COMPARABLE SERVICES
- <2> PAYING ONLY SOME OF HELPERS CAUSED CONFLICT
- <3> TOOK TOO LONG TO GET MONTHLY

- <p> GO BACK TO MAIN SCREEN (NO OTHER REASONS ON THIS SCREEN)
[goto KX18]
- <n> NO OTHER/FURTHER REASONS [goto tKX19]

==>

>KX18b< PROGRAM LIMITATIONS / CONFLICT / CHANGED MIND

PROBE: Could you be more specific please?

PROBE: Anything else?

REPEAT IF NECESSARY: Why did [YOUc] or anyone acting on [YOUR] behalf *decide* not to participate in the [PROG] program?

- <1> CONFLICT WITH PROGRAM STAFF ABOUT HOW SPENDING MONTHLY
- <2> TOO MUCH MONITORING OF HOW TO SPEND MONTHLY OR TOO MANY RULES ABOUT THAT
- <3> CHANGED MIND/DECIDED TO STAY WITH CURRENT PROGRAM
- <4> HOME CARE AGENCY WOULD NOT PROVIDE OTHER SERVICES IF NOT PROVIDING PERSONAL ASSISTANCE SERVICES

<p> GO BACK TO MAIN SCREEN (NO OTHER REASONS ON THIS SCREEN)
[goto KX18]

<n> NO OTHER/FURTHER REASONS [goto tKX19]

==>

>KX18c< EMPLOYER RESPONSIBILITIES

PROBE: Could you be more specific please?

PROBE: Anything else?

REPEAT IF NECESSARY: Why did [YOUc] or anyone acting on [YOUR] behalf *decide* not to participate in the [PROG] program?

- <1> RECRUITING, SCREENING, AND HIRING WORKERS TOO DIFFICULT
- <2> TURNOVER/ WORKER(S) RESIGNED
- <3> TRAINING OR SUPERVISING WORKERS TOO DIFFICULT
- <4> TOO DIFFICULT TO GET BACKUP WORKERS
- <5> PERFORMANCE PROBLEMS WITH WORKERS
- <6> ABUSE/THEFT BY WORKER
- <7> LANGUAGE PROBLEM

<p> GO BACK TO MAIN SCREEN (NO OTHER REASONS ON THIS SCREEN)
[goto KX18]

<n> NO OTHER/FURTHER REASONS [goto tKX19]

==>

>KX18d< FAMILY AND HEALTH

PROBE: Could you be more specific please?

PROBE: Anything else?

REPEAT IF NECESSARY: Why did [YOUc] or anyone acting on [YOUR] behalf *decide* not to participate in the [PROG] program?

- <1> FAMILY MEMBER / FRIEND NO LONGER AVAILABLE AS WORKER
- <2> FAMILY MEMBER / FRIEND NO LONGER AVAILABLE TO HELP MANAGE CARE (BUT NOT AS REPRESENTATIVE)
- <3> HEALTH DETERIORATED / NEEDED HIGHER LEVEL OF CARE
- <4> WANTED A NURSE TO SUPERVISE WORKER / CHECK ON CLIENT

<p> GO BACK TO MAIN SCREEN (NO OTHER REASONS ON THIS SCREEN)
[goto KX18]

<n> NO OTHER/FURTHER REASONS [goto tKX19]

==>

>KX18e< FISCAL RESPONSIBILITIES

PROBE: Could you be more specific please?

PROBE: Anything else?

REPEAT IF NECESSARY: Why did [YOUc] or anyone acting on [YOUR] behalf *decide* not to participate in the [PROG] program?

- <1> PAYROLL/FILING TAXES TOO DIFFICULT
- <2> KEEPING TRACK OF EXPENSES TOO MUCH TROUBLE

<p> GO BACK TO MAIN SCREEN (NO OTHER REASONS ON THIS SCREEN)
[goto KX18]

<n> NO OTHER/FURTHER REASONS [goto tKX19]

==>

>KX18f< OTHER

PROBE: Could you be more specific please?

PROBE: Anything else?

REPEAT IF NECESSARY: Why did [YOUc] or anyone acting on [YOUR] behalf *decide* not to participate in the [PROG] program?

<1> SPECIFY

<p> GO BACK TO MAIN SCREEN (NO OTHER REASONS ON THIS SCREEN)
[goto KX18]

<n> NO OTHER/FURTHER REASONS [goto tKX19]

==>

>tKX19< CATI CHECK: IS NUMBER OF RESPONSES FOR KX18a-f LESS THAN 2?

<1> YES [goto tL0]

<0> NO

==>

>KX19< Of the reasons you just told me about, what was the most important reason [YOUc] *decided* not to participate in the [PROG] program?

PROBE: Or why did someone (else) acting on [YOUR] behalf decide not to participate?

PROBE: Could you be more specific please?

INTERVIEWER: READ CHOICES IF NEEDED.

PROGRAMMER: DISPLAY REASONS FROM KX18a, KX18b, KX18c, KX18d, KX18e, and KX18f.

<1> FILL REASON1

<2> FILL REASON2

<3> FILL REASON3

<4> FILL REASON4

<d> DON'T KNOW

<r> REFUSED

==>

L. **BORROWING AND SAVING**

>tLo< CATI CHECK: DID CLIENT EVER RECEIVE CASH?

<1> YES

<0> NO [goto tL3]

==>

>L1< Finally, having the [MONTHLY] may make it easier to borrow and to save. The next questions are about that.

PROBE: Remember that the study will only report averages for groups of people.

==> CONTINUE WITH L2

>L2< During the entire time [YOUc] [ENROLLED: [HAVE] been] [DIS/DEC: [WERE]] getting the [MONTHLY], did [YOU] *borrow* money to buy or do something to help [YOUm] be more independent, or to hire extra help?

PROBE: Please include borrowing from family or friends, as well as a bank or other financial institution.

PROBE: For example, borrowing money to modify [YOUR] home or a vehicle or to buy equipment.

<1> YES

<0> NO

<d> DON'T KNOW

<r> REFUSED

==>

>tL3< CATI CHECK: WAS THE CLIENT PARTICIPATING IN CASH PROGRAM In [PMONTH], AND IS CLIENT IN SSI OR FNS SAMPLE?

<1> ENROLLED LAST MONTH & IN SSI OR FNS SAMPLE AND tJ29=1 or J30=1 [goto L5]

<2> ENROLLED LAST MONTH & IN SSI OR FNS SAMPLE AND tJ29 ne 1 or J30 ne 1 [goto tL6]

<0> DISENROLLED In [PMONTH] OR DECEASED In [PMONTH] OR NOT IN SSI OR FNS SAMPLE [goto Bothsmp]

==>

>L5< As of the beginning of [PMONTH], about how much had [YOUc] accumulated over time as savings from the [MONTHLY] in the account held by the [FISCAL] from [PROG]? Was it less than \$2,500?

PROBE: Did [YOU] have any left from the [MONTHLY] after paying [YOUR] expenses each month?

PROBE: Your best estimate is fine.

<2> NONE

<3> LESS THAN \$2,500 [goto L5a]

<4> MORE THAN \$2,500 [goto tL6]

<5> MORE THAN \$2,500 [goto L5b]

<d> DON'T KNOW

<r> REFUSED

==>[goto tL6]

>L5a< Was it ...

<1> Less than \$500

<2> At least \$500 but less than \$1,000

<3> At least \$1,000 but less than \$1,500

<4> At least \$1,500 but less than \$2,000, or

<5> \$2,000 or more?

<d> DON'T KNOW

<r> REFUSED

==>[goto tL6]

>L5b< Was it ...

- <1> Less than \$3,000
- <2> At least \$3,000 but less than \$4,000
- <3> At least \$4,000 but less than \$5,000, or
- <4> \$5,000 or more?
- <d> DON'T KNOW
- <r> REFUSED

==> [goto tL6]

>tL6< CATI CHECK: IS THIS CASE IN THE ...

- <1> FNS SAMPLE
- <0> SSI SAMPLE [GOTO L8]

==>

>tL7< CATI CHECK: DURING THE TWO-WEEK REFERENCE PERIOD, DID THE CLIENT LIVE ALONE OR WITH SPOUSE ONLY (B5_1=1 OR (B5_2=2 AND B5_3 THROUGH B5_8 = -2))?

- <1> YES, ALONE OR WITH SPOUSE ONLY
- <0> NO, NEITHER [goto L9]

==>

>L8< Not counting any savings that a[n] [PROG] program [FISCAL] might have been holding for [YOUm], how much did [YOUc] [B5_2=2: and [YOUR] [husband/wife]] have in checking and savings accounts as of the beginning of in [PMONTH]?

PROBE: Please consider all of the bank accounts you and [YOUR] (husband/wife) hold, whether designated for the PROG program or not.

- <0-10,000> DOLLARS [goto Bothsmp]
- <d> DON'T KNOW [goto L10]
- <r> REFUSED [goto Bothsmp]

==>

>L9< Not counting any savings that a[n] [PROG] program [FISCAL] might have been holding for [YOUm], how much did [YOUc] and all other members of [YOUR]household have in checking and savings accounts as of the beginning of in [PMONTH]?

PROBE: Please consider all of the bank accounts you and all other members of [YOUR] household have, whether designated for the [PROG] program or not.

PROBE: The people living in the same household as [YOUc] during [THOSE-2-WEEKS].

PROBE: The [2-WEEK-PERIOD].

<0-10,000> DOLLARS [goto Bothsmp]

<d> DON'T KNOW

<r> REFUSED [goto Bothsmp]

==>

>L10< Perhaps you could give me a range. Was it more or less than \$2,500?

<1> MORE THAN \$2,500 [goto L12]

<2> \$2,500 [goto Bothsmp]

<3> LESS THAN \$2,500

<d> DON'T KNOW [goto Bothsmp]

<r> REFUSED [goto Bothsmp]

==>

>L11< Was it ...

<1> Less than \$500

<2> At least \$500 but less than \$1,000

<3> At least \$1,000 but less than \$1,500

<4> At least \$1,500 but less than \$2,000, or

<5> \$2,000 or more?

<d> DON'T KNOW

<r> REFUSED

==>[goto Bothsmp]

>L12< Was it ...

- <1> Less than \$3,000
- <2> At least \$3,000 but less than \$4,000
- <3> At least \$4,000 but less than \$5,000, or
- <4> \$5,000 or more?
- <d> DON'T KNOW
- <r> REFUSED

==>

>BOTHSMPC<

INTERVIEWER CHECK:
IS [PPCG] THE SAME PERSON AS
[PIFCG]?

ASK IF NECESSARY.

- <1> YES
- <0> NO

==>

>END< Those are all the questions I have. We appreciate very much your patience in answering them. Your answers will help us learn how to improve [AR,NJ: personal] [FL: home] care services. [IF PW SAMPLE=1 AND TREATMENT: Soon, we will be calling to interview [PPCG], who was identified in this interview as the person who is paid and who now helps [YOUc] the most] to learn about how things are going from his or her point of view. [IF ICG SAMPLE=1: [Soon,] We will (also) be calling to interview [PICG], who was identified several months ago as the person who helped [YOUc] the most at that time Is his/her address and phone number still:

INTERVIEWER: READ AND ENTER ANY CHANGES.

[FILL B14_add]
[FILL B14_ph]

Thank you so much for your time today.

>L_NO< INTERVIEWER: IS THERE A REASON WE CANNOT CONTACT [ICG]?

- <1> YES, DECEASED
- <2> YES, UNDER 18 YEARS OF AGE
- <0> NO